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"IT'S A VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN

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“IT’S A *VERY* TRICKY COMMUNICATION SITUATION”:
A COMPREHENSIVE INVESTIGATION OF
END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information at the
University of Kentucky

By
Sara Lynn Shaunfield

Lexington, Kentucky

Director: Dr. Kevin Real, Associate Professor of Communication

Lexington, Kentucky

2015

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ABSTRACT OF DISSERTATION

“IT’S A *VERY* TRICKY COMMUNICATION SITUATION”: A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN

Family caregivers encounter immense negative consequences including decreased quality of life and increased rates of morbidity and mortality that stem from physical burdens, emotional distress, depression, social isolation, and loss of financial security. Although communication is an important aspect of caregiving, communication tasks are reportedly difficult for end-of-life family caregivers. The goal of this study was to explore the variety of communication stressors experienced by end-of-life family caregivers to gain insight into the communication tasks caregivers perceive as most difficult and the reasons why.

Qualitative data was achieved through in-depth, face-to-face interviews with 40 caregivers currently providing care for a family member diagnosed with Alzheimer’s disease and related dementias ($n=20$; ADRD) and Glioblastoma ($n=20$; brain tumor [GBM]). A grounded theory approach was employed to gain insight into end-of-life family caregiver communication experiences. The results revealed that communication is perceived as a burden for end-of-life family caregivers. Not only does communication burden exist, end-of-life family caregivers experience immense tension and stress regarding a variety of relational contexts when communicating with the care recipient, others (family, friends), and clinicians. The results further revealed that communication burden stems from the caregiver’s attempt to negotiate between two opposing extremes: a desire to protect the patient and others versus a need to protect oneself. Thus, internal tension occurs when end-of-life family caregivers contemplate whether and how to engage in difficult conversations, and then again when following through. The presence of these contradictory tensions induced the emergence of barriers and therefore communication burden within various aspects of the end-of-life caregiver experience.

Added insight into communication burden was achieved through a supplementary scale development study in a sample of ADRD and oncology end-of-life caregivers ($N=263$), which revealed communication burden as significantly associated with caregiver burden and quality of life. Implications for the advancement of interpersonal and health communication theory as well as practical tailored interventions targeting end-of-life family caregivers are discussed.

KEYWORDS: Family Caregiving, End-of-Life Care,
Communication Burden, Health Outcomes,
Mixed-Methods

Sara Lynn Shaunfield

April 28, 2015

“IT’S A *VERY* TRICKY COMMUNICATION SITUATION”:
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Dedicated to my grandfather, William Harold Albritton with love.

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CHAPTER I

Introduction

The United States [U.S.] Census Bureau (2010) reported 40.2 million older adults living over the age of sixty-five. Moreover, the elderly population has been projected to increase to an astonishing 88.5 million by the year 2050 (U.S. Census Bureau, 2010). As the number of persons living over the age of 65 dramatically increases in the coming years, the number of unpaid family caregivers will also rise.

In the U.S., more than 65 million individuals (i.e., 29% of the population), mostly family members, have taken on the responsibility of unpaid caregiver for persons who are chronically ill, disabled, or aging (National Alliance for Caregiving [NAC], Nov 2009). Most caregivers report providing care for a relative (86%) or parent (36%), while 70% of caregivers report providing for a person over the age of 50 (NAC, 2009). Many caregivers provide for older adults and report the following reasons: old age (12%), Alzheimer's/dementia (12%), cancer (7%), mental/emotional illness (7%), stroke (5%), and heart disease (5%).

Family caregivers are the foundation of the U.S. long-term care system as they provide unpaid care that is worth an estimated \$375 billion in services each year (NAC, 2009). Further, informal caregivers provide, on average, 20 hours of care per week, while 13% provide a minimum of 40 hours a week (NAC, 2009). As a result of the extensive care and personal responsibilities, family caregivers encounter vast physical (Terrill, Garofalo, Soliday, & Craft, 2012) and emotional health problems (Alexopoulos, 2005; Bevans & Sternberg, 2012; Braun & Beyth, 2008; Garlo, O'Leary, Van Ness, & Fried, 2010; Phillips, Gallagher, Hunt, Der, & Carroll, 2009). This study focused on family

caregivers who provide end-of-life (EoL) care for individuals who suffer from a progressive chronic or terminal illness.

Caregiver Burden

Family members, who assume the primary caregiver role essentially, become the healthcare delivery system for the patient (NAC, 2009). Caregiver responsibilities include making critical health care decisions, assisting with activities of daily living (ADLs; e.g., dressing, bathing, feeding, physically transporting, medication administration) and instrumental activities of daily living (IADLs; e.g., shopping, cooking, cleaning, transportation to medical appointments, managing finances), providing in-home treatments, and administering medications (Holtslander, 2008), often without proper training (NAC, 2009).

As a result of the arduous responsibilities, caregivers often encounter immense negative consequences ranging from increased mortality that stem from the physical burdens, emotional stress, depression, social isolation, and loss of financial security (NAC, 2009; Terrill et al., 2012). The stressors of caregiving often negatively influence caregiver health (Terrill et al., 2012). Further, caregivers report significantly reduced quality of life (NAC, 2009) and higher rates of depression than the general population (Phillips et al., 2009; Rhee, Yun, & Park et al., 2008), of which elderly caregivers are at an even higher risk (Alexopoulos, 2005). The literature on caregiving has identified these hardships as caregiver burden. Various forms of caregiver burden have been thoroughly documented in the caregiving literature.

Scholars have identified a few aspects of the caregiver's background context associated with increased burden (Gallicchio, Siddiqui, Langenberg, & Baumgarten,

2002; NAC, 2009). Some of the background context elements associated with increased burden include those who provide primary care, caregivers who had no other choice, unemployed caregivers, and caregivers with less than a college education (NAC, 2009). Spouses and children report increased levels of depression when compared to other caregiving populations (Gallicchio et al., 2002). Lastly, old age, poor socioeconomic status, and reduced informal support are significant predictors of ill outcomes including decreased quality of life and high rates of caregiver burden (NAC, 2009).

Communication Burden

Although communication is an important aspect of caregiving, communication tasks are often difficult for the caregiver. Many caregivers report a desire for more open communication with care recipients; however, caregivers are often reluctant to initiate communication concerning sensitive topics, as these topics are perceived as difficult to discuss (Fried, Bradley, O'Leary, & Byers, 2005). The recognized difficulty may stem from the patients' lack of reported desire for increased communication with the caregiver. The discrepancy in caregiver and patient communication desires is unfortunate given that caregiver desire for increased communication with care recipients is associated with increased burden and emotional turmoil (Fried et al., 2005; Savundranayagam et al., 2005). On the other hand, caregivers and patients who describe communication with one another as adequate report the lowest burden (Fried et al., 2005). These findings indicate that unmet caregiver communication needs with the care recipient may serve to increase caregiver burden. The purpose of this study was to conduct a comprehensive investigation into the communication stressors experienced by family caregivers.

A thorough review of the caregiving literature reveals that problematic communication yields difficulties for caregivers. Henceforth, I refer to this additional area of burden related to communication as caregiver communication burden. Communication burden stems from the necessary communicative tasks and responsibilities required for care provision that causes the caregiver undue stress or distress. Although, a comprehensive investigation of communication difficulties has yet to be conducted in a single study, the results of a conglomeration of research studies have revealed seven potential categories of communication that could be problematic for EoL family caregivers: a) informing and involving family members about prognosis and disease progression (Houts, Nezu, Nezu, & Bucher, 1996; Waldrop, Kramer, Skretny, Milch, & Finn, 2005); (b) expressing feelings of caregiver stress and exhaustion (Wilks & Croom, 2008); (c) disclosing to family and friends a need for assistance (Wittenberg-Lyles, Washington, Demiris, Parker Oliver, & Shaunfield, 2014); (d) communicating with others about sensitive issues and care decisions (Roscoe, Osman, & Haley, 2006; Waldrop et al., 2005); (e) communicating with the patient about his/her own illness and care preferences (Fried et al., 2005; Gillespie, Murphy, & Place, 2010; Waldrop et al., 2005); (f) inability to communicate with patients in advanced stages of illness (Savundranayagam, Hummert, & Montgomery, 2005); and (g) seeking information and support from medical staff (Braun & Beyth, 2008; Imes, Dougherty, Pyper, & Sullivan, 2011; Kutner et al., 2009).

Although, reports of caregiver communication difficulties are prevalent throughout the caregiving literature, the potential construct of caregiver communication burden is new and has yet to be explored in its own right. Funk and colleagues (2010)

called for higher-level qualitative research in the context of EoL caregiving that applies existing concepts from the literature and/or refines existing theories. Therefore, the goal of this project was to answer this call by conducting a comprehensive exploration of the variety of communication stressors experienced by EoL family caregivers, and gain insight into the communication tasks caregivers perceive as most difficult and the reasons why.

Theoretical Framework

The stressors of EoL family caregiving are complex, and in order to comprehensively investigate family caregiver communication burden and outcomes, researchers must take a holistic approach. In order to gain in-depth insight into caregiver communication burden and the potential influence on outcomes, Demeris, Parker Oliver, Wittenberg-Lyles' (2009) theoretical model Assessing Caregivers for Team interventions (ACT) was utilized as a lens for conducting a comprehensive investigation of EoL family caregiver communication burden. The ACT model was founded upon the original stress process theory and extensive research in the context of EoL family caregiving. The overall goal of the ACT framework is to inquire into the difficulties experienced by the caregiver-patient unit for the implementation of tailored interventions to enhance caregiver and patient outcomes. Although prior research suggests that communication issues may be present as part of the ACT model (see Wittenberg-Lyles et al., 2012), researchers have yet to comprehensively investigate communication burden as a potential stressor that requires the attention of health care practitioners.

The impact of stress on caregiver well-being was influential in the development of Demeris et al.'s (2009) ACT theoretical model, which emphasizes ongoing assessment of

the patient-caregiver unit by evaluating the caregiver's background context (i.e., geographical local, sex, age, caregiver relationship to the patient, race, religion, support services, employment, occupation, marital status, educational status, length of time in caregiving role, and hours per week providing care), stressors (i.e., primary, secondary, and intrapsychic), and health outcomes (i.e., depression, anxiety, burden, quality of life) related to the caregiving experience. The ACT model was designed for use by an interdisciplinary health care team (i.e., physician, nurse, social worker, chaplain) to conduct holistic needs assessments to develop and deliver interventions customized to mediate the effect of stressors on individual hospice caregiver outcomes (Demiris et al., 2009).

Although communication complications have been presented throughout the caregiving literature as a problematic issue (see Edwards et al., 2012; Mitrani et al., 2005; Zhang & Siminoff, 2003) that could potentially impact caregiver outcomes (see Bachner et al., 2006; Braun & Beyth, 2008; Braun et al., 2010; Savundranayagam et al., 2005), the stressors delineated within the ACT theoretical framework do not specifically outline caregiver communication difficulties as part of the three stressor types. Research is needed that conducts a comprehensive investigation into the various communication problems reported in the literature. Gaining comprehensive insight into caregiver communication will enable health care practitioners to conduct a more holistic needs assessment. By investigating communication burden using the ACT theoretical framework as a lens for inquiry, health professionals will be able to more easily identify and ameliorate communication issues that could potentially influence caregiver and patient outcomes through tailored interventions

Purpose/Rational

The ways caregivers perceive and approach communication tasks are extremely important for understanding the family caregiving experience. By gaining insight into the stress associated with caregiver communication responsibilities and caregiver burden, researchers will be able to better understand the necessary communication dynamics and barriers that function to shape the caregiving experience and influence caregiver outcomes.

A better understanding of communication burden will provide a foundation for the development of future interventions to be used by healthcare professionals for identifying caregivers in need of support, resources, and timely intervention to ultimately improve caregiver and patient quality of life. This study answers the call for an investigation of family caregiver communication stressors that contribute to caregiver burden (Garlo et al., 2010) required for the development of holistic interventions tailored to meet individual, personal, caregiving, and situational needs (Zarit, Femia, Kim, & Whitlatch, 2010). In sum, researchers have yet to conduct a comprehensive exploration of the heterogeneous communication difficulties experienced by EoL family caregivers as a potentially influential aspect of burden and caregiver quality of life.

Given that little is known about communication as a potential stressor that influences caregiver outcomes, comprehensive investigation into communication burden was conducted which was later supplemented by a small investigation into the relationship between communication burden and caregiver burden and quality of life. The next chapter provides background information regarding the construct of caregiver burden, family conflict and relational strain encountered by EoL family caregivers, a

compilation of the communication issues that are reportedly difficult for EoL family caregivers, and an overview of the ACT theoretical framework.

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CHAPTER II

Literature Review

Consistently, informal family caregiving has been reported as significantly associated with adverse physical and psychosocial health outcomes, coronary heart disease, psychiatric morbidity, burden (Terrill et al., 2012), social isolation, and psychological problems (Roth Perkins, Wadley, Temple, & Haley, 2009). As a result of the substantial caregiving responsibilities, family caregivers often report high levels of physical, social, emotional, psychological, and financial burden, which negatively impacts caregiver health, well-being, and quality of life, reducing their ability to provide optimal patient care, engage in informed decision-making, and practice self-care (Given, Given, & Kozachik, 2001).

Unfortunately, caregivers report unease associated with difficult communication tasks and responsibilities that are necessary to provide quality care (Casarette, Crowley, Stevenson, Xie, & Teno, 2005; Fried et al., 2005; Gillespie, Murphy, & Place, 2010; Houts et al., 1996; Kutner, Kilbourn, Costenaro, et al., 2009; Roscoe et al., 2005; Savundranayagam et al. 2005; Waldrop et al., 2005; Wilks & Croom, 2008; Wittenberg-Lyles et al., 2014). Moreover, EoL family caregivers will benefit from interventions that provide tools and strategies for more effective and satisfying communication with recipients (Fried et al., 2005; Haley, 2003; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010; Northouse, Kershaw, Mood, & Schafenacker, 2005; Wittenberg-Lyles, Demir, Parker Oliver, Washington, Burt, & Shaunfield, 2012; Zarit, 2004; Zulman, Schafenacker, Barr et al., 2012), family members (Bachner, O'Rourke, Davidov, & Carmel, 2009; Holst, Lundgren, Olsen, & Ishøy, 2009; Kramer, Kavanaugh, Trentham-

Dietz, Walsh, & Yonker, 2010, 2011; Mitrani, Feaster, McCabe, Czaja, & Szapocznik, 2005), and health care professionals (Aoun, Kristjanson, Currow, & Hudson, 2005; Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurzeler, & Bradley 2005; Deschepper, Bernheim, Stichele, et al., 2008; Harding, Selman, Beynon, et al., 2008; Hudson, Quinn, Kristjanson, Thomas, Braithwaite, Fisher, & Cockayne, 2008; Imes et al., 2011). However, before interventions can be tailored to EoL caregiver needs (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003), future research is needed that investigates communication as an additional stressor that should be incorporated in the ACT model, and the potential impact on caregiver outcomes (Wittenberg-Lyles et al., 2012; Wittenberg-Lyles et al., 2014; Zarit, 2004).

First, I thoroughly review the literature regarding end-of-life caregiver hardships, as well as the burdens and challenges EoL caregivers routinely face. Next, I define the construct of communication burden and review the different facets of communication burden in detail. Finally, I review and discuss the ACT theoretical model as a guiding framework for the design of this study, and identify a need to gain insight into communication burden and the potential influence on EoL family caregiver outcomes.

End-of-Life Caregiver Hardships

The family members who provide informal care for a loved one diagnosed with a progressive chronic or terminal illness often endure complex financial, physical, psychological, and social burden as a result of the experience and caregiving responsibilities that precipitate adverse caregiver and patient health outcomes (Bookman & Harrington, 2007).

Family caregivers encounter substantial financial strain. Up to 35% of US workers report that they are currently providing or have recently provided care to someone aged 65 or older (Bond, Thompson, Galinsky, & Prottas, 2002). Further, approximately 40% of caregivers provide a duration of five or more years (NAC, 2004) and approximately one-fifth provide care for over 10 years (Donelan, Hill, Hoffman, Scoles, Feldman, Levine, & Gould, 2002).

Because the amount of time needed to provide adequate care for someone approaching the end of life, caregivers must often make changes to their career plans by reducing hours, quitting their jobs altogether, and commonly postponing the fulfillment of retirement dreams (Austorm & Lu, 2009). An astounding two thirds of working caregivers report either reducing their work hours or taking unpaid leave in order to garner time to meet the responsibilities of care provision (Family Caregiver Alliance [FCA], n.d.); consequently the workforce faces decreased productivity and lost wages in paid leave, while family caregivers encounter reduced financial stability.

Informal (i.e., family) caregivers lose an average of \$659,139 due to the effects of caregiving on loss of Social Security, pension benefits, and wages (Coberly & Hunt, 1995). Furthermore, family caregivers must often foot the bill for prescription drugs, assistive equipment, medical copayments, clothing, and home modifications required for care provision (Anonymous, 2008; Taylor, Schenkman, Zhou, & Sloan, 2001). Forty-eight percent of caregivers reported using at least one of seven external services (e.g., respite, transportation, home-delivered meals) to supplement caregiving (NAC, 2004). Overall, informal caregivers receive little, if any, government assistance to finance the necessities to provide adequate care (Taylor et al., 2001).

Family caregivers employ various strategies to compensate for the expense of caregiving; some of the strategies include postponing expenditures seen as less immediate such as major purchases, home improvements, future plans, career advancement, leisure activities, and spending on the caregiver's own health and dental care (Anonymous, 2008), thus influencing adverse caregiver outcomes.

Upon accepting the arduous responsibility of providing EoL care for a family member, the caregiver essentially becomes the health care delivery system for the patient. In addition to the financial burden, the physical hardships of providing EoL care include vast physical burdens that involve assisting with activities of daily living (ADL's; e.g., dressing, bathing, transporting, administering medication) and instrumental activities of daily living (IADLs; e.g., shopping, cooking, cleaning, finances). Moreover, for the caregivers of recipients who suffer from physically and/or cognitively degenerative diseases, the physical hardships associated with providing care continue to intensify along the progressive disease trajectory (Wilks & Croom, 2008).

The responsibilities required for providing informal care to individuals approaching the end of life result in adverse health outcomes for family caregivers (NAC, 2004). In fact, caregiver need for assistance with ADLs and IADLs has been significantly associated with increased levels of caregiver burden and ill health outcomes (Garlo et al., 2010). Caregiver physical health is highly influenced by the stressors of caregiving, more so than psychological health (Pinquart & Sörensen, 2007). Reduced caregiver physical health outcomes are related to several factors, including the length of time in the caregiver role, non-spousal caregivers, higher caregiver burden and depression scores, old age, lower socioeconomic status (SES), reduced informal support, cohabitation with

the care recipient, and the presence of care recipient behavior problems and cognitive impairment (Pinquart & Sorensen, 2007).

Although the adverse impacts of caregiving on caregiver health are well documented in the literature, caregivers are often reluctant to report problems with their own personal health (Ferrell, Ervin, Smith, Marek & Melancon, 2002; Roth et al., 2009), which is likely a result of the common tendency of caregivers to focus on the care recipient's needs over their own (FCA, n.d.). Furthermore, caregiver self-care practices have been strongly associated with outcomes related to psychological distress, which may exist as a protective factor for caregiver health and well-being despite the number of other caregiving stressors (Zarit, 2010). Similarly, Pinquart and Sorensen (2007) conducted a comprehensive meta-analysis on the effects of caregiving on physical health and concluded that ill health as a result of caregiving is strongly linked to the presence psychological distress.

Taking on the role of informal caregiver yields stress-related illnesses, consisting of anxiety disorders, depression, and fatigue. These illnesses compromise the caregivers' health and serve to significantly increase psychological morbidity (Mahoney, Regan, Katona, & Livingston, 2005), jeopardizing the caregiver's capacity to provide care (Bookman & Harrington, 2007; Mitrani et al., 2005). Caregiver distress is caused by the caregiver's subjective interpretation of their caregiving activities rather than the caregiving workload (Savundranayagam & Montgomery, 2011). As a result, the most damaging effects on caregiver health and well-being are reportedly due to psychological and mental health problems (Kramer et al., 2011; Pinquart & Sorensen, 2007; Roth et al., 2009).

EoL family caregivers experience psychological burden and distress due to concerns resulting from heightened feelings of guilt, anxiety, physical and mental strain, difficulty managing patient pain and symptomology, and frustrations stemming from adverse treatment side effects (Rhee et al., 2008). Female caregivers, in particular, are highly susceptible to psychological distress resulting from the physical burden of providing care (care intensity, trajectory, and extended hours of daily care; Hirst, 2005). Further, caregivers of patients with cognitive and functional deficits suffer from psychological distress as a result of embarrassment due to care recipient behavioral problems (Montoro-Rodriguez, Kosloski, Kercher, & Montgomery, 2009). Like physical hardships, the psychological stress, anxiety, and depression continue to increase in tandem with patient decline, mobility, and cognitive issues (Dumont, Turgeon, Allard, Gagnon, Charbonneau, & Vézina, 2006; Yun, Lee, Park, et al., 2011).

As a result of heightened psychological distress family caregivers report high levels of depression. For example, approximately 70% of family caregivers have clinically significant depression (Zarit, 2004), and their anxiety and depression scores are approximately two times higher than the general population (Yun et al., 2011). These statistics are alarming, given that adverse caregiver health is reportedly more strongly associated with depression than physical stressors (Pinquart & Sorensen, 2007). Dumont and colleagues (2006) investigated the psychological distress of family caregivers providing care for a loved one with advanced cancer and found that caregiver depression severity is related to the number of patient symptoms (Dumont et al., 2006). Patients approaching death suffer from numerous comorbidities (Given, Wyatt, Given, Sherwood, Gift, DeVoss, & Rahbar, 2004), placing EoL caregivers at increased risk of developing

psychiatric and physical health problems. Unfortunately, caregiver psychological distress as a result of caregiving does not simply disappear following the care recipient's death; in fact, psychological distress often results in complicated grief which is highly associated with caregiver suicide and other adverse mental health outcomes (Kramer et al., 2011).

Caregiver loneliness further contributes to caregiver depression and psychological distress. For example, in a study investigating caregiving loneliness and depression in Alzheimer's spousal caregivers, Beeson (2003) reported loneliness as the most significant predictor of caregiver depression. Similarly, social isolation (Alexopoulos, 2005), and lack of social support (Phillips et al., 2009) has been linked to caregiver depression. Such reports are unfortunate given the propensity of caregivers who report high levels of loneliness and social isolation (NAC, 2004).

In addition to the financial, physical, and psychological influences on quality of life, caregivers often suffer from social isolation. For example, many EoL caregivers forgo pleasurable activities in order to focus on providing optimal care (NAC, 2004; Wittenberg-Lyles et al., 2014). Further, EoL caregivers who provide for patients with increased comorbidities report higher incidence of daily schedule disruptions (Given et al., 2004); therefore, in addition to giving up enjoyed activities, these caregivers are isolated from family and friends because of the scarcity of time for interactions (Aoun et al., 2005; Neufeld & Harrison, 2003; Wittenberg-Lyles et al., 2014), which results in relational deprivation (Beeson, 2003). Similarly, EoL family caregivers report feeling abandoned by family and friends in a time of immense need. For example, caregivers report feeling distress after becoming a family caregiver, due to unfulfilled and missing offers of family support and unmet expectations for social interaction with friends

(Neufeld & Harrison, 2003). Furthermore, individuals, new to the caregiving role, are often unaware of their isolation because they are overwhelmed by care responsibilities, and therefore do not seek the supportive assistance that is critically important for reducing stress (Tebb & Jivanjee, 2000). In addition to being isolated, caregivers are also strained in their social and personal lives due to competing demands on their time and energy.

Family caregivers are on average women in their late 40s and 50s (Wilks & Croom, 2008); the demands of caregiving, family needs, and the pressures of work that exist for this particular demographic often overshadow the individual needs of caregivers and their ability to function within their roles (NAC, 2004). Given the average caregiving demographic, family members who provide EoL care not only experience difficulties providing for the patient, but they must also extend their efforts to fulfill other competing roles (e.g., spouse, parent, professional) and relational role shifts (e.g., adult child caring for parents), which further contributes to caregiver stress, reduced life quality, and obfuscates support needs (Wittenberg-Lyles et al., 2014). For example, employed caregivers who have children are more likely to experience psychological strain and less likely to find meaning in the caregiving experience than those without children (Kim, Baker, Spillers, & Wellisch, 2006). Researchers have identified this phenomenon as role-strain (Gordon, Pruchno, Wilson-Genderson, Murphy, & Rose, 2012) or role overload (Gupta, Pillai, & Levy, 2012) which emerges from competing demands and support from family and work environments, further intensifying caregiver stress, burden, ill health outcomes (Gordon et al., 2012), and inhibiting psychological adjustment (Kim et al., 2006).

As a result of the conflict and stress emanating from competing role demands, caregiver age and spousal status have been established as significant predictors of caregiver burden, depression, and patient institutionalization (Gupta et al., 2012; Pinquart & Sorensen, 2007; Rhee et al., 2008). Moreover, informal family caregivers have been recognized as a highly vulnerable demographic in part due to competing demands experienced as a result of role-strain (Gupta et al., 2012). However, an additional source and perhaps the biggest source of vulnerability is the caregiver's responsibility to navigate and maintain family relationships during a time brimming with stress and uncertainty for all involved.

One of the most significant hardships faced by informal family caregivers is the increased strain on family members' relationships. One relationship that is significantly influenced by the provision of informal care is the relationship between the caregiver and recipient. The caregiver-care recipient relationship is based on reciprocity, meaning, what impacts one also impacts the other (Gordon et al., 2012). In fact, caregivers who report having a good relationship with care recipients experience less burden (Gupta et al., 2012). Further, researchers have recently highlighted the importance of patient support on caregiver well-being. For example, Gupta et al. (2012) found that support provided by patients can significantly reduce the impact of role overload and overall feelings of burden for caregivers (Gupta et al., 2012).

On the other hand, caregivers, especially spouses, who provide care for persons with Alzheimer's or other dementia-related illnesses are at high risk for depression due to a loss in relational intimacy, loss of communication, the end of future planning, and a loss of both social and recreational interactions (Austrom & Lu, 2009). As the care recipient

loses memory of people, places, and events, family caregivers lose intimacy with the recipient and thus begin to grieve the loss of their loved ones (Sanders & Adams, 2005) often heightening the caregiver's sense of social isolation (Tarrier et al., 2002). Care recipients who suffer from cognitive deficits are unable to provide support to the primary caregiver, resulting in increased caregiver burden as compared to caregivers of non-cognitively impaired recipients (Gupta et al., 2012). Therefore, the caregiver-patient relationship is not only influenced by competing role demands, but by the patient's illness and ability to communicate effectively. Although the caregiver-care recipient relationship is significantly impacted, the relationships among other family members are also highly influential in affecting caregiver quality of life and outcomes.

Family also plays a significant role in magnifying and reducing caregiver stress (Wall & Spira, 2004). The declining health of a family member often results in increased tension and challenges placing strain on family members' relationships (Wall & Spira, 2004) and compounding family troubles (Given et al., 2001). For example, siblings frequently share caregiving tasks when caring for a parent, but the responsibilities are often divided unequally which results in family conflict and resentment (Hare, 1995). Moreover, preexisting conflict that exists between family members tends to spill over and is amplified when a family member is diagnosed with a terminal illness (Neufeld & Harrison, 2003). Both previously recognized and unrecognized issues of relational strain are exacerbated when one member of the family suffers from health decline (Wall & Spira, 2004). As a result, EoL family caregivers who report reduced levels of caregiver strain are usually from supportive families in which members express themselves openly to reach agreement regarding different aspects of care and work together to help one

another cope with the demands of caregiving (Schrodt, 2005). Therefore, it is important that family members practice open and honest communication so they can assist one another by working as a team, during care transitions and when making critical care decisions.

Family involvement in decision-making can help patients and families gain a sense of coherence in the face of chaos (Murray, Miller, Fiest, O'Conner, & Jacobsen, 2004). Shared decision-making stems from effective communication between healthcare providers, family members, and the patient. Further, shared decisions are often more efficient and result in decreased healthcare costs (Murray et al., 2004). The prevalence of caregiver burden is reduced when members of the caregiving family hold similar perceptions regarding the care recipient, the presence or absence of caregiver burden, and caregiver depression (Kramer et al., 2010; Schrodt, 2005). Although open and effective communication can support caregiver decision-making and reduce burden, communication about death and dying can be one of the most difficult topics of discussion for family members.

The expressed difficulty experienced by family members regarding EoL conversations is illustrated by the prevalence of family conflict that often erupts as a result of disagreements among family members and primary caregivers regarding patient care decisions (Pearlin et al., 2009). When multiple family members attempt to assist the caregiver in decision-making, conflict often emerges because of different perceptions and lack of communication concerning what constitutes quality of life for the care recipient (Gardner & Kramer, 2009). Deficient communication between caregivers and family members contributes to conflict and increased difficulties with decision-making and

postponement or neglect of advanced care planning, which sadly results in poor end-of-life care for the care recipient and adverse caregiver outcomes (Gardner & Kramer, 2009).

The family caregiver must often take over the role of surrogate decision maker for the patient, which may further incite family tension. For EoL caregivers, decision-making processes are altered in tandem with their shifting responsibilities due to the patient's changing cognitive and functional abilities (Edwards, Olson, Koop, & Northcott, 2012). The caregiver's role in decision-making changes throughout the illness trajectory; first in a supportive role, then managing role, and then finally taking over completely (Edwards et al., 2012). Depending on the diagnosis and the patient's cognitive and communicative function, commonly caregivers become the spokesperson for the patient when the individual is unable to communicate his or her EoL care preferences. As such families often encounter ethical dilemmas concerning the care recipient's self-determination and autonomy (Wall & Spira, 2004) resulting in further conflict and family strain (Gardner & Kramer, 2009). Thus, the surrogate role adds additional responsibility and amplifies caregiver stress.

Caregivers for seriously ill patients who take on the role of surrogate decision maker often have limited conversations and knowledge of the patient's preferences causing them immense uncertainty and anxiety when making significant life decisions (Braun & Beyth, 2008). For surrogate decision makers, hardships can emerge as a result of medical complications, personal issues, and a need to negotiate family roles (Braun & Beyth, 2008). Fear of being held responsible for decisional outcomes is an immense source of burden and anxiety for family caregivers, especially those who are surrogates.

For example, many caregivers fear feeling and being held responsible for adverse outcomes and death that would result in internal family conflict and blame (Braun & Beyth, 2008). The ways in which families manage decision making and resolve conflicts that emerge at the end of life have the potential to reduce or increase caregiver depression and anxiety (Mitrani et al., 2005).

Although the family caregiving literature reveals and alludes to many communication tasks and responsibilities that are difficult for the caregiver (Fried et al., 2005; Pruncho, Burant, & Peters 1997; Savundranayagam et al. 2005; Wittenberg-Lyles et al., 2012), communication has yet to be investigated as a stressor in itself, which may influence caregiver burden and quality of life.

Communication Burden

Family members who provide informal EoL care for loved ones diagnosed with a progressive chronic or terminal illness endure complex financial, physical, psychological, and social stressors and burden associated with providing care that leads to a decrease in the caregiver's health and well-being and a reduction in the patient's quality of life and even death (Bookman & Harrington, 2007). Although the caregiving literature clearly illuminates dimensions of burden experienced by informal family caregivers, it does not encapsulate a comprehensive view of caregiver burden.

A thorough review of the caregiving literature reveals an additional area of burden related to communication, which will be referenced henceforth as *communication burden*. Based on a compilation of prior research findings, I have identified a construct I have coined, communication burden. For the purposes of the research presented here, I have defined communication burden as the stress resulting from communicative tasks and

responsibilities required for care provision that cause the caregiver undue distress. The compilation of past research findings reveals that communication burden may be associated with the following communication tasks: (a) informing and involving other family member in care decisions and end-of-life discussions (Houts et al., 1996; Waldrop et al., 2005); (b) expressing feelings of stress and exhaustion from caregiving tasks (Wilks & Croom, 2008); (c) communicating about sensitive issues and care decisions with others (Roscoe et al., 2005; Waldrop et al., 2005); (d) disclosing to family and friends a need for assistance with care duties (Wittenberg-Lyles et al., 2014); (e) communicating with the patient about his/her own care preferences (Fried et al., 2005; Gillespie et al., 2010); (f) inability to communicate with patients in advanced stages of illness (Savundranayagam et al. 2005); and (g) seeking support and information from health care professionals (Casarette et al., 2005; Kutner, 2009).

Although, caregiver burden has received substantial attention over the past few decades (see Savundranayagam et al., 2005), *communication* burden is a novel and largely un-investigated construct and potentially associated with adverse family caregiver outcomes. Below, I review evidence supporting the existence of the construct of communication burden and the potential influence on outcomes. The following discussion is organized according to the seven categories of communication burden I identified and assembled based on the compilation of extant research, which were reviewed above.

Informing/Involving Family Members About Illness and Disease Progression

Notable tension emerges when family caregivers attempt to inform and/or involve other family members about the patient's illness, disease progression, and decisions that

have been or will be made on the patient's behalf. As a result, caregivers report experiencing a form of internal conflict regarding their own appraisals of the situation, in addition to external conflicts that commonly erupt between family members as a result of different perceptions regarding the patient's status and care needs (Neufeld & Harrison, 2003). Conflict often emerges between caregivers and family as a result of divergent perceptions regarding the patient's health care needs (Hare, 1995). Furthermore, when ineffectively managed, family conflict can become a source of tremendous psychosocial burden and stress for caregivers (Neufeld & Harrison, 2003).

Family conflict can be managed in a variety of ways, some more healthy than others. Unfortunately, in the emotionally charged context of EoL care, conflict management can be demanding, which sadly adds more stress and hardship for the caregiver to navigate in addition to their daily care responsibilities (Zhang & Siminoff, 2003). In a study of late-stage oncology caregivers, Zhang and Siminoff (2003) discovered that families tend to avoid discussions about cancer in order to reduce psychological distress, protect one another, and maintain a positive attitude. Disruption to the family environment may be one of the most substantial caregiver stressors (Scharlach & Dalvi, 2006). Therefore, the EoL family caregiver's responsibility to inform and involve family members in aspects of patient care may influence a felt sense of communication burden.

Expressing Feelings of Stress and Exhaustion

Although caregivers desire someone to talk to and a support system to help them through the caregiving experience, they often avoid expressing their feelings in order to maintain a sense of independence and pride (Coe & Neufeld, 1999; Imes et al., 2011). A

few studies reveal that caregivers are reluctant to impose upon family and friends to express their support needs (Egbert, Koch, Coeling, & Ayers, 2006; Wittenberg-Lyles et al., 2014). Finally, caregivers reportedly feel as though patients do not fully comprehend the impact illness has on them (Imes et al., 2011). Meanwhile recent research suggests that caregivers who avoid discussing their feelings of stress and exhaustion may be unable to obtain emotional release, which could lead to further adverse psychological and health outcomes (Wittenberg-Lyles et al., 2014).

Communication About Sensitive Issues and Decisions

Initiating conversations about sensitive issues and decisions are expressly difficult for EoL family caregivers. Due to the raw nature of EoL discussions, family members have a tendency to respond by critiquing decisions made by the caregiver, which commonly involves the exchange of disparaging comments and conflict (Neufeld & Harrison, 2003). Conflict among family members at the end of life is further intensified as the patient's symptoms become more distressing and when the family is aware of the approaching death (Kramer et al., 2010). In support of these claims, Scharlach and Dalvi (2006) suggested that the psychosocial stressors of caregiving might produce a larger impact on caregiver burden than other stressors. The tension that ensues among family members and the resulting stress and anxiety adversely affects caregiver well being (Braun & Beyth, 2008; Scharlach & Dalvi, 2006), which may further deters the caregiver from engaging in sensitive EoL care discussions.

Family disagreements at the end of life often emerge from the necessity to make difficult and emotionally laden decisions in which family members have divergent care preferences (Kramer, Boelk, & Auer, 2006; Kramer et al., 2010). In fact, two thirds of

family disagreements result from the necessity to make decisions regarding treatment alternatives, discontinuation of treatment, hospice enrollment, and facility placement (Zhang & Siminoff, 2003). Furthermore, when the family has a history of past conflict, conflict during EoL care is highly prevalent (Kramer et al., 2010), especially when the prior conflict was unresolved (Kramer et al., 2006). As a result, when the caregiver is part of a family with a history of confrontation and disagreements, the caregiver is significantly more likely to refrain from discussing sensitive issues and decisions (Braun & Beyth, 2008; Scharlach & Dalvi, 2006; Wittenberg-Lyles et al., 2014), which may cause further caregiver anxiety and strain, especially when s/he desires family input and support. Therefore, the seemingly simple act of planning to initiate family discussions about EoL care and decision-making may further intensify caregiver communication burden.

Disclosing Assistance Needs to Family and Friends

Similarly, family caregivers experience vast barriers that prolong and even prevent the caregiver from disclosing a need for assistance with care tasks to members of their social network. In fact, seeking support has been identified by EoL hospice caregivers as one of the most difficult aspects of caregiving (Wittenberg-Lyles et al., 2014). Although communication is largely important to the provision of informal EoL care, family caregivers must know how to ask for help (Jansm, Schure, & Jong, 2005). One reason caregivers neglect to reveal support needs to members of their social network is because support is a reciprocal process, and as a result, they commonly opt not to seek support in order to evade the emotional toll of reciprocating due to insufficient emotional

capacity and time (Wittenberg-Lyles et al., 2014). However, there may additional reasons that family caregivers opt not to reveal their assistance needs to friends and family.

A recent study, found that family caregivers disclose support needs differently to friends and family members because they perceive the existence of different relational boundaries among the two. With regard to friends, family caregivers feel discomfort asking for support because this is seen as overstepping friendship boundaries, a perception that instrumental tasks involve too much responsibility for a friendship, and fears regarding the impact on the friendship (Wittenberg-Lyles et al., 2014). Further, EoL caregivers forgo seeking support from family because it is perceived to be too burdensome and stressful for many reasons, such as: ingrained family communication barriers, to deter acknowledging the lack of support and resulting emotional turmoil, the anticipation of criticism of their care effort (see Wittenberg-Lyles et al., 2014). Likewise, Neufeld & Harrison (2003) reported that caregivers are reluctant to ask for assistance because they others will interpret a need for support as evidence of the caregiver's inability to provide care and cope with their circumstances (Neufeld & Harrison, 2003). In addition to concerns of their own stress, family caregivers report reluctance to ask for help due to an awareness of non-care related stressors experienced by family members (e.g., preexisting emotional problems, geographical distance, having young children; Wittenberg-Lyles, Goldsmith, Demiris, Parker Oliver, & Stone, 2012; Wittenberg-Lyles et al., 2014). For these reasons, caregivers report being ill inclined to seek instrumental and informational support from family and friends. However, a comprehensive investigation of communication burden is needed to explore the existence of the findings reported above and potential other reasons EoL caregivers avoid seeking support.

In addition to perceived relational boundaries that inhibit disclosure of support needs, caregivers describe other barriers that keep them from seeking support such as, personal beliefs and values (e.g., need for independence, sense of personal responsibility, pride; Coe & Neufeld, 1999), prior experience with mismatched, incompetent, missing, or unfulfilled offers of support (Neufeld & Harrison, 2003), social isolation (Tebb & Jivanjee, 2000), felt need to ask patient permission to seek support (Wittenberg-Lyles et al., 2014), a need to maintain complete control of care tasks, decision-making, and care management, and an inability to trust others to provide adequate patient care (Wittenberg-Lyles et al., 2014). Wittenberg-Lyles et al. (2014) reported that EoL family caregivers do not trust others to provide adequate care for the patient. Care provision requires medical expertise and knowledge (e.g., patient symptoms, needed medical equipment, medication side effects), which serves as a barrier to caregiver acceptance of outside support from the caregiver's social network and even formal support services (Wittenberg-Lyles et al., 2014). As a result of the barriers cited by EoL caregivers for not disclosing or accepting assistance, Kim et al. (2006) recommended that health care providers encourage family caregivers, to communicate their support and assistance needs to members of family, social networks, and health care professionals. However, this is easier said than done as evidenced by the communication burden experienced as part of EoL caregiving. A comprehensive in-depth investigation of communication burden will provide the necessary insight into the communication problems and barriers that prevent EoL family caregivers from seeking support so that services can be tailored to assist caregivers in that task.

Communication with the Patient Regarding Preferences

Many caregivers report a desire for more open communication with care recipients; however, caregivers are often reluctant to initiate communication concerning sensitive topics, as these topics are perceived as difficult to discuss (Fried et al., 2005). The recognized difficulty may stem from the patient's lack of reported desire for increased communication with the caregiver. The discrepancy in caregiver and patient communication desires is unfortunate given that caregiver desire for increased communication with care recipients is associated with increased burden and emotional turmoil (Fried et al., 2005). However, Fried and colleagues (2005) reported that caregivers and patients who describe communication with each other as adequate report the lowest burden. These findings indicate that unmet caregiver communication needs may serve to increase caregiver burden.

Additionally, caregivers experience an increase in burden when divergent perspectives exist between caregiver and care recipient. Patients and caregivers are often unaware of the other's needs or perceptions, and it is possible that lack of communication could result in increased caregiver burden. For example, Sharp, Butow, Smith, McConnell, and Clarke (2005) investigated the impact of met and unmet needs on caregiver burden for persons diagnosed with cancer. The authors found most caregivers perceive patients as having more unmet needs than patients themselves report which sadly results in intense emotional turmoil (Sharpe et al., 2005). Therefore, it is likely that discrepancies between caregiver and patient perceptions of met needs may impact caregiver burden as caregivers likely assume more responsibility to meet what they perceive as the patients' unmet needs. Given et al. (2001) attributed divergent perceptions

as extending from long-standing family communication patterns. Moreover, oncology caregivers who attempt to protect patients by not discussing patient needs have been reported to encounter increased burden and reduced quality of life (Sharpe et al., 2005).

Caregiver perceptions also impact the quality and quantity of patient-caregiver communication regarding EoL topics. Imes and colleagues (2011) investigated partners' experiences living with severe heart failure and discovered that caregivers experienced difficulties communicating with patients based on perceptions that the patient was not being fully forthcoming about the negative aspects of their disease. Moreover, the caregivers also avoided engaging in EoL conversations as a means of maintaining hope for the patient (Imes et al., 2011). Similarly, in a study of oncology caregivers, Lobchuk (2006) found that caregivers rarely discuss patient symptoms because they perceive such topics to be taboo and threatening.

Family caregivers are often unsure of the patient's EoL preferences and wishes due to inadequate or non-existent communication. In fact, less than 20% of families report having discussed EoL concerns and care preferences, thus surrogate-patient agreement sadly ranges from poor to moderate (Gardner & Kramer, 2009). The stress experienced by surrogates results from expectations to make medical decisions without knowing patient preferences or the outcome of their decisions (Braun & Beyth, 2008; Fried et al., 2003). The lack of communication and agreement concerning EoL issues is a common source of conflict that contributes to ineffective decision-making, advanced care planning, and poor end of life care (Kramer et al., 2006).

There are many reasons that caregivers avoid engaging in EoL conversations with patients. For one, many avoid engaging patients in EoL discussions due to fears about the

illness and impending death (Bachner & Cammel, 2009). As a result, terminal patients and their caregivers report immense difficulties when attempting to discuss these issues; Bachner et al. (2009) coined the term mortality communication. Another reason caregivers delay or avoid EoL discussions is to preserve strength. EoL discussions are emotionally draining, and as a result the caregivers who are already experiencing emotional distress may choose to avoid communication as a means of preserving strength (Bachner & Carmel, 2009). Moreover, cancer patients and family members often use silence as a tool to avoid emotional distress; sadly, the silence in fact increases the stress and emotional suffering of patients, caregivers, and family members (Zhang & Siminoff, 2003).

Caregiver-patient avoidance of communication regarding EoL issues and care preferences results in ill outcomes for both the caregiver and the patient. For example, when caregivers and patients avoid communicating about sensitive illness-related issues or hold back when discussing certain topics, patients experience intense isolation while their caregivers experience immense anxiety and psychological distress stemming from uncertainty regarding their loved one's needs (Zhang & Siminoff, 2003). Moreover, Porter and colleagues (2005) suggested that low levels of disclosure may cause poor relationship functioning. Another adverse outcome of communication avoidance is the caregiver's inability to accurately assess the patient's condition and needs (Zhang & Siminoff, 2003). Furthermore, poor communication quality is strongly associated with caregiver distress and depression (Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010).

Although there are many problems associated with caregiver-patient communication regarding EoL care preferences, effective communication has been

shown to improve the caregiver-patient relationship (Edwards et al., 2012; McLean & Jones, 2007), encourage perspective taking (Lobchuk, 2006), foster congruent perceptions regarding EoL preferences (Gardner & Kramer, 2009), increase intervention acceptability (Fried et al., 2003), reduce conflict (Lobchuk, 2006), improve decision-making capacity (Braun & Beyth, 2008), reduce caregiver psychological distress (e.g., guilt, uncertainty, depression, emotional exhaustion; Bachner et al., 2009), reduce caregiver burden (Braun & Beyth, 2008), and result in an overall decrease in health care costs (Fagerlin et al., 2002). Therefore, caregiver communication burden that stems from ingrained barriers in the caregiver-recipient relationship can vastly influence individual, community, and societal costs.

Inability to Communicate with Patients in Advanced Illness

Patients are often unable to communicate during advanced stages of illness. The inability to converse with patients is problematic for several reasons. First, when the patient is no longer able to communicate his/her care preferences, the caregiver must take over decision making completely (Edwards et al., 2012) often without adequate knowledge of the patient's preferences (Braun & Beyth, 2008) resulting in exceptional unease (Mitrani et al., 2005). When the patient is unable to communicate, caregivers commonly rely on other information to determine the patient's psychological and physical pain (e.g., analgesic use, facial expressions, functional decline, and agitation; (McPherson & Addington-Hall, 2004), which causes immense fear and unease, particularly when attempting to discern pain management needs (Mitrani et al., 2005; Wittenberg-Lyles et al., 2012). Alzheimer's and dementia caregivers, in particular, must manage communication breakdowns throughout the illness trajectory, especially in the

final stage when patients become fully dependent. As a result communication has been identified as an essential facet of Alzheimer's caregiving (Alzheimer's Association, 2010; Small, Gutman, Makela, & Hillhouse, 2003).

In addition to the inability to communicate with patients and the difficulties encountered when attempting to decipher patient needs, family caregivers also experience a form of relational loss when unable to communicate with their loved one. Caregivers report feeling a loss of support due to the inability to communicate about relational issues and decision-making with the patient, which could precipitate psychological distress (Savundranayagam et al., 2005), depression, and anxiety (Braun et al., 2010) for the caregiver. So the family caregiver not only assumes the responsibility of making decisions, and identifying and managing patient pain, they also experience a loss of the relationship with their loved one, and therefore begin to grieve (Sanders & Adams, 2005).

Seeking Support and Information from Health Care Professionals

Although family caregivers require guidance and information from health professionals to provide adequate care for their loved ones (Imes et al., 2011), they often experience problems when attempting to seek support and/or information from health professionals. Barriers that prevent caregivers from seeking support involve communication process barriers, health system barriers, and family challenges (Aoun et al., 2005). Communicating with health care professionals, especially physicians, is strenuous due to their use of ambiguous medical jargon and incomplete information resulting in poor caregiver understanding of the medical condition, prognosis, and treatment options (Braun & Beyth, 2008). Similarly, caregiver understanding of the patient's condition and treatment alternatives is strongly affected by physician

communication as discussions of patient terminality are often avoided until the last month or week of patient life (Cherlin et al., 2005), thus likely inhibiting caregivers from seeking appropriate supportive advice and services. Caregivers describe a desire for more information from providers regarding ways of treating symptoms, where to search for information, illness progression, and expectations for the future (Imes et al., 2011). As a result of existing communication barriers, caregivers report having numerous unanswered questions, yet they feel unable to pose them (Harding et al., 2008). Moreover, the communication issues that exist between the caregiver and provider prevent health professionals from fully understanding the difficulties endured by caregivers while providing patient care (Imes et al., 2011), which could ultimately impact patient care.

Additional barriers that prevent caregivers from obtaining outside assistance include unavailable information regarding service availability (e.g., respite), service inflexibility, and personal barriers to seeking outside assistance (e.g., guilt, beliefs, misconceptions; Aoun et al., 2005). Moreover, when services do exist, caregivers report avoiding and resisting formal agency support in order to maintain family privacy, feeling obliged to do something in return, and dishonor from admitting assistance needs (Coe & Neufeld, 1999). Another barrier preventing family caregivers from accepting formal support services exists due to a desire to maintain control, thus limiting the role and ability of supportive staff to assist (Wittenberg-Lyles et al., 2014). Moreover, recent research reveals that caregivers perceive outside support services as creating more work and burden rather than the intended purpose to help with tasks and alleviate stress (Williams, Williams, Zimmerman, Munn, Dobbs, & Sloane, 2008; Wittenberg-Lyles et al., 2014). As a result of problematic barriers that exist for obtaining information and

support, family caregivers report a need for more improved information exchange with providers (Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004). Caregivers' unmet needs for expert information could potentially lead to frustration and a felt sense of communication burden, which requires further investigation.

Although various topics and issues have been identified as difficult for EoL family caregivers, the caregiving literature lacks a comprehensive investigation into the various communication problems as described by EoL family caregivers. Moreover, the existing caregiving literature largely provides a descriptive depiction of communication problems while providing minimal insights into the reasons caregivers perceive specific communication tasks to be troublesome. The current study fills this gap, not only by conducting an in-depth investigation into the communication tasks that caregivers perceive as problematic, but going beyond the surface to discern why the identified communication tasks are perceived as stressful. The newly identified construct of communication burden presented in this study, should be evaluated as part of EoL caregiver-patient needs assessments to identify caregivers in need of individualized services which could potentially enhance patient and family outcomes.

EoL family caregivers require interventions that provide tools and strategies for more effective and satisfying communication regarding EoL issues (Zarit, 2004). Zarit et al. (2010) investigated the relationship among risk factors (e.g., behavioral problems, family conflict) and caregiver outcomes (e.g., overload, depression). Due to the heterogeneity of findings, the authors concluded that interventions must be tailored to specific personal, caregiving, and situational needs. In order for end-of-life care services to be effective, researchers and practitioners must get past the "one size fits all" approach

to care (Lunney et al., 2003, p. 2391). In order to facilitate the individualization of EoL caregiver interventions by health care professionals, Demiris et al. (2009) developed a theoretical model to assist with the challenging task of conducting ongoing caregiver needs assessments, and therefore was an appropriate lens for inquiry in the current study.

ACT Theoretical Framework

Interventions provided to EoL caregivers are generic consisting of respite care, one-on-one education, referral to support groups (Harding & Higginson, 2003). Unfortunately, the limited and generic interventions provided to EoL caregivers do not meet their unique needs, specifically because caregiver burden is subjective and related to support (Goldstein, Concato, Fried, Kasl, Johnson-Hurzeler, & Bradley, 2003). The impact of stress on caregiver well-being was influential in the development of Demiris et al.'s (2009) theoretical model Assessing Caregivers for Team interventions (ACT), which emphasizes ongoing caregiver assessment for the development of tailored interventions delivered by EoL interdisciplinary teams to improve caregiver subjective experiences and health outcomes. Although communication problems have been described as a significant problem that could potentially impact caregiver outcomes (see Bachner et al., 2006; Braun & Beyth, 2008; Braun et al., 2010; Savundranayagam et al., 2005) the stressors delineated within the ACT theoretical framework do not specifically outline the communication difficulties as part of the three stressor types. By adding communication burden to the ACT theoretical framework, health care practitioners will be able to more easily identify and ameliorate communication stressors that influence caregiver and patient outcomes with interventions tailored to individual caregiver needs.

The theoretical model known as ACT was founded on extensive prior research on caregiving and Pearlin, Mullan, Semple, & Skaff's (1990) original stress process theory that emphasizes the influence of stressors, moderators/mediators, and stressor outcomes. According to stress process theory, the environmental and social stressors influence caregiver outcomes, but the effects can be buffered or directly impacted with moderating and mediating variables. For Pearlin et al. (1990) moderators included social and personal resources (e.g., sense of mastery, self-esteem) that could attenuate stressors, which can effect or change the situation that is producing the stressors. Mediators (e.g., instrumental, informational, emotional support, and coping) have the potential to directly affect the relationship between stressors and outcomes. Outcomes, on the other hand, consist of health and mental health problems. Pearlin et al.'s (1991) original stress process theory was later modified by Meyers and Gray (2001) who conducted extensive research to identify specific caregiver background variables that characterize "at-risk" caregivers. Meyers and Grey's research produced a robust and parsimonious predictor model for caregiver satisfaction with hospice care, caregiver quality of life, and caregiver burden that emphasized the interrelated and dynamic nature of the various factors providing a foundational framework for the ACT theoretical framework.

Demiris and colleagues (2009) developed the ACT model by adopting and modifying the work of Pearlin and colleagues (1990) and Meyers and Gray (2001); the final ACT model resulted in a theoretical framework that specifically calls for the identification of individual caregiver background variables, stressors, outcomes, and mediators to inform EoL (i.e., hospice) caregiver needs assessment for the delivery of customized services. The ACT model considers the caregiver and patient as a unit of care

in which members of the hospice interdisciplinary team (i.e., physician, nurse, social worker, chaplain, volunteer coordinator) conduct ongoing needs assessments of the caregiver-patient unit in order to develop and deliver tailored interventions to mediate the effect of stressors on caregiver outcomes (Demiris et al., 2009).

In the ACT model, background context variables consist of geographical location, sex, age, caregiver relationship to the patient, race, religion, support services, employment, occupation, marital status, educational status, length of time in caregiving role, and hours per week providing care. The health care team should consider the influence of the caregiver's background context when conducting the needs assessment and developing tailored interventions. Additionally, the

ACT model consists of three stressor types (i.e., primary, secondary, intrapsychic).

Primary stressors consist of the physical tasks of caregiving (e.g., exhaustion, hospice acuity, caregiving trajectory). Secondary stressors involve the personal impact of the caregiving tasks on the caregiver (e.g., time for self-care, life disruptions, isolation, lack of privacy, financial problems, and myths). Intrapsychic stressors include the caregiver's thoughts, feelings, and awareness of the caregiving role (e.g., identity, self-identity, role mastery, role negotiation; Demiris et al.,

2009; Wittenberg-Lyles et al., 2012). The outcome variables in the ACT model include hospice satisfaction, caregiver quality of life, anxiety, social effects, and perceptions of patient outcomes.

The mediating variables included in the ACT model are identified as internal and external. Internal mediators include coping, which mediates the impact of stressors on outcomes because anxiety and other psychological complications result from limited

coping strategies and personal resources. The caregiver's social network is also an internal mediating factor (Demiris et al., 2009). External mediators include hospice care, social support, and implementation of the ACT model itself. The ACT model serves as a mediator because when the stressors outweigh the resources needed to cope, the implementation of ACT becomes a mediator to improve caregiver outcomes (i.e., hospice satisfaction, caregiver and patient quality of life; Demiris et al., 2009).

The focus on both process and outcome variables emphasizes and makes possible continuous quality improvement for EoL services that are tailored to the unique needs of caregivers to ultimately improve outcomes and holistic service delivery (Demiris et al., 2009). Further, the model emphasizes a bidirectional informational flow between members of the interdisciplinary team, caregivers, and patients, which is necessary to achieve the goal of comprehensive holistic EoL care services (Parker Oliver et al., 2009).

Prior research suggests that caregiver communication issues may be present within the three stressor types outlined in the ACT model (see Wittenberg-Lyles et al., 2012). Communication burden as a stressor that potentially impacts caregiver and patient health outcomes should be further investigated as part of the ACT theoretical model. By revealing and identifying specific communication difficulties within the stressor types, the framework can be further elaborated to include a more comprehensive view of the caregiving experience and the difficulties encountered that produce adverse caregiver outcomes. In addition to making a more comprehensive model, adding communication burden to the ACT framework will ensure that members of the health care team recognize

communication aspects as a potential stressor. This is significant given the previous evidence that medical practitioners commonly attend to the biomedical rather than biopsychosocial aspects of care and well being (McNamara & Rosenwax, 2010) in which communication burden resides.

The ACT theoretical model is a useful tool that can be used to improve the experiences of family caregivers and patients through a process of conducting ongoing assessments of the caregiver-patient unit regarding the background context, stressors (i.e., primary, secondary, intrapsychic), and caregiver outcomes to undergird the interdisciplinary (holistic) design and implementation of tailored EoL care services that meet the unique needs of individual caregivers.

The ACT theoretical model is a novel approach to EoL care delivery that is based on extensive research, theoretical development, and modifications that translate stress process theory research into a practical tool that can be applied in an EoL care setting to enable the delivery of truly holistic services (Demiris et al., 2009). Although communication is fundamental to the implementation of the ACT theoretical model regarding communication and collaboration between team members, caregivers, and patients, evidence exists suggesting that communication may be a stressor that should be assessed and addressed by tailored EoL services (Wittenberg-Lyles et al., 2012).

Overall, the EoL care literature is overflowing with evidence that caregiving is replete with difficulties, burden, and emotional distress, causing negative health outcomes for the informal caregiver (e.g., increased morbidity, mortality), which in turn, negatively impacts the patient's quality of life and death (FCA, 2009). The vast burden experienced by EoL caregivers involves the following dimensions: financial (e.g.,

retirement, quit job, high cost of patient care; FCA, n.d.; Given et al., 1992), physical (e.g., exhaustion, illness, pain), emotional (e.g., anxiety, depression, decreased quality of life), social (e.g., isolation, relational impact). The next section develops and presents the research questions and hypotheses for this dissertation.

Research Questions and Hypotheses

The goal of this dissertation was to conduct an in-depth exploration of caregiver communication burden and the potential influence on caregiver outcomes that was founded on higher-level qualitative research that applies existing literature findings in order to extend EoL caregiving research (see Funk et al., 2010). Rather than focusing on the objective stressors (e.g., physical, instrumental tasks) when investigating the mental health of caregivers, the subjective perception (e.g., loneliness, depression, relational deprivation, loss of self, coping ability) of the caregiving situation requires attention (Beeson, 2003; Garlo et al., 2010). Researchers should also investigate the relational, contextual, and communication influences on EoL caregiver health and well-being (Garlo et al., 2010; Given et al., 2001; Fleming, Sheppard, Mangan, Taylor, Tallarico, Adams, & Ingham, 2006).

The main objective of this dissertation project was to gain comprehensive insight into EoL family caregiver communication burden; therefore qualitative research methods were primarily utilized in order to achieve a thick description of communication burden as described by caregivers in their own words. Thus, the following research questions were used to guide this study:

RQ1: How do communication stressors manifest for family caregivers who provide EoL care?

For the second research question, a supplementary investigation was conducted regarding the existence of caregiver communication burden by modifying, appending, and refining an initial pilot communication burden measure (see Chapter 5), based upon the enhanced insight and understanding of caregiver communication burden experienced by EoL family caregivers cultivated during the participant interview process.

RQ2: Can a reliable and valid measure of EoL family caregiver communication burden be developed?

A potential association exists between high levels of caregiver burden and communication difficulties (Garlo et al., 2010), which should be investigated and considered in the development of tailored EoL caregiver interventions aimed at ameliorating EoL caregiver stress, burden, and anxiety (Mitrani et al., 2005). Although the EoL caregiving literature reveals that communication tasks are often difficult for the caregiver (Fried et al., 2005; Savundranayagam et al. 2005; Wittenberg-Lyles et al., 2012), these tasks have not been investigated as a stressor in itself and a potential predictor of caregiver outcomes (Garlo et al., 2010; Given et al., 2001; Fleming et al., 2006). In order to supplement the newly elaborated construct of caregiver communication burden, I further conducted an introductory investigation into the influence of communication burden on caregiver outcomes using the ACT theoretical model as a guiding framework. Thus, I proposed the following hypotheses:

H1: Communication burden is significantly associated with caregiver burden when controlling for background context variables.

H2: Communication burden is significantly associated of caregiver quality of life when controlling for background context variables.

H3: Communication burden is significantly associated with quality of life over and beyond caregiver burden when controlling for background context variables.

This chapter provided an overview of the hardships that affect EoL caregiver quality of life and well-being, the communication burden experienced by EoL family caregivers, and the potential influence on caregiver outcomes. The ACT theoretical framework was outlined and used as a guide for conducting a comprehensive qualitative investigation into the experience of EoL family caregiver communication burden and to gain supplemental insight into the potential influence of communication stressors on caregiver burden and quality of life. The following chapter provides a description of the qualitative methodology used to conduct this study.

CHAPTER III

Qualitative Method

EoL family caregivers encounter significant hardships and burden that decrease their quality of life and increase mortality (NAC, 2009). In addition to the burden commonly reported, new research is accumulating that suggests an additional caregiver stressor exists, which I refer to as communication burden that involves communication tasks required for care provision that cause the caregiver undue stress or distress (Shaunfield et al., 2013). The main objective of this study was to gain insight into caregiver communication burden and investigate the potential impact on caregiver outcomes. For this study, the ACT theoretical model (Assessing Caregivers for Team interventions) provides a useful framework for conducting a comprehensive investigation of the potential influence of caregiver communication burden on outcomes. This chapter provides an outline of the methodology, participants, and data analysis for this study.

Approach

The methodological approach for this dissertation project was developed in light of distinct gaps in the literature regarding EoL family caregiving. Although extensive research exists regarding the EoL family caregiver experience (see Andershed, 2006; Pinquart & Sorensen, 2003, 2007; Robison et al., 2009), there are many areas that remain uninvestigated, (Funk, Stajduhar, Toyne, Aoun, Grande, & Todd, 2010; Garlo et al., 2010), particularly with regard to communication stressors. Three EoL caregiving research deficiencies identified by caregiving scholars will be discussed to support the methodological choices made for this project. First, research regarding caregiver burden within the context of EoL care has been conducted and validated largely within disease-

specific illnesses (Funk et al., 2010). The majority of EoL caregiving research has been conducted in populations of caregivers providing for advanced cancer patients (Aoun et al., 2005; Funk et al., 2010; Garlo et al., 2010; McMillan, 2005; Stajduhar, Funk, Toye, Grande, Aoun, & Todd, 2010) and Alzheimer's disease and related dementias (ADRD; Garlo et al., 2010). The fact that caregiver burden research has mainly been conducted in ADRD and oncology caregiver populations gives credence to the difficulties experienced by these two caregiver types, in particular. Although the proposed hypothesis that communication stressors would be strongly associated with caregiver burden was based on the results of a small pilot study (Shaunfield et al., 2013), this investigation builds on the pilot work by investigating communication stressors within a caregiving population in which caregiver burden has been validated and established based on abundant extant research. Moreover, communication burden is a novel construct, and therefore should be investigated in light of and informed by a broad understanding of caregiver burden in these particular contexts.

As previously mentioned, the literature on EoL caregiving contains a vast array of qualitative research studies (Badr & Taylor, 2009; Braun & Beyth, 2008; Cherlin et al., 2005; Coe & Neufeld, 1999; Deschepper et al., 2008; Edwards et al., 2012; Fried & O'Leary, 2008; Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003); however, the interpretation of qualitative EoL caregiving research tends to be more descriptive and is largely atheoretical (Funk et al., 2010). As a result, higher-level qualitative research is needed in the context of EoL caregiving that applies existing concepts from the literature and/or refines existing theories (Funk et al., 2010). The qualitative portion of this project not only utilized existing concepts (i.e., caregiver burden), but a new construct was

identified, designated, investigated, and measured (i.e., communication burden), in hopes of extending the literature and conceptualization of caregiver burden outlined by the ACT model by unveiling communication-related stressors that should be assessed and incorporated when tailoring interventions to EoL caregivers and patients.

Lastly, although prior research has referenced the potential influence of communication on caregiver health outcomes (Aoun et al., 2005; Austrom & Lu, 2009; Beeson, 2003; Braun & Beyth, 2008; Gardner & Kramer, 2009; Garlo et al., 2010; Neufeld & Harrison, 2003; Mitrani et al., 2005; Pruncho et al., 1997; Tebb & Jivanjee, 2000; Wittenberg-Lyles et al., 2014), to my knowledge a paucity of research exists that conducts a comprehensive investigation of the communication burden experienced by EoL family caregivers. Moreover, Garlo and colleagues (2010) reported a need for research that investigates the potential association between high levels of caregiver burden and communication stressors in order to gain insight into specific factors that affect caregiving coping abilities for the development of more efficacious psychosocial interventions. In order to make such claims, quantitative data must be collected from a large sample of EoL family caregivers. This study answers the call for future research, that further supports descriptive accounts of communication difficulties by conducting a supplementary investigation to explore which of the seven communication burden categories identified in the literature can be measured empirically, and discover whether an association exists among communication burden and caregiver outcomes.

Research Design

This project was designed primarily from a qualitative methodological approach with the goal of gaining a comprehensive understanding of caregiver communication

burden. To further supplement the qualitative findings, a mixed methods approach was employed to initiate the investigation of communication burden and outcomes. A concurrent triangulation mixed methods design (Cresswell & Clark, 2011) was employed, to explore caregiver communication stressors through in-depth participant interviews. Throughout the interview process, the author made memos and notes in order to refine, further develop, and re-test a measure of communication burden in relation to caregiver outcomes (i.e., caregiver burden, quality of life). As the main focus of this dissertation, and for the purpose of clarity, the qualitative methods (i.e., participants, recruitment, procedure, data analysis) are described below. The methods for the auxiliary quantitative component are reviewed in Chapter V.

Study Participants

The primary objective of this dissertation project was to gain comprehensive, qualitative, insight into the communication burden described by EoL family caregivers. Prior to revealing the qualitative findings derived from interview transcripts, it is necessary to understand the disease contexts faced by the participant-caregivers, which undoubtedly shaped the communication difficulties they discussed. The interview participants consisted of the following: a) caregivers currently providing care for a family member diagnosed with Alzheimer's disease and related dementias (ADRD); and b) caregivers currently providing care for family member diagnosed with Glioblastoma (GBM). Provided below, a brief overview of ADRD is presented, followed by a description of GBM.

Alzheimer's Disease and Related Dementias (ADRD)

For the qualitative data collection, Alzheimer's caregivers accounted for 95% of the ADRD caregiver participants; additionally, two caregiver participants provided care family members diagnosed with other dementia forms (i.e., Lewi Body dementia, Frontal temporal dementia). A brief overview of dementia is provided below, along with the specifics of Alzheimer's disease. ADRD is a general term that refers to diseases affecting a person's cognitive abilities and function. Alzheimer's disease is the most common form of dementia; currently up to 80% of dementia cases have been diagnosed as Alzheimer's disease. Other types of dementia under the ADRD umbrella include Dementia with Lewy bodies (DBL), Vascular dementia, Mixed dementia, Parkinson's disease, Frontotemporal lobar degeneration (FTLD), among others (Alzheimer's Association, n.d). Although the symptoms of related dementias vary, to be diagnosed as having dementia, the patient must be significantly impaired in at least two core mental functions (i.e. memory, communication/language, focus/attention ability, reasoning/judgment, visual perception). Many forms of dementia are progressive, which means that symptom onset begins slowly and gradually becomes worse. The severity and specificity of symptoms vary greatly among the different forms of dementia (Alzheimer's Association, 2014).

Nationally, 5.2 million Americans (i.e., one in nine over the age of 65) suffer from Alzheimer's disease (AD; Alzheimer's Association, 2014); recent projections reveal the number of cases is expected to triple by 2050 as the baby boomers continue to age (Alzheimer's Association, 2011). Although AD has been identified as the sixth leading cause of overall death, and the fifth leading cause of death for individuals over age 65,

the disease is inherently ambiguous due to the unknown cause, lack of preventative measures, or a cure (Alzheimer's Association, 2014).

In the United States, Alzheimer's disease is unique – unlike other disease-types, individuals may survive between two and twenty years, while the majority of AD patients live an average of 8 years post-diagnosis (Alzheimer's Association, 2010; FCA, n.d.). Persons diagnosed with AD experience a variety of symptoms that progress over time, which have been identified within three distinct stages (i.e., early, middle, and late stage): a) During the early stage, individuals experience symptoms of depression, apathy, social withdrawal, poor judgment; they lose the ability to cook, shop, and manage finances, and the ability to make new memories and remember recent conversations; b) In the middle stage, onerous behaviors begin to emerge (e.g., paranoia, anger, irrational/violent behavior, wandering, hallucinating, difficulty eating, incontinence, repetitious questions/statements; Alzheimer's Association, 2010; FCA, n.d.). During the middle stage, patients become more reliant on others for activities of daily living (e.g., getting dressed, bathing, brushing teeth, toileting, taking medication). This stage is also evidenced by increased difficulty communicating and comprehending new information, loss of the ability to read, write, and do arithmetic, and the loss of coordination and spatial orientation. Moreover, in the middle stage, individuals with AD gradually require more supervision and care 24/7 (Alzheimer's Association, 2010; FCA, n.d.). c) In the final stage of AD, individuals lose the ability to recognize loved ones, places, and objects, can no longer communicate, and become bed-ridden and reliant upon 24/7 care until fatality. This stage also results in a loss of basic functions such as swallowing, smiling, walking, and participating in personal care activities. Because of the progressively

debilitating and long-term nature of AD, family members usually assume the caregiver role.

Glioblastoma (GBM)

GBM is a highly malignant and aggressive tumor that arises from glial (i.e., supportive/normal tissue) of the brain. Common symptoms associated with GBM include immense headaches, memory loss, behavioral changes, seizures, nausea/vomiting, fatigue, impaired cognition, speech dysfunction, and loss of sensation/movement on one side of the body (American Brain Tumor Association [ABTA], 2014; 2015). While this tumor is relatively rare (i.e., 3.19 of 100,000 people; Thakkar et al., 2014), GBM is ranked as the third most common type of primary brain tumor (ABTA, 2014), and is more prevalent in older adult populations with a median diagnostic age of 64 years (Thakkar, Dolecek, Horbinski, et al., 2014). GBM is indicative of poor prognosis and low survival estimates, “only a few patients reaching long-term survival status of 2.5 years and less than 5% of patients survive 5 years post-diagnosis” (Thakkar et al., 2014; p. 1987). Without treatment, the median survival rate post-diagnosis is three months, and with treatment the median survival rate increases to 15 months (ABTA, 2015; Thakkar, et al., 2014).

GBM tumors contain various cell types and because of this, some cells may respond to specific therapies, while others may not be affected to any extent. The treatment for GBM is highly complex, usually requiring a combination of therapy modalities (e.g., surgical resection, radiation, chemotherapy; ABTA, 2014; 2015; Thakkar et al., 2014). The initial steps of treatment typically involve the use of medication to relieve brain pressure, after that surgery is performed to safely remove as

much tumor from the brain possible. Unfortunately, GBM is unlikely to be removed entirely because the tumor has finger-like tentacles that reside near areas where sensation, movement, or speech would be adversely affected from a surgical intervention (ABTA, 2015). Unlike other forms of cancer, the main goal of treatment for GBM is to extend life expectancy and alleviate patient symptoms.

Recruitment

In order to gain descriptive insight into the communication stressors experienced by EoL family caregivers, ADRD and GBM caregivers were recruited. To be eligible to participate in the interviews, EoL family caregivers were required to meet one of the following criteria: (1) currently providing local care for a family member diagnosed ADRD or GBM; (2) currently overseeing the care of a loved diagnosed ADRD or a GBM who resides in a long-term care facility. Additionally, to participate, family caregivers had to meet the following criteria: (1) be at least 18 years old, and (2) able to meet face-to-face for approximately one hour.

For the purpose of this study EoL family caregivers were defined as those who provide assistance (e.g., psychological, social, spiritual, practical, pain/symptom management) to a member of immediate or extended family diagnosed with either a progressive chronic or terminal illness to live as well as possible until death (Stajduhar et al., 2010). The person for whom the family caregiver was providing could be concurrently receiving “palliative, hospice, generalist, and/or specialist end-of-life care services” (Stajduhar et al., 2010, p. 587S).

After receiving Institutional Review Board approval, the interview participants were recruited through referrals made by two physicians at two out-patient healthcare

clinics: a) Neurology clinic – specializing in memory disorders, and b) Neuro-Oncology clinic – specializing in brain cancers. Over the course of four months, the author waited at both healthcare clinics (max 2 days/week per clinic) for participant referrals from the physicians. Before making a referral, both physicians would informally assess patient and accompanying family caregivers to determine eligibility for this study. If eligible, the physician asked if both the patient and caregiver would consent to have a researcher come in and talk to them about participating in an important caregiver study. Following referral receipt, the author entered the clinical exam room, engaged in introductions, and explained that she was a doctoral student (e.g., not clinical, not a doctor/nurse), and briefly discussed the purpose and benefits of the study, participation details, and formally assessed participant eligibility. Eligible and interested participants were asked to provide contact information and to share a couple dates/times that would be convenient to schedule the interview. The caregivers were encouraged to specify a location that was both convenient and comfortable for the interview – The author was open to traveling to surrounding counties within that state to conduct the interview. The interviews were scheduled in advance and after receiving confirmation the day before, the author met participants at their chosen time and location with the study materials (e.g., audio-recorder, IRB consent form, demographics questionnaire, interview protocol, remuneration form).

Procedure

Following study consent, participants completed a brief questionnaire (see Appendix A) chosen to capture the demographic (i.e., age, gender, race, marital status, work status) and background context variables (i.e., relationship to patient, caregiving

duration, hours per week providing care) presented as part of the ACT model. Next, semi-structured, face-to-face interviews were conducted with each caregiver participant. During the interview, caregivers responded to open-ended questions regarding their experiences communicating with the patient, family members, and health care professionals. Each interview was audio-recorded and later transcribed verbatim.

Following the interview, participants were compensated for their time with their choice of four different \$15 gift cards (i.e., Kroger, Wal-Mart, Starbuck's, Panera Bread), and completed a remuneration form confirming compensation receipt. Next, the participant-caregivers were told about the scale development and asked if they would be willing to participate – following consent for participating in the survey portion, the caregiver chose whether to have a Qualtrics survey link emailed or if they preferred a mail-in paper survey. Depending on method of survey delivery preference, the participants provided the appropriate contact information (i.e., mailing address, email address).

To investigate RQ1 (How do communication stressors manifest for family caregivers who provide EoL care?), a 32-question interview protocol was developed, which was informed by a combination of the three stressor types of the ACT model (i.e., primary, secondary, intrapsychic), insights obtained through the author's prior research experience, and the seven communication stressor categories identified from an extensive review of the extant caregiving literature. The interview protocol was comprised to elicit responses in regards to the following four components: (1) what it means to be burdened by family caregiving; (2) which of the seven communication burden categories resonate; (3) stories regarding communication with family, the patient, friends, and health care

practitioners; and (4) specific topics that cause conflict and/or are difficult to initiate. To ensure the achievement of the above goals, the stressors delineated in the ACT model were used as a guide for developing the interview questions regarding general caregiver burden and communication burden. Follow-up questions were used to probe participants for elaboration, clarify issues, and confirm interpretations throughout the interview process. See Appendix B for a full draft of the interview protocol.

Qualitative Data Analysis

EoL family caregiver communication experiences and related difficulties have yet to be the subject of comprehensive research. To my knowledge, a paucity of research exists regarding EoL family caregiver communication burden – What is *known* has been *inferred* based on the results of a thorough literature review and categorization of findings that pertain to caregiving and communication. Because EoL family caregiver communication stressors are largely unknown, a grounded theory approach was employed to gain comprehensive insight into the phenomena from the participants’ perspective. Moreover, Glaser and Strauss (1976) maintained that when using a grounded theory approach, “all is data,” meaning that the researcher is able and even encouraged to utilize data from a variety of relevant sources (e.g., interviews, literature, media, etc.) – A perspective that strongly supports the initial step of this project that involved conceptualizing communication burden, based on the author’s own research experiences and the communication stressor categories found in the literature. For the qualitative portion of this study, the caregiver transcripts were analyzed inductively through latent content (Lincoln & Guba, 1985) and constant comparative methods (Glaser & Strauss, 1967).

To answer RQ1, initially, two coders independently read five (12.5%) randomly selected transcripts while using the communication stressor categories derived from the literature as a lens for inquiry. The objectives for the initial inquiry involved: a) noting the communication stressor categories reported in the caregiving literature; b) identifying additional or other communication stressors discussed; and c) highlighting the ways in which personal, contextual, and/or experiential factors appeared to influence or magnify the communication stressors described by caregivers. Next, the coders met in person to review the transcripts (with memos) together and discuss initial thoughts, insights, and observations, which resulted in the co-development of initial categories. For the second round of analysis, both coders independently reviewed five randomly selected transcripts while using the initial categories as a lens for inquiry. Again, the coders met in person to review the transcripts and discuss new insights used to refine the categories and definitions. After achieving successful analysis, discussion, and agreement based on 10 transcripts (e.g., 25% of the data), minor revisions were once again made. Next, an experienced qualitative researcher conducted an audit of the analysis progress and interpretations of the data. The audit served as means of checking the coders' perceptions, interpretations, and to assist with and further enhance an inductive reconceptualization the data. Overall, working with the auditor was conducted as a means of meeting expectations of methodological rigor through the establishment of trustworthiness (Lincoln & Guba, 1985).

After gaining clarity and direction from the audit, the author independently reviewed all of the analysis documents up to that point (e.g., transcripts with memos, analytic and meeting notes, category frameworks used for initial analysis – in order of

progression) and collapsed the present categories into larger themes (see Glaser & Strauss, 1976). Next, the author independently re-coded the original 10 transcripts (unmarked) to test the new, succinct, and comprehensive thematic coding framework. After minor revisions, both coders met again to discuss the new framework, definitions, and conceptualizations. The changes were highly intuitive for the second coder because the themes were not new, but simply collapsed from that which both were already familiar. At this point, both researchers independently coded five additional transcripts using the finalized coding framework. Coding was conducted in Microsoft Word using an editing feature (i.e., track changes) to highlight and code the units of text according to the thematic framework. After combining the coded transcripts, it became very clear that both coders were interpreting the communication stressors depicted in caregiver talk in a similar fashion. Because there was significant agreement among the coders, the remaining 25 transcripts (62.5%) were divided between the two researchers and the remaining analysis was completed independently.

CHAPTER IV

Qualitative Results

Family caregivers encounter significant hardships and burden that decrease their quality of life and increase mortality (NAC, 2009). Extant research suggests the presence of another form of caregiver burden that stems from the caregiver's communication responsibilities. Communication burden, involves communication tasks required for care provision that cause the caregiver undue stress or distress (Shaunfield et al., 2013). The goal of the research presented here, was to gain comprehensive insight into the communication stressors as described by end-of-life (EoL) family caregivers. A grounded theory approach was utilized to analyze interview transcripts. This chapter provides in-depth detail into the qualitative findings of this study.

Study participants consisted of 40 family caregivers (20 ADRD and 20 GBM), currently providing care for a loved one diagnosed with a chronic or terminal illness. Interviews ranged in duration from 30 minutes to 2 hours, with an average length of one hour and three minutes, resulting in 1,014 total pages of single-space transcript. All participants were residents of a state located in the east south-central region of the US.

Overall, interview participants ranged in age from 22 to 86, with an average of 58.7 years. ADRD caregivers' ages ranged from 22 to 86, with an average of 61.45. GBM caregivers ranged from 38 to 71, with an average age of 55.95. Out of the 40 interview participants, 31 were women and 9 were men. One participant identified as American Indian, and two identified as African American, 37 identified as Caucasian. EoL family caregivers reported completed a variety of education levels: three completed less than high school, 11 finished high school/GED, seven attended some college/trade

school, three had an Associate's degree, six a Bachelor's degree, eight had a Master's degree, one had a Doctoral degree, and one participant had a Professional degree.

The familial role of the caregivers in this study consisted of 22 spouses, 13 adult children, three siblings, one in-law, and one parent. While the majority of caregivers ($n=28$) lived with the care recipient, nine interview participants lived 1-10 miles away, two lived 11-30 miles away, and one family caregiver lived 100 miles from the care recipient. Combined, the majority of caregivers were either retired (42.5%) or employed full-time (35%), while the remaining caregivers indicated the following employment status: part-time (5%), not employed (15%), and disabled (2.5%). Overall, the average length of time providing care ranged from 3 months to 12 years, with an average of 3.04 years. In terms of day-to-day care, family caregivers provided a range from 1-5 hours of care per day to 24-hour care. Table 4.1 and Table 4.2 provide an overview of the demographics for participants.

The following section summarizes the qualitative findings of family caregiver communication burden based on a grounded theory approach. First names presented here are pseudonyms used to protect the identity of study participants. To provide interpretive context, after each pseudonym the following information is provided: disease context (i.e., ADRD, GBM), relationship to the recipient, caregiver age, and caregiver-care recipient gender composition (i.e., female [F]; male [M]).

The research question for this dissertation project explored the ways in which communication stressors manifest for EoL family caregivers. As previously discussed, the first round of coding was conducted using the seven categories of communication burden identified in the literature as an initial coding lens: (a) informing and involving

other family member in care decisions and end-of-life; (b) expressing feelings of stress and exhaustion from caregiving tasks; (c) communicating about sensitive issues and care decisions with others; (d) disclosing to family and friends a need for assistance with care duties; (e) communicating with the patient about his/her own care preferences; (f) inability to communicate with patients in advanced stages of illness; and (g) seeking support and information from health care professionals.

The initial analysis revealed two important features of the interview data. First, the seven communication burden categories reviewed in the literature review not only resonated with caregivers, but further insight was gained regarding the personal, contextual, and experiential factors that influenced and magnified the stresses associated with communication. Second, given the revelation of numerous complexities inherent in caregiver communication burden, the author chose to revisit the data with fresh eyes through a grounded theory approach in order to gain true insight into the communication experiences as described by EoL family caregivers.

Following initial analysis to confirm the existence of the seven categories, to answer RQ1, the author conducted an inductive analysis in which the transcripts were examined through a process known as open coding in which the data was deconstructed, analyzed, compared, conceptualized, and categorized (Glaser & Strauss, 1976). The inductive approach to data analysis using grounded theory revealed that overall EoL family caregivers report a dualistic existence that stems from a tension felt while maintaining focus on life while remaining conscious of impending death and uncertainty. After the care recipient receives a terminal diagnosis, EoL family caregivers become constrained to a largely binary existence between life and death; as a result

communication tasks become very arduous as caregivers attempt to find an appropriate balance between providing quality care and a need to attend to their own needs. As a result of the continuous oscillation between an interplay of the two extremes, frustration and stress emerges, not only when the caregiver must engage in uncomfortable conversations with the care recipient, others (i.e., family, friends, acquaintances), and health care professionals, but stress and concern also manifests while simply contemplating and preparing for the encounters.

The stress and burden experienced by EoL family caregivers when engaging in sensitive conversations and while planning to express themselves emanates from an immense fear of the potentially detrimental outcomes of the interaction. The dreaded outcomes of communication exchanges often inhibit caregivers from talking about their concerns, needs, and experiences. A split reality emerges, for EoL family caregivers, which originates from the discovery of the terminal diagnosis; therefore, the disease itself, and the caregiver's response to the disease in particular serves as a barrier to communication, causing the family caregiver immense anxiety, thus making the initiation and fulfillment of communication tasks feel like a tremendous hassle. Although, EoL family caregivers acknowledge a need to engage in specific communication tasks necessary to provide quality care and promote their own wellbeing, there are many barriers and simultaneous, yet contradicting forces that stand in caregivers' way of achieving their goals.

Thus, the inductive approach revealed that communication burden stems from the caregiver's attempt to negotiate between two opposing extremes: the desire to protect the patient and others versus the need to protect oneself when contemplating whether and

how to engage others and then again when following through. The most salient dualisms revealed within the communication barriers include the following: (a) protection of the patient and others vs. attending to one's own needs, (b) certainty vs. uncertainty, (c) optimism vs. preparation, (d) openness vs. closedness, (e) anticipating vs. seeking support, (f) trust vs. distrust, (g) inclusion vs. seclusion, (h) pride vs. shame, and (i) presence vs. absence. The presence of these contradictory tensions induced the emergence of barriers and therefore communication burden within various aspects of the caregiver experience, including, the care recipient's disease symptoms, perceived taboo topics, the caregiver as guardian, anticipating versus seeking support, and specific obstacles and tensions that prevent EoL caregivers from seeking expert advice and support. These results are detailed in the following (see Table 4.3 for a visual representation of the qualitative themes).

Symptoms as Communicative Barrier

Family caregivers described stress and frustration that resulted from a need to communicate with care recipients, and the difficulties encountered when attempting to engage their loved ones, which was largely attributed to disease symptomology creating a barrier to communication. While the ADRD literature reveals family caregiver difficulty communicating with care recipient's is due to the associated symptoms, this is a new finding in the GBM caregiving literature as little research has been conducted in the context of GBM caregiving. The symptoms that presented as barriers to caregiver communication included, behavioral changes, language deficits, and fatigue/apathy are reviewed below.

Behavioral Changes: “It’s a Constant Battle with Her These Days”

Caregivers described feeling overwhelmed by the care recipient’s behavioral changes associated with the disease symptomology, causing family caregivers significant strain when attempting to obtain the compliance of the care recipient. Behavioral issues were a common concern for both ADRD and GBM caregivers. Karen [GBM, Sibling, 56, F-F] disclosed that her stress results from her efforts trying to convince her sister, diagnosed with aggressive GBM to behave:

But she'll start that screaming and stuff. Her husband won't say nothing to her, so I have to. I ride with her, and I feed her, or give her medicine...One time, on the way up here, we stopped somewhere to let her go to the bathroom and she started screaming! We came out of the bathroom in that little country place and these people were all looking, I know they thought I done something to her. I had to beg her to stop, I said, 'Please quit screaming, don't do that' and she said, 'If I don't do that, nobody will come help me.' I said, 'Sharon, I'm right here in the bathroom with you. You don't need to do that.'...If she don't want to take her medicine, that's a battle. The trip before last, she's just having severe headaches. And I tried to give her medicine or whatever, and I looked, and she spit it out in her hand. I said, 'That's not going to help you if you don't take it. I'll get you a drink.' I put it back in her mouth. I said, 'Here, swallow this.' It's a constant battle with her these days, and it's very hard for me to help her when she acts up.

In this example, because the care recipient’s husband and primary caregiver found his wife’s behavior overwhelming, Karen took on the responsibility to calm and persuade her sister to behave when she was acting out. Karen further explained that her efforts to communicate with and convince her sister to comply were a constant struggle, resulting in feelings of immense pressure and anxiety. For ADRD patients, behavioral issues often emerge in the form of inappropriate (sexual) touching and cussing. Joyce [ADRD, Child, 68, F-M] provided an example of the difficulties she encountered when attempting to persuade a loved one with cognitive deficits to act appropriately:

We had a hard time trying to convince dad – you know, talk to dad about not touching people. That it’s inappropriate. Because this wasn’t my father going

around touching women inappropriately. Which I know that's part of the disease, which I wasn't – you know, you're thinking well, he's dirty old man, but they're not. Last Christmas we were all at my aunt's home, and by the way, she has Alzheimer's... I knew he was not right; he was being more attentive to my aunt; wanting to kiss on her and wanting to touch her. When we would go out to eat lunch together we would never let the two of them sit together. It was always a big fight trying to get dad to leave her alone. It's so frustrating trying to communicate with someone who isn't able to understand.

In this example, similar to Karen, Joyce described feeling immense frustration when trying to communicate with and seek compliance from someone who presents cognitive deficiencies. Like most caregivers, Joyce attributed her father's behavioral problems to his illness, and therefore the illness acts as a barrier that prevents her from being able to get through to her dad, which is a very demanding task. Further, Joyce was embarrassed by her father's behavior—and she was especially embarrassed *for* him because she knew her father would have never behaved in such an inappropriate manner prior to his disease. Throughout the interview, Joyce continued to share stories of her father's inappropriate behavior towards women and the significant stress that ensued from reprimanding her father for something he was unable to , but at the same time was absolutely unacceptable. Joyce's need to scold her father in order to protect both him and others from his disease symptomology caused her immense stress because in the back of her mind, she felt guilty and knew this was not truly her father. Behavioral changes associated with a disease that affects cognition (e.g., ADRD and GBM) often obstruct the caregiver's goals to provide quality care and protect the patient and others. EoL caregivers described immense communication burden resulting from a need to continuously referee and fight with care recipients in order to achieve compliance. Further, caregivers attempted to negotiate a tension felt as a result attempting to remind one and remain certain that the behavioral problems were a result of the disease.

Language Barriers: “The Communication Things are Really Hard”

In addition to the difficulties resulting from attempts to halt or circumvent behavioral problems, EoL family caregivers described their efforts to communicate with the loved one as incredibly strenuous, especially when the care recipient’s symptoms present as dysfunctional language – which created an immense barrier to effective communication. One example of this occurred in Julia’s [GBM, Spouse, 38, F-M] depiction of what caused her the most stress when caring for her husband with a terminal brain tumor:

Well the communication things are really hard. So I get real stressed out when, for instance just trying to ask him what he wants to eat is sometimes turning in to this hour-long fiasco, you know? Because he can’t remember the name of a restaurant. Or can’t remember what the types of food is called that he wants, maybe he wants tacos and, we’ve been two hours of him trying to explain to me what a taco is, because he can’t remember the word taco.

In this example, Julia explained that the stress she experiences most was due to her husband’s language deficit and the fact that he either can not find the word he wants or he substitutes one word for another. Like all caregivers in this study, Julie attempted to make her husband comfortable, content, and happy; which was an extremely strenuous and time-consuming task as a result of the language barrier that existed due to the disease. Further, caregivers like Julia expressed the difficulties they endured when trying to help their loved one and understand their needs, while at the same time preserving the care recipient’s dignity. Similarly, Emilee [ADRD, Child, 22, F-F] shared her experience trying to decipher her mom’s needs:

She’ll get upset all the time. Her moods are up and down and if she starts crying most of the time I ask her what’s wrong she’s like, ‘I love you’. She knows something’s wrong but she can’t express how she’s feeling. It’s hard just because she gets very upset and she can’t tell me – the communication is off and it’s very difficult for me to figure out what she needs, which makes me upset.

Although Emilee is a young adult caregiver, the way she characterized the stress she feels when attempting to discern her mother's needs, was no different from Marie [ADRD, Child, 58, F-M], a speech pathologist and experienced family caregiver, who depicted her frustrations when communicating with her dad by saying:

His speech is hard to understand. When I don't know what he wants, it is really frustrating. There were some nights when he was tired and I just didn't know what he was saying. Well, being a speech pathologist it is really hard. It is like, 'Slow down Dad. One word at a time.' Very frustrating – He gets frustrated and I get frustrated.

Although Marie was a speech pathologist, experienced at helping individuals with language deficits, and a second-time caregiver, her experience did not prevent her from becoming stressed and frustrated when trying to discern her father's speech to determine his needs. For Marie, this was especially difficult because she had to balance talking to her father as her dad versus the way she talks to her clients, which need to continuously balance between two very different roles. For many EoL family caregivers, language barriers were especially burdensome because they were unable to intelligibly and accurately assess the loved ones' pain and symptom management needs thus causing a tension between a need for certainty while in a constant state of uncertainty regarding the loved one's needs.

Additionally, when asked to discuss communication tasks that are perceived as difficult, many caregivers described the frustration that erupts as a result of repetitive behaviors and inquiries from the care recipient. Joe [ADRD, Spouse, 77, M-F] provided one such example when he shared, "Occasionally I feel bad because I'll snap at her because three or four times in ten minutes she says, 'Where are we going?' It's exhausting answering the same question over again, but one good thing about dementia is

she forgets it in five or ten minutes and it's all over.” For Joe, a lot of his burnout stemmed from the repetitive behaviors associated with ADRD, but he was not only frustrated by the repetitive questions and repeating his responses, he became angry with himself after he eventually snapped at his wife because of something he knows she can not help – a symptom of Alzheimer's disease. As a result, Joe experienced immense internal conflict when he felt annoyed as a result of his wife's disease symptomology and his natural and inevitable response to her behavior—which caused him immense guilt. Although, caregivers like Joe recognized that repetitive behaviors are part of ADRD, such acknowledgement did not prevent caregivers from becoming irritated. Because repetitive behaviors are a symptom of the disease, there is no way to control it, and therefore ADRD caregivers were stuck within a persistent bind and forced to oscillate between understanding and a natural response – thus, influencing significant communication burden for these caregivers.

Fatigue / Apathy: “I Get Angry [and] Resentful...Because He's so Low-Energy”

Not all communication problems stemmed from symptoms related to cognitive function. Many caregivers described care recipient fatigue and apathy as a source of tension in their communication encounters, which in turn impacted and altered the dynamics of their relationships with care recipients. For example, when asked about whether caregiving and the disease had changed her relationship with her husband, Natalie [GBM, Spouse, 38, F-M] replied:

We have had a lot of fights that stem from his lack of energy. So the biggest side-effect that he has experienced long-term is tiredness. And that's a problem because it's made our life much smaller than it used to be... I find myself trying to make sure that [our son] is not too loud or too rambunctious, and focus on making dinner, and then he's tired so I don't want to run around – I would like to go out! Or do something, lets play a game, lets do this! But he doesn't have any energy,

so now we don't do the *fun* stuff together and then also I don't do anything *else* because he wants me to be with him because he feels bad if I'm out running around in circles and then I'm feeling angry because he's not doing anything. And so, the conversations we've had about that have been really hard, and sometimes I could be a much better person about it. And I think, when I get snappy with him and I'm like, 'Look! Could you plan ahead a little more, and can you please get this done?' He's like, 'Yea, yea, yea,' and he drags his feet and I get snappy with him. And then we have to have this conversation about like well "Why don't you...well I do all this, why can't you do more of this?" and...at the end of the day, it feels really nasty because it drags him down and it hurts our relationship, but it's really about his illness...I've gotta adjust to it and I'm angry. I'm angry at the world for having given us this situation. And he feels bad. So the conversations are not good around that.

In the above example, Natalie described the unpleasantness she experienced a result of her husband's immense fatigue due to his disease. The majority of her anger, the impetus to their fights, and perceived relational change and decline, originated from her husband's lack of energy – a symptom of GBM. Further, Natalie discussed feeling frustrated that her husband's fatigue had significantly dominated the content and tone of their conversations, impacting their relationship. While she acknowledged a need to adjust the way she perceives her husband's lack of energy and attribute it to his disease rather than his person, it was easy to associate his fatigue as negligence rather than a symptom, which influenced their communication exchanges, impacted their relationship, and caused her emotional pain because in the back of her mind she knows it is not his fault. Further, this example provides insight into the perpetual pull between certainty and uncertainty in regards to the patient's symptoms. Clearly, the anger and resentment toward her husband's disease and symptoms has created a barrier that keeps Natalie and her husband from having fruitful conversations – instead their communication manifests into complaining sessions and arguments that ends with both feeling terrible afterwards.

Many caregivers, Like Natalie, not only described the disease as a barrier to communication, it also prevented them from nurturing their relationship and achieving intimacy at a very difficult time. Similar to concerns over fatigue, many EoL family Caregivers described feeling distressed over their loved ones' apathetic attitudes and the caregiver's continuous efforts to persuade the care recipient to fight. Ronald [GBM, Spouse, 65, M-F] illustrated this sentiment when he stated:

I get aggravated at her because she don't try. You know? We have problems over that. She told me that she guess she should just give up, and ever since then she just give up. She don't want to try, don't want to do nothing that makes her feel good, that makes her feel better. And I try to get her to go to the gym with me and get exercise, the doctor wanted her to do that, she won't, she went twice, and she didn't want to do that. We have problems like that you know? Getting her to suit up and fight.

Ronald described feeling as if his wife had given up, which was something he refused to accept. For Ronald, his communication burden was the result of his continuous efforts attempting to persuade his wife to do things he was certain would make her feel better. When asked if he spoke with his wife's health care providers about her apathy, Ronald characterized her doctors as being unhelpful because they attributed the apathy as a side effect of his wife's brain tumor and subsequent depression. Although the doctors confirmed her behavior as a symptom, Ronald remained unconvinced and therefore uncertain, and thus continued to stress over and attempt to persuade his wife to do the things she normally did before the diagnosis he was certain would help.

When persuading did not work, caregivers adopted different strategies of gaining compliance. For example, Kathleen's [GBM, Child, 59, F-F] mom refused to go to the grocery store, so in order to get her there she had to "orchestrate outings...if we say, 'We're going to pick up a sandwich.' She'll agree to that – and then once you get her out,

we're going to the grocery, and she's stuck. So we have to kind of finesse and finagle to get her to do things she needs to do." Caregivers described various strategies for gaining compliance (nagging, begging, finagling, asserting) to encourage a multitude of behaviors such as bathing, eating, taking medication, exercising, playing games, and attending doctor's appointments which were all a source of communication burden for EoL family caregivers.

Taboo Topics

Although, caregivers admitted to the potential benefits of communicating with others about their experience, fears, and concerns, there were five topics caregiver's generally deemed as taboo and therefore tried to avoid. Thus making many important conversations difficult and stressful to initiate, even when the caregiver recognized the benefits of having said conversations. Perceived taboo topics therefore influenced many of the dualisms that produced communication burden. The five taboo topics depicted by family caregivers included finances, the disease, end-of-life concerns, the future, and the caregivers themselves.

Along with politics and religion, finances tends to be at the top of the proverbial 'topics to avoid list,' a standard that holds true for family caregivers. When asked to share the aspects of caregiving they worry over that caused the most distress, most caregivers identified finances as a highly concerning, yet difficult topic to broach with others. The difficulties stemmed from the caregivers' beliefs they should be able to handle the expenses themselves and not burden others, and the perception that others might critique their financial contributions.

The disease and its progression was another topic that caregivers were disinclined to discuss with the care recipient and family for a variety of reasons. Caregivers were inclined to follow the care recipient's lead with regards to how, when, and the amount of communication permitted regarding the disease and/or the progression. Many caregivers went so far as to only learn about as much about the disease as the care recipient wanted to know. Caregivers also acknowledged that "illness" and "disease" are not topics that are generally accepted in Western society and therefore were essentially forbidden topics of conversation. Caregivers, particularly spousal caregivers, avoided discussing the disease and progression around the young adults of the family in an attempt to shield them from facing a harsh reality.

Given the above, it is not surprising that caregivers also sidestepped topics associated with the end of life. Mostly, caregivers put off having conversations about the end of life because they perceived these topics as being morbid, because "to discuss those things is like [we've] given up." In addition to feeling discomfort initiating end-of-life conversations and discussions, EoL family caregivers explained a reluctance to begin due to feelings of being overwhelmed by the process, uncertainty regarding necessary steps (e.g., Advanced directives, Will, Power of Attorney, Do Not Resuscitate), and health literacy – many caregivers in this study considered EoL preferences as funeral and estate planning only.

While it is not surprising the above topics of conversation are considered taboo, the final two, in a healthy context are likely main topics of discussion: the future, and oneself; however, in the context of a terminal disease, created significant strife for EoL caregivers. A majority of caregivers described the difficulties encountered when

attempting to have conversations about the future. Natalie [GBM, Spouse, 38, F-M] summed up many similar sentiments when she shared the topics that cause her the most distress, “These topics [concern and uncertainty over the disease progression, and concern and uncertainty over what the future holds], are all connected to me. They’re all about what's gonna happen to him, and then what's gonna happen to me, and then what gonna happen to [our son].” Like Natalie, most caregivers either avoided talking about the future or held “pie in the sky” conversations about future plans, all the while trying to stay grounded knowing that the bright future discussed was unlikely. Caregivers, like Natalie, were incapable of broaching conversations with care recipients that were grounded in reality. Although EoL caregiver’s needed to consider a realistic future, they were inhibited by a tremendous fear of actuality.

The final taboo topic within the context of EoL family caregiving consists of the caregivers themselves. Most individuals that undertake the immense responsibilities involved in providing informal care to a family member do so because they have an altruistic and caring nature to begin with. It is not surprising then, that family caregivers shied away from talking about themselves, especially with regard to their emotions, feelings, concerns, and general well-being since most felt as it is not about the caregiver, but about their loved one. Additionally, many caregivers felt by talking about their caregiving experience, they would be admitting failure. The five taboo topics described above provide a thread for interpreting and fully understanding the remainder of the findings presented in this chapter.

Caregiver as Guardian

Family caregivers encountered a general struggle and difficulty when an opportunity arose enabling them to express their feelings, concerns, and experiences, because as caregivers, they felt an innate responsibility to protect the patient and others at their own expense.

Protection of the Patient: “My Needs is Secondary, as Long as [He’s] Taken Care of I’m Fine”

Overall, EoL family caregivers reported a tendency to avoid topics related to the disease as well as their own fears, concerns, and feelings in an effort to protect the care recipient. Caregivers were inclined to succumb to communication barriers that emerged, maintain a positive attitude, and by ensuring the sustained focus on their loved ones’ well being.

Communication barriers: “You don’t want him to feel guilty, but yet he needs to understand.” Family caregivers felt an innate need to protect the care recipient from harm, which often constructed communication barriers, which impeded them from achieving their own needs. As a result of perceived communication barriers, family caregivers explained how they must carefully manage the revelation of perceived taboo topics in a way that does not induce feelings of guilt or burden on the part of the care recipient. For example, when talking about the conversations that were easiest and most difficult for her, Joan [ADRD, Spouse, 76, F-M], a second-time caregiver admitted:

I think it was easier to talk with my dad than it is with [my husband], because you don’t want him to feel like it’s a burden and you don’t want him to feel guilty because you’ve got to sit here and take care of him. That’s a fine line, and then to actually say how you really feel. So like I said, I think it was easier with ... because dad did say, ‘Listen, when I’m at myself I know what’s going on, when I’m not don’t feel guilt’ and all of this. Dave has not come to the point of doing

that yet. He doesn't understand, I think, how hard it is maybe; he hasn't come to the point of understanding that yet. And it is hard because you don't know how...you don't want him to feel guilty, but yet he needs to understand that it is hard sometimes.

In this example, Joan demonstrated the tension she felt between her desire to talk about her feelings and experiences and her efforts to protect her husband by avoiding discussions that might inflict guilt. Further, because she had prior caregiving experience, Joan believed that the barrier preventing her from broaching topics concerning her experiences and concerns, stemmed her husband's lack of understanding nor overt recognition of their situation. In a sense, Joan was waiting for permission to talk about topics important to her, because she believed doing so before her husband is ready would cause him harm. In this case, the barrier preventing Joan from disclosing her feelings and concerns with her husband stems from her desire to protect her husband which influences her to wait for permission that is not forthcoming.

Stephen [GBM, Spouse, 43, M-F], on the other hand, functioned as a sounding board for his wife to help her relieve the stress she feels, but he refused to reciprocate due to his determination to protect and care for his wife:

I guess for me, like I said, I'm usually very open and blunt about things, for me, it helps prevent the stress from building – It's my outlet. When all this first started that's when the stress would started to build and, you know, I can't go complain to my wife about it [laughs]...But I needed to be there and let her complain to me, so... you just got to take it and then you have to turn and deflect it somewhere else, but I didn't have anyone to deflect it to...I mean she's completely stressed out, she's not feeling well, she's not wanting to feel like she's dumping on her son and her husband and... She feels guilty, and you're just – you're trying to get the answers and talk to her in a manner that doesn't give her any feeling that she's any kind of burden. We did not discuss, you know, my lack of needs, although...like I said, it wasn't, I guess, that big a deal. It's not like I was going to complain to her about I don't get to see my friends as much now [laughs].

While Stephen admitted that open communication was means by which he commonly relieved stress, he was unable to open up about his caregiving experience. The barrier that prevented Stephen from disclosing his stress was twofold; for one, he was focused on protecting his wife above himself, and second, he was disconnected from his social network and therefore had nowhere to release his feelings and thoughts, which caused immense communication burden. As a result, the caregiver's response to the disease has created a barrier and obstacle for Stephen, in that he was unable talk to his wife at the expense of relieving his own stress.

Similarly, when asked to share a word that depicts her experience talking to her husband about his Alzheimer's diagnosis and her own feelings, Tammy [ADRD, Child, 57, F-M] explained that it's like, "Nothing, because I don't. It's non-existent. N/A; not applicable." After which, she shared, "Sometimes I wish we could kind of talk about it more openly, but he is not open to that, and right now I guess we're okay." Many caregivers like Tammy wanted and needed to discuss their fears, concerns, and feelings regarding the caregiving situation and care recipient's diagnosis, yet many reluctantly abstained because their loved one was perceived as not open to having those discussions. EoL family caregivers believed that initiating conversations regarding their experiences and concerns would inflict further stress upon and ultimately harm the care recipient; therefore caregivers concealed their feelings in an effort to protect the patient. Although caregivers, like Stephen and Tammy, acknowledged the benefits and need to engage in an open dialogue between themselves and the care recipient, the majority felt they could put it off a little longer, if it meant protecting their loved ones. Thus, the EoL family caregiver commonly loses the internal battle between the caregiver's desires to protect

the patient versus attending to their own needs creating a profound sense of communication burden.

Withholding: “I keep that information from him...” Another way EoL family caregivers protected their loved ones was by actually withholding information they believed would be harmful for the care recipient to know. However, although the caregiver believed the information would have negative consequences, they still felt shame and hardship as a result of their protection efforts, therefore influencing communication burden due to the tension between openness and closedness. For example, when asked to talk about her experience communicating with her father diagnosed with an aggressive form of Frontotemporal dementia, Lacey [ADRD, Child, 39, F-M] shared:

How do you communicate to the person who actually has it? I mean, it's very difficult. The only thing we've done so far, and maybe it's wrong I don't know, is I just told him that the doctor said that he does have dementia. And he said, 'well what does that mean?' I just said, "You just have some memory loss, and it could affect your keeping up with your money or keys or sometimes you might forget things that you wouldn't normally forget.' And that's all we have told him, we haven't said that there's only a 10-year lifespan. Some people argue with me, 'Well does he know that?' and I'm like, "No!"— Why would you tell somebody that? I mean it's different if you had cancer, everyone knows that term and what it means. I'm very concerned with potentially talking about things in front of him, but I also worry that if he were to realize how bad things are that it wouldn't be a good outcome...I worry about him taking his own life. Not that he's ever said he would, but you always worry—they're not in their right mind-state. Could this happen? Could they do that? Could they feel like they're a burden on us? You know what I'm saying?

Lacey demonstrated the enduring and overwhelming fear associated with disclosing prognostic information to the care recipient, which she believed could cause potential harm. Although many disapproved of her decision to withhold diagnostic details from the care recipient, Lacey firmly believed she was protecting her father by keeping that

information from him. Further, Lacey revealed the difficulty encountered by family caregivers when not only communicating with care recipients, but the stress associated with ensuring the harmful information remained concealed. The act of remaining closed versus open in regards to withholding information from care recipients, caused many caregivers significant stress and communication burden.

Similarly, Tammy [ADRD, Child, 57, F-M] expressed her need to keep her husband from learning that violent behavior is a symptom of his disease, when she explained, “He has asked me to bring him information about his disease, and I’m, ‘Oh yes, down the road we can do that.’ I keep that information from him because if he doesn’t know that he’s supposed to get violent, why get violent? I don’t want to be giving that idea.” Tammy chose to keep secret from her husband the fact that violence occurs along with the disease progression. For Tammy, keeping that information from her husband not only protected him from worrying about his own future, but she believed it could potentially protect her from having to confront violence as a symptom of her husband’s progressive disease. Thus, knowing the disease specifics, in Tammy’s mind, could precipitate dreadful behavioral problems for her husband so she went to great lengths to ensure specific information was kept from him. In this instance, Tammy’s communication burden presented as a need to remain vigilant in order to keep others from revealing potentially harmful information to her husband; unfortunately, she later described feeling guilt as a result of her secret-keeping efforts. In addition to going through significant efforts to ensure that potentially harmful information was suppressed, for caregivers like Lacey and Tammy, communication burden further emanated from

two conflicting desires; one, a need to protect the care recipient, and two, the guilt incurred as a result of their deceit.

Optimism: “There’s gotta be a way to be...both really positive but also more accepting of the real possibility of death.” Although, caregivers were informed of the terminality of the care recipient’s disease, when around their loved ones, EoL caregivers struggled to maintain a positive attitude and engage in conversations that promoted optimism. In an effort to protect the care recipient, EoL caregivers would often forgo a need to be prepared in order to support and protect the patient by remaining optimistic. When asked about their experiences communicating with care recipients, the majority of caregivers, like Betty, shared that they “spend a lot of time telling [them] everything’s gonna be fine, and working very hard to believe it—because that needs to come through.” To protect loved ones, EoL family caregivers attempted to avoid discussions involving taboo topics related to the disease and symptoms, instead they preferred to establish and nurture a positive atmosphere by remaining optimistic – all the while secretly attempting to prepare mentally for the inevitable future. Likewise, Clara [GBM, Spouse, 52, F-M], vividly described her struggle to protect her husband:

I have strange thoughts sometimes, why did this happen? Why’d this happen to me? Why, why is he sick? But you just have to be positive and think, “Well we’re going to get through this.” Because if you don’t think positive you’ll get down so bad...and I was scared, I just am nearly helpless myself, I’m so frightened. And I couldn’t cry by him, it was hard not to. It’s just sad...you just think, “Well what’s tomorrow going to bring?” And you think – well you know, “One day you will wake up and he won’t,” you know? Given everything I know is going to happen, it’s so hard to put on a happy face, be positive, and keep my fears from him. But I do for him.

Clara’s poignant description of suppressing her fears and remaining positive for the benefit of her husband illustrates the significant bind EoL family caregivers as a result of

attempts to protect the patient at the expense of their own needs for future preparation.

Unfortunately the contradictory bind and tension yields significant burden for EoL family caregivers when communicating with the patient and others.

While EoL caregivers attempted to maintain a positive and optimistic attitude to protect their loved ones,' this strategy would sometimes backfire by putting the caregiver in a precarious situation. One example of this occurred in Natalie's [GBM, Spouse, 38, F-M] discussion of concern over her efforts to encourage a positive attitude:

Sometimes I wish [my husband] would say, "this [death] could *happen* and that's *okay* if it happens...this is what I'm gonna do to be okay about it." I wish sometimes that there was a way—but when he talks like that, he gets very depressed, which is not—like the way that he manages it makes me think that he's resigned himself and is depressed about it. So it doesn't work in terms of getting me any sense of relief...So I live in this sort of fear that if something happens neither of us are really ready for it because we've done too much denying of it, but there's gotta be a way to be both in denial and pos—a way to be both really positive but also more accepting of the real possibility of death—we manage. There's something in how you could communicate there that we're missing. That [my husband] doesn't know how to do.

In this example, Natalie depicted her efforts to remain positive as causing her to suffer an endless internal battle between optimism and preparedness. Natalie recognized that denial will leave her family unprepared in the future if the disease is, in fact, terminal; however, she was unable to broach the topic with the care recipient for fear that such conversations would cause him significant grief. The examples illustrated above are among many in which EoL family caregivers commonly revealed a continuous internal struggle between two competing goals: a need to remain optimistic and maintain hope as a means of protecting and promoting their loved ones' emotional health and well-being; which was in direct competition with the opposing goal, a need to engage in realistic and pragmatic conversations to ensure future preparedness. The constant contest between the two

contending goals caused EoL family caregivers' exceptional stress and anxiety when even considering the act of initiating these essential conversations with the care recipient, much less, actually following through. Here again, the duality creates a communication barrier that stands between the caregiver's intention to protect the patient and satisfying one's own needs.

Focus on the patient: "At the expense of..." Another protective approach taken by EoL family caregivers was to maintain focus on what they considered to be of greatest importance – fulfilling the care recipient's needs above all others, including the caregiver's own family and personal needs. The stringent emphasis on the needs of the care recipient precipitated stressful encounters and communication burden for EoL family caregivers. As exhibited by Joyce [ADRD, child, 68, F-M], a long-distance caregiver who provided for her father who lived 170 miles away, who felt stressed and split over her decision to put her father first:

You're just torn, you know, you don't have time to be... to do the things you need to do for your own family. And my husband is so understanding, I mean anybody else might've just said well, forget it, because I've been pretty much gone for six weeks. But my daughter told me, 'Mom, you've got to go home. Not because Dad is mad but just – You need to go home!'...but my brother had had this vacation planned for last week and I couldn't say, 'you can't do that', so that's why I had to stay a whole extra week. And I had a real hard time trying to get my family to understand that I just couldn't up and leave.

Many caregivers, like Joyce, described an inherent need to protect the patient as taking precedence over many aspects of their lives—including family. In the end, contrary to her daughter's insistence that her husband needed her, Joyce chose to stay and care for her father an extra week – A decision, which Joyce later described as instigating tension in her family relationships which stemmed from the caregiver feeling forced to choose between the care recipient and family. Furthermore, caregivers like Joyce, had a difficult

time conveying their need to put the care recipient above others, because as Brenda [GBM, parent, 57, F-F] explained, “if they’re not in it, they don’t understand.” Much of the dualism, tension, and therefore communication burden experienced by EoL family caregivers originated from the caregiver’s perceived inability to provide an acceptable rationale for their behavior because unless that person was a current or former caregiver, others would be unable to comprehend their role and subsequent choice.

In addition to focusing on the patient at the expense of family, in order to protect their loved ones, EoL family caregivers compartmentalized their lives in order to focus their efforts only on things essential to providing care, commonly at the expense of having a social life and keeping up with friends. Julia [GBM, Spouse, 38, F-M] provided one such example when she stated, “It’s like I circled the wagons and just shut down everything that was not essential. So yeah I had friends that I don’t see, I don’t know what they’re doing or where they are if it wasn’t for Facebook. Because I don’t have time for anybody else’s drama but mine.” Every caregiver, even those who had rocky relationships with the care recipient, expressed a need to care for their loved ones above themselves. For example, when asked what topics are easy for her to discuss, Lane [GBM, Spouse, 65, F-M] said, “I don’t mind talking to other people about his illness...I don’t mind that at all. And then it seems like somebody’s always talking to me about *my* own needs but I always put – my needs is *secondary*, as long as [my husband] is taken care of I’m fine.” Although many caregivers had difficulty discussing the care recipient’s disease, that was not the case for Lane. In Lane’s mind, she was protecting her husband, by making sure others were taking note of him rather than her.

Given the above, it is not surprising that the EoL family caregiver's proclivity to focus on the care recipient rather than oneself extends to the context of the care recipient's clinical visits. Although the caregivers in this study had very different experiences communicating with health care professionals, this was largely influenced by the clinic from which they were recruited. For example, oncology caregivers acknowledged that their loved one's care providers would occasionally inquire into the caregiver's own well-being, while ADRD caregivers were always asked by the physician about themselves. Although the clinics and physicians operated in different ways, the outcome was the same, when asked if they felt comfortable disclosing their own concerns and needs to the care recipient's health care providers, the majority of EoL caregivers, would commonly respond like Joan [ADRD, Spouse, 76, F-M], "I try to be honest with them, to a point; like I said, their main problem is my husband, not me."

Similarly, although they had questions and concerns for which they wanted answers, EoL family caregivers were reluctant to seek information or support to help with caregiving from the loved one's providers. For example, Stephen [GBM, Spouse, 43, M-F], only asked questions of the doctor, related to his wife's care, such as, "What do I need to do for her? What does she need to be doing and not doing?" but nothing – All focused on her in terms of what I need to do as a caregiver for *her*, but not related to *me*." For EoL family caregivers, protecting oneself, was in direct opposition to protecting the care recipient, which was a significant disconnect between the goal to provide quality care for the care recipient and the need to take care of their own needs. Here again, caregivers illustrated a stressful and unremitting tension they negotiated between protecting the care recipient by ensuring the focus was on them, and attending the

caregiver's own needs through deciding whether to be open versus closed. Unless the situation was no longer bearable, EoL family caregivers were inclined to focus on patients at the expense of themselves.

While EoL family caregivers expressed a reluctance to disclose feelings and concerns with their loved ones' health care professionals unless they were invited to do so, it is regrettable that when health care professionals inquired it was perceived as insincere. Therefore EoL family caregivers felt unable to talk about issues and get information to help reduce their burden. When asked whether she talks about her experience with her husband's health providers, Natalie [GBM, Spouse, 38, F-M] explained she would be surprised to learn that other caregivers are asked about themselves:

My experience overall with doctors is that their job is to take care of the patient and answer questions. And they are *not* very cognizant about what that's gonna do to either the patient or the caregivers—to hear that information.... They never ask how I'm doing... I mean I'd be shocked if you get other people who are saying that the doctors ask about them...I'm not sure that it occurred to me that they should! It's really interesting because in certain ways the only people that have asked and I have the opportunity is his nurse.

She further explained that although she rarely talked about her experience, on occasion when asked Natalie [GBM, Spouse, 38, F-M] shared about her stress and uncertainty with the nurse when she elaborated, "I mean really, the only thing has been stress...and some of these concern over what's gonna happen—or just expressing that sensation of you know, tell me its gonna be okay. Or I'm scared." Like many EoL family caregivers, Natalie remained reluctant to discuss her feelings with health providers because she was rarely asked, and when her husband's nurse did inquire about her wellbeing she would only do so when completely overwhelmed. In those rare instances, Natalie focused on her

fears and uncertainty regarding the future. Natalie needed someone to affirm that everything would be fine, but that was not something the nurse could do – especially with regard to a level IV brain tumor.

Some caregivers reported being asked about their own wellbeing by physicians, but they felt the question was intended to be polite rather than a sincere attempt to gain information, which was aptly described by Stephen [GBM, Spouse, 43, M-F]:

Yeah, I've not discussed [with] any of them. They'll occasionally, as a kind of aside, say "How are you doing?," "I'm fine." But that's not part of the conversation with them. More of a polite but very patient-centered focus on [my wife] and what's going on with her, not so much on what's going on externally. Which I guess that's not to say they haven't asked occasionally, but I always say I'm fine.

In the example above, Stephen revealed that the occasional inquiries into his own wellbeing were just part of a script, rather than a heartfelt question; instead the focus of the conversations were always centered on wife's illness and symptoms.

Protection of Others: "This is a Lot of Responsibility to Put on..."

Comparable to EoL the family caregiver's innate need to protect the care recipient by anxiously managing the content, outlook, and tone of their communication both with and in the presence of their loved one, caregivers also attempted to protect important others by concealing the caregiver's own experiences, concerns, and needs, in an effort to safeguard against augmenting others' existing stress, cumbersome responsibility, and relational side-effects. The significant others that EoL family caregivers endeavored to protect included friends and family in general; however, they were especially careful to insulate children and grandchildren from knowing the truth about the harsh reality that both the care recipient and caregiver were working to overcome.

Although EoL family caregivers described a strong desire to be open and talk to others about their concerns, feelings, and experiences surrounding their loved one's terminal disease diagnosis, caregivers were disinclined to verbalize their sensibilities because they felt it is more important to shield their friends and family from such unpleasantness, thus they chose closedness over openness. Unless the friend was a *former* caregiver, EoL family caregivers were reluctant to share their experiences surrounding their role and concerns about the care recipient with their friends. Thus caregivers were inhibited from seeking support and venting frustrations for fear it would affect the friendship or saddle the friend with unnecessarily burden. Marie [ADRD, Child, 58, F-F], for example, avoided talking about her experiences because she was concerned her friends were not *truly* interested:

I'm afraid they'll be like, 'Oh no, she's going to talk about it again.' Sometimes I feel like, you know, because I don't want...to bore people or whatever, with talking about it, so I probably don't talk about it as much as maybe I could or should.... I fear – because I don't want them to be like, "Oh my God, here she goes again."

In this example, Marie illustrated an internal struggle to conceal her experience from her friends for fear they would perceive her to be nuisance, versus achieving the relief and support she needs. Thus, Marie, and the majority of other caregivers, found herself caught in a bind between two polar opposites, thus generating communication burden that manifested from a perceived inability to be open and seek support. While Marie completely avoided talking about her experiences with her friends, Katie [ADRD, Spouse, 71, F-M] described a reluctance to ask her closest friend to become her Power of Attorney, should anything happen to her prior to her husband's passing:

I was nervous to ask because I felt like I was putting so much responsibility on her and I was nervous and thinking, 'Gosh, you know, this is a lot of

responsibility to put on my very best friend' and because I adore her so much and we have such a close relationship you feel guilty putting responsibilities on anybody you care that much about.

Many caregivers, like Katie, felt unable to ask even their closest friends, for assistance because helpful tasks were believed to be too much responsibility to place on a close friend. Moreover, many caregivers worried that asking for favors would be inappropriate, because they were friends – not family. However, unlike most caregivers, although Katie's asking was a violation of the perceived friend boundary, she had no other family members she trusted, so she did eventually ask for the favor, but only after much deliberation, stress, and anxiety. Additionally, the above example illustrates that on rare occasions the caregiver's need to seek support outweighs a need to protect others. However, in Katie's case, the support she sought from her friend was actually to ensure her husband would be protected, should anything happen to her.

While many caregivers denied themselves an opportunity to share their experiences with and/or ask friends for assistance because it would be inappropriate, EoL caregivers were also hesitant to include members of family, and therefore chose to remain secluded in their caregiving efforts. For example, despite recognizing that she needed to talk to someone for her own sanity, Tammy [ADRD, Child, 57, F-M] stated, "I think you have to be open about it but I think it depends on your family and how much you want to protect your family. But again, I think you need one person to be able to open up completely with." For caregivers like Tammy, prior to seeking emotional, instrumental, or physical support, they forced themselves to negotiate the polar ends of a tense duality when considering which was most important, seeking assistance versus safeguarding others—in this case the family. This is yet another example of the tense binary EoL

caregivers must negotiate which stems from the disease as a hindrance to achieving multiple goals. In a similar vein, caregivers chose to protect family members by excluding them as a result of difficulties those particular members were experiencing in their own lives. For example, Chloe [GBM, Child, 35, F-M] explained her reasons for keeping her feelings from already overwhelmed family members:

If that person's under a lot of stress – like right now it's my husband, he's under a lot of stress, so I can't really go to him and talk to him about it my stress, because he's stressed out. So he's already on the negative side, and if you go in with more negative, then it's just going to kind of escalate into something else...so I'm keeping the stresses down on him.

In this example, Chloe admitted that she strives to shield others, in this case her husband, from intensifying the stress he already feels. In so doing, she oscillates between two polar extremes: protecting others by excluding them by concealing her own needs versus including them in order to seek and obtain support. Unfortunately, EoL family caregivers were prone to neglect one's own needs in favor of protecting others; thus the caregiver denies her/himself a much-needed outlet. Likewise, Edith [GBM, Spouse, 70, F-M], whose husband was diagnosed with a terminal brain tumor four months prior, decided not to tell their family about his diagnosis because she hoped to safeguard her family from the pain she felt:

Well after the doctors at first said he wouldn't live three months. Three months! After that, those words couldn't come out of my mouth to my family. I didn't want to, you know, it hurt me so deeply and I was protecting, I was protecting them over me because I knew if I said that to them it would break their hearts. I didn't want to hurt, it—me so bad when the doctor told me that I, it just took part of my life that I've never gotten back.

In the above example, Edith described a need to protect family from feeling the way she felt after learning of her husband's terminal diagnosis. Throughout the interview, Edith disclosed feeling immense burden and despair and was in desperate need of support –

even so, her inclination was to protect her family by excluding them at the expense of herself. However, at the end of the interview, Edith came to the realization that she should disclose to family:

Well I, I've enjoyed the interview with you and I think that it's really helped me a lot and I think that I've just talking with you and being here with you I think I'm going to be able to go home and really communicate. And I feel like I really should go ahead and talk with my sisters and my brother and things about this sickness that me and Bobby are dealing with, and give more detail about it, more to let them understand more about what me and him are going through.

The above example, illustrates that caregivers have a need to seek support from others, and although they may not realize it, they are making things worse by protecting others at their own expense. Moreover, the simple act of providing EoL caregivers an opportunity to express their feelings and concerns, like Edith, helped many participants work through the communication burden endured by providing an opportunity to rationally work through the opposing forces at work to achieve a solution that would mutually benefit the patient, others, and themselves. Many caregivers, like Edith, chose to keep their loved one's diagnosis from family entirely, while others chose to disclose the disease, but sugar-coat the reality; which was a common occurrence for both ADRD and GBM caregivers. In a sense, while in a state of immense emotional turbulence, EoL family caregivers made irrational decisions based on their conjectured opinions the information would have on others when deciding whether and how much to include friends or family to their reality.

Moreover, the well being of the children, adolescents, and young adults of the family were considered a top priority before all other family members by EoL caregivers. As a result, caregivers went to great lengths to safeguard the youngest members of the family from losing their innocence, suffering the loss of the relationship with the care

recipient, or enduring emotional pain. Tammy [ADRD, Child, 57, F-M] who was a caregiver for her dad, for example, protected her children by excluding them from learning of her daily stresses, experiences, and concerns by managing how much she includes them by revealing the bare minimum carefully managing the types of supportive care she allowed her children to provide:

With my children I want them to maintain that grandfather/child relationship so I think they see him differently a little bit, so I try to protect that. Is it good or bad? I don't know; that's just how I choose to do it...I'm talking about the day-to-day care stuff. Last week they knew openly what was going on with grandpa. 'No, he wasn't doing good after recovery, he was really sick' all this kind of stuff, but I'm talking about the day-to-day frustrations where I'm feeling a little bit pissed...It's hard being a child again even though you may not realize it, and I know from experience.

Tammy later described the difficulties she endured taking care of her dad and her grief over the loss of her role as a child to a father, which was one of the reasons, she no longer encouraged her children to visit from college because she wanted to preserve the grandchild identity and relationship with their grandfather. Although her objectives were noble, Tammy has forced herself into a continuous battle she negotiated between a desire to protect her children versus herself and her desire to include her family versus a need to remain secluded in her anguish.

Like Tammy, Pam [ADRD, Child, 55, F-M] also kept information from her daughter because she, “[tries] to kind of shield her from that – I don't want her to worry about me.” Pam's attempts to suppress information stemmed from her instinctive need protect her child by precluding details of the situation that she believed would cause her daughter to be fearful of her own wellbeing. While, Tammy and Pam intended to minimize the harm on the young adults of the family by withholding information about the situation and their experience, Joe [ADRD, Spouse, 77, M-F] also kept information

from his two adult children, but for a very different reason and with a very different result:

We have two children. The daughter is here; the son is up in [different state]. They enquire about her periodically – not a lot, but they’re not doing anything right now, and I’m not asking them to because if something happens to me—our daughter, it’s going to fall on her, and I’m just going to wait and let her do her share then, as [my wife] gets worse. So I’m just trying to do most of it now because if, like I said, as time goes on my daughter is going to have to step in.

In this example, the EoL family caregiver refused to share much of anything with his two adult children, instead, Joe’s attempted to manage an immensely emotional and irrational situation with a rational mind, which caused him to put off involving his children “too soon.” Joe believed he was protecting them in the present in order to preserve future assistance, when can no longer physically and emotionally provide for his wife alone. Unfortunately, his attempts to handle the situation with a rational mind inhibited Joe from obtaining the support of his children that he desperately needed and desired. Which was revealed later in the interview when he acknowledged his support needs, and frustration with his children. According to Joe, his children had yet to offer him any form of support, and more importantly, only checked in on their mother periodically. Although he admitted he wished for solace from his children, Joe chose to protect them over himself, for the time being, in hopes that he could count on them in the future. Joe’s attempts to remain rational in a largely chaotic situation created a tense binary he incessantly negotiated, influencing his communication burden, and as a result his accruing resentment could potentially affect the relationship with his children.

Self-Protection: “I Am Fighting My Thoughts”

As previously illustrated, EoL family caregivers consider themselves at the bottom of the protection totem pole. However, caregivers not only carefully approached

communication tasks in order to protect the care recipient and significant others, they also considered the impact that the sharing of experiences, concerns, and support needs would have on themselves before they could talk to persons outside of the caregiving unit.

Regarding one's own wellbeing, for EoL family caregivers, there were two main factors that contributed to the way caregivers chose to communicate and seek support, including fears concerning the outcome of the communicative encounter and apprehension of having to deal with pre-existing family drama.

Fear the outcome: “Fear of the unknown is worse than fear of the known.”

When deciding whom to inform and involve, family caregivers anticipated the potential outcomes they fear, such as, becoming vulnerable and being subject to others' incongruous responses. In regards to vulnerability, caregivers were concerned with becoming emotionally vulnerable from involving others by disclosing sensitive information, and making themselves susceptible others' incongruous and intrusive responses. Therefore, more often than not, caregivers chose to protect themselves by remaining secluded as opposed to including others in their experience.

Vulnerability: “Opening that emotional box...there's not a time for it.” When EoL family caregivers invited others into their world by sharing intimate details of the life shared with the care recipient, they were opening themselves up to not only the emotional consequences of revisiting painful feelings, but to the hurtful and inappropriate responses of others. Caregivers openly described feeling emotionally vulnerable as a result of disclosing concerns and experiences, asking for assistance, and when recounting the events of the day or week.

As previously illustrated, EoL family caregivers recognize a need to care for their own personal well being by talking about their experiences and obtaining support. When discussing her past attempts to seek support through a professional counselor, Natalie [GBM, Spouse, 38, F-M] explained why the outcome was detrimental to her goals as a wife, mother, and caregiver:

Taking care of me, I don't really feel like I probably do a very good job—emotionally, on the emotional side. I tried to go *see* somebody and then it wasn't very *helpful*. And I think that's something to think about when you're thinking about services providing to family [caregivers]—you both want somebody to understand, and then you don't. You both want it to be heard and recognized, and then you want to pretend it's not there. And I don't know what to do about that, because when I went to counseling it was like—I felt like she was just gonna open this box up and I couldn't—I CAN'T fall apart! And so opening that emotional box, there's kind of not a time for it—because if you open it all the way, you risk falling yourself into that hole, and then whose gonna take care of everybody *else*?

In this example, Natalie felt her counseling session was disadvantageous rather than beneficial, because voicing her experience and concerns forced her out of denial, making her vulnerable to the realization that her husband of three years would likely not be around in 12 months and would not see their one-year-old son grow to be a man. Her efforts to obtain support did not comfort her, but instead tore apart her hopes for the future and made her face reality, which was too much to absorb. Caregivers like Natalie, described walking a fine line between maintaining the right amount of denial, while at the same time, acknowledging the facts.

A delicate balance existed for EoL family caregivers when opening up to others because they feared becoming vulnerable to their own emotional responses and the potential outcomes of the response. Joan [ADRD, Spouse, 76, F-M], for example, explained why she finds it easier to talk about objective topics rather than her subjective experience:

Probably anything to do with the illness more than your personal time and that; you don't want to admit that you can't do it, I guess. I don't know, honey... Personal because you don't want to ... I don't know. You don't want to feel like you can't do it. You don't want to admit you're a failure.

For Joan, talking about her subjective caregiving experience and needs meant an acknowledgement that she failed to accomplish her goal to provide quality care for her husband. Not only that, but Joan was embarrassed that she was experiencing her own difficulties with the caregiving situation and did not want others to perceive her as a failure. Thus, Joan chose to maintain her pride than feel shame by disclosing her needs to outside others. Caregivers shared similar sentiments regarding their reasons for not seeking emotional and instrumental support; commonly reporting because it would “make [them] feel incapable” or “weak.” In the above examples, although the context (professional vs. personal) was different, the outcome was the same: rather than assuaging the stress and burden, the result of talking to others and seeking support made family caregivers emotionally vulnerable, thus impacting their ability to cope and carry on. The constant tension caregivers faced when choosing between a desire to unload their burdens to someone else and the consequential emotional turmoil, accentuated caregiver communication burden as the caregiver attempted to negotiate between the two extremes. For EoL family caregivers, allowing oneself to become emotionally vulnerable was often perceived as a lose-lose situation.

Unlike Joan, many caregivers felt burdened by the responsibility to keep outside others informed and updated on the objective facts like the disease and the progression. When asked to share a word that depicts her sentiments talking to her family about her own experience, Mallorie [ADRD, Child, 34, F-F] said, “Exhausting,” and then further elaborated:

Just trying to relate. And then I've got to relive everything just to tell her. I have to go back through the whole day or week or whatever it's been...It's a responsibility to get all that back to her, and on top of that, I have to relive all my pain and sadness again to do it.

In this example, Mallorie emphasized the emotional pain she experienced when keeping her family updated on the daily and weekly events. Further, she clearly depicted the act of keeping family informed as an additional “responsibility,” that was not only a supplemental caregiving duty, but one that made her vulnerable causing her to re-confront emotions she was working hard to repress so that she can continue on and protect the care recipient.

Vulnerability: “It’s an ordeal...every time.” In addition to fears of becoming vulnerable to one’s own emotions, EoL family caregivers expressed a fear of opening themselves up to the judgments, opinions, and expectations of others. Concerns over becoming susceptible to others’ judgments was a significant concern for Jolene [ADRD, Child, 38, F-F], an adult child who reluctantly cared for her estranged mother, who would only occasionally disclose her experience to others:

I probably do talk some about my, you know, just stress about getting it done for her. Probably [with] friends of mine, like I have a devotion group. But, I mean, I’ll talk about them with my devotion group but they’re not easy and then I start crying or feel embarrassed, like I am with you, I feel embarrassed that I don’t...I don’t have a good relationship with my mom.

Jolene did not have a close and loving relationship with her mother, and while she felt it was her responsibility to provide care for her mom, she had a hard time sharing her experience with others, particularly because her fears and uncertainty stemmed from her mother’s abandonment of Jolene and her father. Aside from talking to her husband on rare occasions, Jolene seldom discussed her caregiving experiences and concerns because she felt she would be judged for not having a good relationship and as uncaring because

she “[does] if out of guilt, not because [she] wants to.” Overall, Jolene avoided discussing her caregiving concerns to protect herself, and when she allowed herself some momentary relief, it resulted in emotional turmoil. For Jolene, the communication burden she endured was precipitated by a perpetual need to share with others and obtain support, which for her, contrasted with a need to protect herself from the judgment of others. Thus, inhibiting Jolene from talking openly about her experiences needed to sooth the frustration, resentment, and anger she felt while providing for her mom.

Like Jolene, when asked if she talks to others about her caregiving experience, Katie [ADRD, Spouse, 71, F-M] explained, “No; you really can’t because people would think that you’re complaining, they would think, ‘They’re your husband, you should be taking care of him’; ‘don’t you expect stress, don’t you expect to be tired?’ They also sort of see you as in the retirement thing rather than the caregiver role.” Katie weighed her need to talk about her experince against how she believed others perceived her caregiving role, which caused communicaiton burden and thus influenced her reluctance to seek relief and care for herself. Similarly, many caregivers, like Shirley [GBM, Child, 55, F-F], feared judgements because “they think that I’m just sitting here watching TV and cooking little meals and washing some dishes every once in a while. You know, I don’t think they realize the extent of everything that has to be done.” In instances such as these, EoL family caregivers were reluctant to openly disclose their need for support for fear of being judged by others, therefore they chose to remain closed because their need to unload was inhibited by an even stronger desire to protect oneself from the judgment and expectations of others—causing a torturous form of communication burden.

Although she was one of few caregivers who expressed this specific sentiment, Kathleen [GBM, Child, 59, F-F] shared that her fear of asking for assistance stemmed from others' expectations of reciprocity when she stated, "[I wouldn't ask] for just anything, for very most I wouldn't feel like...I would feel like it has to be so reciprocal, kind of thing. A lot of my other friends I wouldn't feel real comfortable asking them to do things." Other than a former caregiver friend, Kathleen explained that she would not ask the majority of her friends for assistance because she did not have the time or energy to reciprocate, thus she avoided making herself vulnerable to an outcome she feared – impractical expectations. This example further illustrates the communication burden that stems from the contradiction between including others and secluding oneself.

In addition to becoming vulnerable to others' judgments and expectations, caregivers also feared opening themselves up to hearing contrary opinions – which were particularly cumbersome when trying to make important care decisions for loved ones. For Julia [GBM, Spouse, 38, F-M], all decisions were difficult because her husband's large family wanted a say:

Every. Big. Difficult. Decision. With the first choice of treatment, I had to make the decision to come here instead of going to [another center] which is like forty-five minutes from our house. From here, it's like three hours. And we could have went to a cancer treatment center that was like less than an hour and his parents and two of his sisters disagreed with that. They wanted us to go to [nearby center] so it would be easier on him. Then there's actually another cancer treatment place that's like thirty minutes from our house in the other direction...and his Daddy went there to have treatment for prostate cancer so they're all like, 'Well if it was good enough for Daddy then it's good enough for [husband]'. But it's not because we're not even in the same ballpark here with prostate cancer and terminal brain tumors, so I listened to what everybody said, you know the medical professionals, and even argued with [my husband] because he was wanting to make it easier on me I think, and I was like, No we're going, they've got the best thing. I don't care what you say, we're doing it.' It's an ordeal, yeah – with his family every time.

By informing and involving others into the caregiver and care recipient's illness experience, caregivers, like Julia, feared that outside others would perceive that as an open invite to share in the decision-making. Additional (unwanted) opinions only made the decisions more difficult for caregivers, especially when they felt a need to acknowledge, discuss, and then manage potentially numerous and conflicting opinions before coming to a decision. And in the case of Julia and her husband, time was of the essence. Often tensions emerged for EoL caregivers between making decisions individually (seclusion) versus family decision-making (inclusion).

Incongruous responses: "Talking with others is the hard part because..." In addition to a fear of vulnerability, another reason caregivers were largely resistant to sharing with and involving others was the result of a tremendous fear of receiving inappropriate feedback. Incongruous responses included feedback caregivers deemed as unsuitable and incompatible with the intent for disclosure – to obtain some form of support. Incongruous responses were detrimental to the caregiver, which resulted in feelings of doubt, the minimization experiences, feeling overwhelmed, and emotional pain. Unfortunately, EoL family caregivers would become fearful, hesitant, and anxious about including and involving others because of prior experiences with incongruous feedback, which inhibited them from future disclosure.

Although in general, Clara [GBM, Spouse, 52, F-M] had a difficult time getting her family to respond to her text updates, (which in of itself is an incongruous response), on occasion, members of her family would respond inappropriately making her feel inadequate:

When I tell them things about things that I've talked to the doctor about and sometimes, especially his sister does it, she'll be like, 'Well did you ask the

doctor that?’ And she’s real forceful when she’s talking like, ‘Well did you ask him *this*? Did you ask him *that*?’ And I’m like, ‘I didn’t think to ask him those things,’ you know, and it makes me feel like I’m not doing good enough, just I’m not doing good enough to satisfy her.

Throughout the interview, Clara explained that the majority of the time when she sends updates to her family, she got no response. However, in some instances, like the one above, family members responded in a way that made Clara feel as if she was not doing a good job. Clara’s intent was to inform family members, and hope for a supportive response, and the feedback she described clearly clashed with her objective. Although she desperately needed support, in order to obtain it, she had to make herself vulnerable to others’ incongruous and hurtful and responses. Therefore, Clara existed in a perpetual bind between the need for support and her fear of the response. In a similar vein, when asked about her reluctance to disclose stress to her brothers, Shirley [GBM, Child, 55, F-F] disclosed:

While I think that I was able to [talk about] my stress related to my job, I don’t think I’m able to de-stress as well from the stress of caring for [my mother]. Because, you know, you don’t ever have a time when you’re completely away from it. And I think that’s something that I find it hard to talk to my brothers about, with. Because they have a life outside of the house, I don’t. They’ll just say yeah I know, yeah I know. But that’s all – nothing’s ever done.

Rather than obtaining the support she needed, Shirley’s attempts to inform and include her uninvolved brothers resulted in augmented stress and communication burden due to her brother’s all too common incongruous response – To ignore her needs. Which sadly resulted in heightened distress for Shirley, which was in direct opposition with the objective of her disclosure.

Another harmful and incongruent response commonly feared by EoL family caregivers occurred when others discounted the caregiver and care recipient’s experience.

For example, when asked what she finds most difficult to talk about, Lacey [ADRD, Child, 39, F-M] shared:

I think the progression...probably about the disease state, you know, talking with others is the hard part because a lot of people will say, "Well maybe you're not taking him to the right doctor, they don't have the right diagnosis," Or you know, "He seems fine, I mean, maybe he's just being lazy." Yeah. I've gotten that, even from his own parents! They just think...and there's days he does seem, if you didn't know he seems fine, and then other days you would realize. But they're not around enough to realize.

For Lacey the hardest conversations to engage in were not difficult as a result of the content, but rather because she often heard responses like the above example, which not only discounted she and her father's hardships, but also suggested that she did not spend eight months going through significant hassles to get her father an official diagnosis of Frontotemporal dementia. Others' overt denial of Lacey and her father's experience were dissonant with her intent to keep others informed and obtain support and therefore resulted in communication burden. Similarly, Rose [ADRD, Spouse, 72, F-M] shared what made her conversations with others difficult:

The thing is, their comments sometimes...Like, it's not a big deal. One of my favorites – I believe my daughter-in-law said this. I said something about he said he wouldn't be here long, and she said, 'Oh, he's talked about dying for years.' I didn't think that was a good thing to say. He has. He has said, 'I'm not going to live. My parents died at this age. My dad died at this age. I won't live past that.' Things like that, because he's fought with depression all of his life. He comes from an alcoholic home...I thought that didn't need to be said.

Her daughter-in-law's response was obviously hurtful to Rose and was incongruous with her expectations because she was seeking emotional support through the telling of her story. When asked what an appropriate response would have been, Rose stated, "Mostly she didn't have to say anything. A lot of times it's better to say nothing. Listen and be concerned about the person...be a good listener. Listen and hear. Hear what the person is

trying to tell you and be compassionate, or pray for them, or whatever.” Because topics related to death and dying are largely taboo in Western society, it was common for people to say inappropriate things without realizing their blunder, in an attempt to fill the uncomfortable silence. As a result of the immense exhaustion and overwhelming feelings of burden due to a very grim situation, EoL family caregivers were sensitive to others’ responses, which was further enhanced by the internal conflict caregivers experienced when disclosing what they perceived to be taboo topics. Likewise, supportive others are likely also struggling to come up with an appropriate response for a topic that they also perceive as taboo. According to Rose, the appropriate response in such a taboo situation was to listen, which would enable the caregiver to express their burdens and obtain some relief. Thus a further tension emanated from the caregivers perceived absence of support outlets while some may have been present.

In addition to responses being hurtful and inappropriate, caregivers like Janice [GBM, Spouse, 64, F-M] were reluctant to disclose the diagnosis or their feelings to others because, “people always say the wrong thing, and so you end up having to take care of them.” When disclosing something as scary as a terminal illness, the purpose was to inform others, caregivers were already emotional and had little support themselves; thus, making it an overwhelming task because they lacked the capacity to support others, therefore conflicting with the caregiver’s goals. Joe [ADRD, Spouse, 77, M-F] further emphasized the sentiments of Rose and Janice, with his remark:

You start talking to somebody about your concerns, and before you know it they’re telling about theirs, almost all the time. You don’t want to hear their problems. I’ve got my own problems. I guess right now it would be good if I was a Catholic and could go to confession, and instead of confessing I could have somebody listen to me.

In the above example, the caregiver suggested that he was reluctant to disclose his concerns to others as a result of past experience and the associated fear of incongruous responses—when, like Rose, all he desired was someone to listen. The majority of caregivers experienced communication burden as a result of the perception they had no one with whom to disclose their experiences and seek support, thus highlighting the presence-absence contradiction as influential in communication burden. Moreover, Joe later revealed that as a result of his fear, aside from his children and pastor, Joe had not told anyone about his wife’s Alzheimer’s disease. Further, the only reason he shared the information with them was to protect his wife in case anything should happen to him.

In a similar fashion, Lois [ADRD, Spouse, 77, F-M] described her experience of disclosing her husband’s Alzheimer’s diagnosis, as turning into a competition of ailments and one-upmanship:

Well, sometimes they say, ‘Well, I have trouble thinking of words too.’ My comment would be, it's kind of a matter of degree. I think a person who lives with him all the time knows... Sometimes I block on a name or something too, or I have trouble thinking of something, but you kind of know when it's reached a pathological state, which discounts his illness and my experience with him.

During the interview, Lois explained the reason she disclosed her husband’s diagnosis was to prepare others for odd behaviors and to circumvent embarrassment for both her husband and herself. Responding in ways that minimized the magnitude of her disclosure by claiming similar deficiencies for themselves was incongruous to her goal to inform others, prevent embarrassment, and seek empathy and support. Based on her past experiences, Lois goes to extreme lengths to conceal her husband’s disease from outside others. Therefore as a result of her preconceptions, Lois negotiated the tension between

inclusion versus seclusion by concealing her husband's disease to outside others. This was done as a means to protect herself from vulnerability.

In addition to the content of responses being unharmonious to caregiver disclosure goals, the outcomes may also conflict with the caregiver's goals due to inappropriate timing and the volume of received responses. For example, Emilee [ADRD, Child, 22, F-F] explained why she avoids talking to her friends about her experience, "I just don't like talking about the progression or the disease with my friends...they'll pick horrible times to bring it up...it's like they just bring it up to see how I'm doing, but it's just way more like a sensitive subject than I guess they see it to be." Although Emilee was rarely afforded an opportunity to socialize, when able, her friends would inquire about the care recipient, which was very difficult for Emilee because she was with her friends to get away from the stress, but the inquiries brought painful emotions to the surface. Although Emilee's young friends intend to be supportive and caring by asking questions, the outcome was incongruous to her goals to get away from the stressful caregiving situation, forget about her concerns, and enjoy being with friends. Thus, Emilee's communication burden emanated from an inability to escape her caregiving role as a result of including others, and the social constructions that bind and prohibit her from telling her friends she does not wish to talk about her mom.

In addition to issues with inappropriate timing, for EoL family caregivers, there was a balance anticipated with regard to the sheer volume of responses—It was difficult for caregivers to achieve a manageable balance between scarce and abundant feedback, in which both extremes caused the caregiver significant communication burden. For

example, Sandra [GBM, Spouse, 64, F-M] described the distress she experienced when her family ignored her updates:

I've tried to be so open with the family, I mean I probably over did it I started texting them when he was in the hospital and I was telling them all these bad things, I would copy all of them, sometimes I would get good responses and other times I would feel like why aren't they responding to me, you know? Maybe they were busy or whatever, but when you're in the middle of you something that is really, really freaking you out, and you're worried and you don't know if your person, if your family member is going to make it through this, and I just wanted someone there with me, you know? At the same time I was like asking for help and support you know? I need somebody here with me, I'm by myself with [my husband] you know?

In the example above, while at the hospital, Sandra and her husband were just informed of her husband's devastating GBM diagnosis. Sandra texted her family in hopes that someone would acknowledge their distress and fear, but aside from some short inquiries, her pleas for acknowledgement and comfort were ignored, which further enhanced her torment. In addition to being ignored, Sandra attributed her family's lack of response to her being too open about the situation. Thus, Sandra was caught in between a desire for support and a fear of overwhelming potential supporters and contradicting her efforts, which further highlights the communication burden that emanates from the inclusion-seclusion contradiction.

Conversely, after sending a mass text to update family on her husband's most recent clinical exam and brain scan, the number of individual responses overwhelmed Clara [GBM, Spouse, 52, F-M] and generated an overpowering sense of communication burden:

I sent it out to them, but when I got ten responses back that I had to respond to individually that's when it got really, this is not fun. And how do you tell his brother, his sister, his son, his daughter, your sister, and his cousin whose really close to him, how do you tell all these different people, 'I can't answer you individually, you're going to have to look on the Caringbridge website from now

on,' you know what I mean? They'd be like, 'How can you say that to me, I'm his son!' And so it's like there's certain people I still have to do one-on-one with because of their importance...it's really stressful to try to answer ten or fifteen people you know? Especially when all these people are asking different questions and stuff... I still don't have a good answer on how to answer fifteen questions at one time.

Caregivers often engaged in efforts to keep family and friends updated with facts regarding the patient's well being, improvement/decline, information from the doctor, etc. A task that was commonly completed through asynchronous modes of communication (e.g., email, text messaging, Facebook, Caringbridge, etc.), which the majority considered to be a less cumbersome means of communicating updates and information about sensitive topics to several people at once. It likely goes unrealized by the recipients of these updates, but these attempts are often an attempt to obtain support and assistance. Unfortunately, it was not uncommon for family members and friends to ignore the caregiver's support-seeking attempts, which was in strong contrast to the sender's intent. And when people did respond, it often occurred as singular inquiries which made communication a burdensome responsibility and chore. The above example is a clear case of communication burden that emanates from a tension between the caregiver's need to keep others informed, while trying to manage the communication back and forth to protect oneself from becoming vulnerable to heightened stress.

Intrusive responses: "Stop projecting yourself and your experience onto me." In addition to feeling vulnerable and the receipt of incongruous responses, another common, yet unwelcome consequence of involving others occurred in the form of intrusive responses; others' inclination to share horror stories and unsolicited advice. EoL family caregivers described being inhibited from sharing with and seeking support from family

and outside others, largely due to an unwillingness and inability to listen to the accompanying horror stories. As in Clara's [GBM, Spouse, 52, F-M] case:

My younger sister came and told me about one of their friends whose husband had brain cancer and surgery – how he deteriorated and for five years he sat in the living room and never talked. He was not the same person and you hear all these different kinds of stories and that scares you. And one of the guys that delivers our coffee, his brother has been sick off and on at least for the last two years. And he felt like he was a big burden on his family – he'd been in the hospital more than home... And they had let him out one Friday night... and he was doing better, but Saturday morning he got bad again and he shot and killed himself... I don't think my husband would ever do that. But you know like people get desperate and it's like all these fears start coming through your mind, and I do try and pray and give all this up to God and stuff. But it's like I am, I am fighting my thoughts you know?

In the above example, Clara described others' proclivity to respond to the news of her husband's terminal brain tumor by sharing horror stories associated with similar diagnoses. As a result, Clara was not only fearful of seeking support from family and acquaintances to shield herself from hearing horror stories (the suicide story in particular), but she later described a refusal to talk to her husband about anything substantial for fear that he might commit suicide. Unfortunately, in an attempt to protect her from hearing horror stories, Clara avoided meaningful conversations with her husband, and therefore precluded herself from preparing for the future. Once again, the caregiver negotiated between a need to protect the patient versus a need to attend to one's own needs. Natalie [GBM, Spouse, 38, F-M] described a similar experience with her mother-in-law:

It's like because she went through something similar with her husband, she thinks she knows what I'm going through. But this is a different type of cancer. Her husband was in his 60's, mine is in his 30's and we have a *baby*, and our life looks really different. We don't know what's gonna happen... its not all necessarily gonna be the same. But every step of the way she's tried to tell me what it's gonna be like and then she puts that into my head, like 'he's gonna be tireder than you've ever seen him before' and then I have that in my *head*... And I

wanna s—and I do say to her, “This is different, stop telling me what to expect and what's gonna happen. Stop projecting yourself and your experience onto me.” It’s really awful!

In the above example, Natalie, who was trying stay positive for the sake of her husband, young son, and her own emotional well-being, was constantly reminded by her mother-in-law of the horrible things that could be part of her future. Unfortunately, her mother-in-law’s intrusive responses were the source of her unwillingness to include her mother-in-law, who was willing and could have been of great help to her family.

In addition to horror stories, EoL family caregivers were also fearful of receiving unsolicited advice as a result of disclosures. For example, as a result of the unsolicited advice of outside others, Rose [ADRD, Spouse, 72, F-M] became concerned about her decision to move she and her husband into retirement living:

I’m concerned with his emotional stability and things. If it would take him out of his comfort zone, more or less. Because some of them at church told me that – they're husbands who died with Alzheimer's – said, ‘Oh no, you can't take them out of that *now* at *this* point in time.’

After she shared her plans to move, Rose’s friends convinced her that it would interfere with her husband’s emotional stability and behavior, which caused her to question the decision she had made and stall the move even longer. However, when asked, Rose admitted that she had not reached out to her husband’s doctor or social worker to obtain an expert opinion. For Rose, who was already overwhelmed with having no support from family and friends, the contrary advice as a result of including others, halted her plans to unburden herself with her home and unnecessary possessions.

Family issues: We don’t get along the best.” In addition to fearing the repercussions of disclosing and or seeking support, many EoL family caregivers felt immense stress and frustration when they communicated with and involved family –

which was largely a result of long-standing tension and extant problems within the family. Many caregivers shared sentiments similar to Natalie's [GBM, Spouse, 38, F-M] about her experience communicating with her mother-in-law, "She and I do not communicate super well and that is extremely stressful. *But* she is there when she needs to be there." As a young mother and wife, Natalie needed the help of her mother-in-law, with whom her communication style was not compatible, making it stressful to obtain support and assistance. In addition to discordant communication, many caregivers were inhibited by past relational strain. However, the need to include others and protect the patient commonly trumped the caregiver's need to protect oneself from confronting dysfunctional and hurtful family issues. For example, many of Emilee's [ADRD, Child, 22, F-F] caregiving challenges stemmed from the strained relationship between her brother and the family friend who assisted her in providing care:

We've never really been too close and I feel like he's just in denial. I don't think he really likes to be around Mom; he just doesn't get along with [family friend], he doesn't agree with any of the medicines that we're adding, taking away, and he's not even available to make the appointment so he's just kind of like taken himself out of the situation. We've learned not to talk about it too much with him really; just anything with him escalates very quickly.

In this example, Emilee and a long-time family friend had taken over the caregiving situation, and refused to involve her brother in an attempt to avoid the complications that arose due to relational strain and discord in the family. Similarly, Shirley [GBM, Child, 55, F-F] explained that her family expected perfection, and her associated inability to say no to her mom, the care recipient, and her brothers:

Now my older brother is just like my mom [laughing], so it, it doesn't do any good to talk to him about it because he expects perfection from everybody else too just not from himself. Which is why, I think he never agrees with anything I do for mom. But you know my younger brother too is – the running comment is, and my younger brother's wife said this to me as well, she said, "Your mom has

always tried to control everybody and everything...but you're the only one that listens to her." So that's why I think it's an issue that they recognize that she has always tried to control me, and that I have given in a lot on things. Because I wanted her to be happy, she's my mom. But to some extent it's really prevented me from being able to tell her no on things during this illness because I've always been the *good* daughter [laughing]. Which I'm sure is why they expect me to take care of mom without any help.

The above example, illustrates the ways in which pre-existing family issues continue to influence EoL family caregivers' ability to ask for assistance and support from members of the family. Shirley had never acquiesced to her mother's wishes, something her brother's were well aware of, thus predisposing them to take advantage of Shirley's kind nature by refusing to acknowledge her needs or assist in any way. Likewise, Mallorie [ADRD, Child, 34, F-F], the youngest of five siblings, explained she was unlikely to involve her siblings because of relational strain amongst them:

If you noticed, I'm 34, my mom is 76. She had me when she was 42. Between me and the sister that is next to me, there's 13 years between us. And between me and the oldest sibling, there is 20 something years between us; I think she's 57 or 58. And we don't talk so...I don't know if I would tell them what's going on with Mom or not. I certainly wouldn't call [my sister] who lives nearby. She's a lot older than me....She's not close with my mother, I don't know exactly what happened in the past, but I wouldn't call her. I know when my other sister came [to town] and met my mother at the doctor, she asked that sister, and she said, "No." I mean, she lives pretty close to the doctor. So no, I would never call her for anything.

Many caregivers were reluctant to seek support from members of the family due to existing conflict and dysfunction. In Mallorie's case, her reluctance to include siblings originated from significant age gaps that inhibited the development of relationships with many of her siblings, and therefore precluded her from seeking and obtaining the support she desperately needed.

Another cause of caregiver stress and reluctance to seek support derived from dysfunctional family dynamics as a result of discordant blended families and relational

strain between the caregiver and care recipient. For example, Ronald [GBM, Spouse, 65, M-F] revealed his hesitancy to involve his stepdaughter in her mother's care when he stated, "I wish that I could talk to her daughter more about it but she wouldn't listen to me she think I was lying to her." While Ronald's barrier to seeking support stemmed from relational strain with his stepdaughter, Jolene's [ADRD, Child, 38, F-F] problems providing care emanated from resentment of her mother for the past estrangement of she and her father:

I don't have any brothers or sisters, but I mean I have a great relationship with my dad. I try as hard as I can with my mom. It's just since I was ten she was lying about an affair and so that's why I don't do well with people that lie. And so this has kind of compounded it, because now she's hiding and lying so it's very frustrating. Like I basically do this out of guilt [laughs] which sounds awful, but it's very, very hard to deal with it. And [the doctor] was like you all need to go to counseling, and I know we do, we, I mean, she got mad that I took her [to the doctor] and the whole time she was talking about stuff from thirty years ago. They got divorced when I was ten and I chose to live with my dad, so it's been an awkward situation. So I'm the only one to take care of her and yet, we don't get along the best...She has two brothers living, and, one sister but, not good relationships with any of them.

Jolene's stress providing care for her mom can be traced back to 30 years prior, when her mom had an affair and abandoned she and her dad. Moreover, her past experience with her mother's compulsive lying, compounded her distress because a symptom of Alzheimer's is hiding and lying, which opened old wounds for Jolene. Furthermore, Jolene was the only child from her parent's marriage and her mother had strained relationships with her own siblings, which made it impossible for Jolene to seek support or assistance from family as there was no one to ask. Although, she could ask her dad, Jolene preferred to protect him from opening old wounds and had not even disclosed her mother's diagnosis or the situation to him. The tension Jolene experiences stemmed a perceived familial obligation to care for her mother versus her wishes to avoid revisiting

the hurtful past. Like in most cases, the obligation to protect the patient takes precedence over the caregiver protecting oneself from emotional harm. This further illustrates the presence of support outlets yet perceived absence due to the caregiver's need to protect others.

Anticipating Instead of Seeking Support

Clearly caregivers were reluctant to invite others into their experience because they felt a need to protect the patient, themselves, and others. In spite of the fact that EoL family caregivers need emotional and instrumental support, they refused to ask for it largely due to a sense of self-reliance. And even those who expressed a desperate need for support, still refrained from asking because they anticipated support offers from willing others rather than openly seeking. Thus creating yet another bind for but for potential supporters because if caregivers will not share their experiences or let on that a need exists, it is unlikely they will receive the needed support.

Pride: "...Because I Like to be Self-Sufficient"

EoL family caregivers exemplified a strong sense of self-reliance and pride, which inhibited them from seeking support from others for fear of feeling shame. Caregivers demonstrated a need to remain self-sufficient in their caregiving efforts because they felt as though they could and/or should do it alone for reasons of personality, family tradition, lack of trust, and because assistance would mean more responsibility for the caregiver.

As formerly discussed, individuals who take on the caregiver role are a specific breed of individual: a person that puts the needs of others ahead of oneself. However, another trait of family caregivers involved a desire to remain self-sufficient. These

qualities combine making a difficult situation even harder, because once the caregiver realized a need for help exists, they were often too independent and prideful to ask for assistance. Lacey [ADRD, Child, 39, F-M] explained why she refused to ask her siblings and other close relatives for much needed assistance:

I think it just depends on the person's personality, and I think my personality is, and I'm very real world, even though it's very sad and...it *is* hard, but I feel like you just have to deal with it, and I think it's when you don't deal with it, that it becomes a lot harder. So we just deal with it, it's the best—it's what we have, and we are just gonna have to work through it. And that's just kinda me.

In the above example, Lacey explained that she would not ask for help because it was not in her personality to do so, instead, she had just pushed through the tough times, which was what she planned to continue while caring for her father. Similarly, Jolene [ADRD, Child, 38, F-F], who previously shared her frustration over her family's lack of support explained, "I don't ask people for help. That's probably—in my in-laws defense, they probably would help more if I would ask. But I just don't, I'm not someone to ask for help...Because I like to be self-sufficient [laughing]." Although she complained about her lack of support throughout the interview, it did not occur to Jolene until asked, that she was not receiving support because she was not asking for it. Suggesting that although she continuously negotiated a bind between remaining independent and prideful versus feeling shame as a result of dependence, she was unaware of the issue until she was specifically asked to consider the reasons she did not have support. Similarly, Joan [ADRD, Spouse, 76, F-M] expanded on her reasons for not seeking assistance from others, "When you are an independent person, always used to doing for yourself, sometimes it can be very, very hard to ask for help. You get used to it more as it goes along but at first it's...if you're an independent person it's hard to ask for help...and I am

very independent.” Further, many, like Janice [GBM, Spouse, 64, F-M] refused to ask for help and would attempt to do it alone, “as long as I think I can do it, I won’t ask others for help.”

Male caregivers mostly described their familial role as provider and protector and the felt responsibility to maintain that role when caring for an ill loved one. For example, Stephen [GBM, Spouse, 43, M-F] explained, “It’s my family, it’s my responsibility, it always has been and it always will be.” Likewise, Joseph [GBM, Spouse, 65, M-F] conferred, “Quite honestly I’d feel badly asking for help within the family. But I would have more trouble asking for help outside the family. We have a, ‘We can take care of ourselves’ kind of attitude even if it’s misplaced.” Poor Joseph is in quite a predicament because not only was he against asking family for help, he was more opposed to asking friends. Which is preventing Joseph from receiving the help he needs both now and will require as his wife’s brain tumor continues to progress. And when asked why he does not ask for support to help him provide care for his only living brother, Billy [GBM, Sibling, 61, M-M] felt it was his responsibility as a member of his family:

The family always takes care of the family. Me and him is the only two left. We've always -- everybody's always took care of the others. It's not something that you have to do; it's something you do because of the love in your heart. It's something you want to do. I could have somebody in there 24 hours a day taking care of him. That's not the deal. The deal is it comes from your heart, and you do what you're supposed to do. You're supposed to keep your faith and everything and a positive attitude.

Both males and females in this study felt a responsibility to care for their loved one, however unlike the women, most of the men absolutely refused to seek support, even if it they strongly needed it because they believed it to be their duty as a male member of the family. This example further illustrates the tendency of EoL family caregivers to bend to

their need to retain pride versus feeling shame, which contradicts with the caregiver's desire for support. To many EoL family caregivers, seeking support would require the caregiver to admit to needing others and therefore being dependent upon them, which contradicts with their independent nature.

In addition to having an independent personality, caregivers were reluctant to ask for help because they did not trust others. For example, Julia [GBM, Spouse, 38, F-M] stated, "Honestly I don't trust anybody else to take care of him. That's terrible too and I know that." Likewise, when asked why he will not ask his stepdaughter to help take care of her mom, Ronald [GBM, Spouse, 65, M-F] replied, "Well [laughing] I wouldn't ask her. I wouldn't ask her... She don't got no sense to take care of herself." Not only did caregivers feel they were best equipped to care for the care recipient, they also feared something would happen in their absence and therefore did not trust fate enough to leave their loved one. Likewise, Edith [GBM, Spouse, 70, F-M] shared her feelings about accepting help from her children:

They offer to do anything, they offer to bring him down here and do his treatments and everything and I know, I know he would be safe with them and I know they'll do everything just like I do, but I can't do it, I'd rather do it myself... I just don't want to be away from him, I'm so scared that something might happen that I wouldn't be there, I would never forgive myself.

Although Edith talked at length about needing a break, in the above example, she explained that although she recognized a need for support, she was unwilling to accept supportive offers because she was too fearful that something might happen while she was away. Here again, the caregiver must negotiate between an elaborate push and pull between two extremes—although caregivers needed support and desired a break, if given

the opportunity, it would not be of any benefit to many because they would suffer significant fear and anxiety as a result of leaving their loved one.

Additional Responsibility: “[It’s] a Logistical Nightmare!”

Another reason family caregivers refused to ask for instrumental support, in particular, was because many felt it would be an added responsibility – just one more thing they needed to manage. This was exemplified in Chloe’s [GBM, Child, 35, F-M] discussion of why she avoided seeking instrumental support, “It can be an added responsibility...It’s also more difficult when certain people that you know can’t clean, or can’t do laundry for crap – you’re actually going to be doubling the work on yourself because you got to fix what they messed up.” Likewise, Clara [GBM, Spouse, 52, F-M] explained, “I suppose I could probably ask different people to pop in at different times, but that would be something else I would have to coordinate.” Natalie [GBM, Spouse, 38, F-M] shared a similar sentiment, however, due to dire circumstances, she actually had to ask for help and coordinate assistance to take care of her husband and family after receiving a diagnosis of colorectal cancer:

It was *really* hard when I was sick, I mean really hard! Because I couldn’t pick up [my son] for 5 weeks and I couldn’t drive, and that was a mess for our family because [my husband] can’t do nights, so I had to ask people to stay with me 24 hours a day...So what happened is, I organized everything so that every body else would take care of me. So I planned—I had a day schedule and I had all the different people that I could call, and I mean I called on best friend’s from high school’s moms and they came—I mean everybody all over *tarnation* and I put them all together so that there was always somebody with me to pick up [my son] for 24 hours for 5 weeks! And then I asked my sister to organize a *meal* train and have people bring food for a certain amount of time, and then one of my friends sent money and hired a personal chef, so like peop—I mean I had—it was a *logistical nightmare* to do, but people totally stepped up to the plate.

While she did ask for help in the past when absolutely necessary, at the time of the interview, Natalie expressed a reluctance to ask for help with her normal caregiving

duties now that she was well. This illustrates the bind and communication burden as caregivers negotiate between including others versus remaining secluded. Although coordinating support efforts could be beneficial, caregivers were unlikely to seek instrumental support because they were overwhelmed by the prospect of including others and thus having to manage an additional task.

Support Anticipation: “I Don’t Think You Should Have to Ask”

Sadly the EoL family caregivers who were the most stressed and in need of assistance were the least likely to ask, instead many felt that others should extend specific offers of support and only then would they accept assistance. Because caregivers have a strong sense of independence and feel it is their own responsibility to provide care, they were unlikely to ask others for assistance. However, every EoL family caregiver in this study said they would accept specific rather than vague and insincere offers. For instance, Chloe [GBM, Child, 35, F-M] stated:

It's hard for me to tell them, "Yeah, you can help me by doing this," because I don't know what to tell them. I'm used to doing it all by myself. It's just kind of – it's a foreign language. It's a foreign something. I don't really know what to do. Like, when my friend came, she asked me all the time, "What can I do to help you?" I'm like, "I don't know." It got to that point where I said, "Listen, I don't know." I said, "The only thing I can tell you is, look around. Use common sense. You see dishes are dirty? Do them. You say my laundry needs done. Do it. That's the only thing I know to tell you. If you see something that needs done, if you feel better about asking me – “Oh, I'm going to do your laundry right quick.” Fine. “Your bathroom, the shower needs cleaning. I'm going to go clean it for you. Where's the stuff?” It's under the sink. Everything that you need is in there. “Okay.”

In this example, when asked open-ended questions regarding her own needs for assistance, she was so overwhelmed that the additional effort of finding something appropriate to ask for made obtaining assistance more trouble than it was worth.

Unfortunately, most caregivers are not as candid as Chloe and refused to openly tell

others to be specific. Because EoL caregivers were inclined to anticipate instead of seeking support, their needs were rarely ever met. As in the case of Sandra [GBM, Spouse, 64, F-M]:

Well, I don't think you should have to ask. I think they should say, "Do you need me to come and stay Monday, Tuesday, and Wednesday?" Then I would have probably said yes. But if you're just real vague, "Well just call me if you need me." That's vague. I don't know what they mean by that. Will you take off work? Will you come? But there's times where we have *hinted*, and they always have a ball game to go – and they're busy with their lives. I'm sorry but people are busy with their lives, and they really would rather that you didn't call sometimes. They'll say it, but they really don't mean it a lot of times.

Vague offers of support were unhelpful to Sandra because she was unsure of what the person would be willing to do, and she did not want to intrude on others' busy lives – Caregivers, like Sandra perceived vague supportive offers as coming from a place of courtesy rather than being truly sincere. Moreover, several caregivers described hinting to others things that would be helpful, instead of overtly asking. Which was likely a strategy to protect the caregiver from incongruous responses. Likewise, instead of openly asking, Joan [ADRD, Spouse, 76, F-M] made light of her request by presenting it in a joking manner:

You don't feel like you deserve it maybe. You feel like you're deserting ... I don't know; I don't know why but it is. It's harder to ask for just ... give me some free time to ... I did tell my son the other day, "If you want to give me a Mother's Day present, give me a free night at a motel so I can sleep." You know? It is hard to admit that you need that time for yourself.

Like Joan, other caregivers felt like there was always more they could be doing to provide better care for their loved ones, causing them to feel as though they do not deserve help. Moreover, because caregivers focused on the care recipient before themselves, they felt uncomfortable asking for support that was not directly care-related. While Joan wanted a night at a motel so she could sleep, others caregivers wanted

someone to take over for a short while so they could “go to a movie,” “get a pedicure,” “go to the park and read,” or “get [their] hair done.” Although these activities would provide caregivers with reprieve and enhance their emotional wellbeing, EoL family caregivers would not ask for help because they felt bad asking for something others might perceive as petty. Again, EoL family caregivers were caught between a dualism: a need for support versus beliefs that to ask would be inappropriate thus precipitating a tendency to remain closed versus open. Similarly, when asked if she sought help from family or friends, Clara [GBM, Spouse, 52, F-M] denied and explained:

I remember cleaning somebody’s bathroom years ago, and I remember how I did it was just like, “I’m coming over to clean your bathroom you know?” And just totally put the person at ease and be like, “Oh you just go spend time with him, or go do your nails or something, don’t worry about it – It’s okay, I know what a dirty bathroom looks like.” It would be totally different on how a person approaches it. Because people are embarrassed of their dirt [laughs].

In addition to providing specific offers, Clara emphasized the importance of how the person communicates the offer. From Clara’s perspective, to ensure a caregiver will even accept a specific offer of support, the person would need to put the caregiver at ease, by giving them permission to take care of themselves, and reassure the caregiver that they are there to help not judge. Several caregivers indicated they would be open to supportive offers, but not until they had a chance to clean and prepare for company. This is yet another dualism caregivers attempted to manage between a need for assistance due to a lack of time, however before accepting help they must ensure things are presentable for others’ eyes, when already overextended and overtaxed.

In addition to anticipating instrumental support from family and friends, EoL family caregivers anticipated rather than sought informational support from the loved ones’ health care providers. For Pam [ADRD, Child, 55, F-M], one of the hardest parts of

caring for her father diagnosed with advanced Alzheimer's disease, was her uncertainty regarding how to communicate to seek compliance, a murky understanding of what to expect in the future, and where to go for help if needed:

If [health care professionals] were to just share, "Okay, you've got this diagnosis, now this is what you're going to be experiencing. And it's normal. But this is where you can get help; this is where you can get the information." Does that make sense? We don't want to do it alone [and] we shouldn't have to figure it out.

Not only were caregivers reluctant to ask for support from family and friends, but also the hesitation extended beyond family and friends, to health care professionals. Caregivers felt they should not have to seek informational support from health care professionals, instead they felt providers should offer the information on their own volition, which was another example of the bind caregivers negotiate on a daily basis between seeking and anticipating support.

In addition to a predisposition to wait for specific offers of instrumental support, EoL family caregivers yearned for an opportunity to talk about their caregiving experience and concerns with others, however, caregivers withheld for specific and seemingly sincere inquiries. For example, Clara [GBM, Spouse, 52, F-M] described her reluctance to talk to her family and friends about her experience:

It's semi-difficult, because again, I just don't do that. If it gets real heavy on my mind and they talk to me enough about it, then it – some of them can pull it out of me. Again, the door has to be opened for me, but I'm not that kind of person. I'm not the kind of person to just sit here and go blah-blah-blah-blah-blah-blah-blah...but it would be beneficial, I'd be the first to tell you that.

Because of EoL caregivers needed to remain independent, they anticipated an invitation to talk about their emotional experience and concerns, even though they admitted that talking to others would be of great benefit. When asked if she shares her stress and exhaustion with others, Emilee [ADRD, Child, 22, F-F] replied, "Not too much, no.

[Family friend] is obviously the only one that I've ever really [opened up to]...and it's because she came to me about it and it seemed like a very proper way. She mostly talks to me about it and then I'll open up." Like Clara, Emilee explained that she only fully opened up to a family friend who helps with caregiving, first of all, because her friend understood the situation, and because the friend specifically and sincerely inquired into her well-being; therefore opening the door for her to talk about her emotions and experiences.

While some EoL caregivers had people who asked about their own wellbeing, many did not, take Joe [ADRD, Spouse, 77, M-F] for example, who was irritated that his daughter would not ask about his or her mother's wellbeing:

[My daughter] may be in denial, she or doesn't want to really know what's going on. I think that might be it. I get a little miffed at that, and they never ask how I'm doing. She never says, 'How are you doing, dad'? Like, 'Dad, how are you doing?' She never does that. I think she doesn't want to know. I think it would [help if she brought asked] because I don't want to bring it up when she's over here. I don't want to say, 'I had a bad time getting her dressed today' or something like that. If she asked how we're doing I would tell her, but somehow I just don't want to bring it up and I don't know if that's strange or not.

Joe was caught in a perpetual bind between a desire to talk about his experience and waiting for an invitation that never came. Regrettably, his daughter's inaction was causing him to feel annoyed with her, which could significantly affect their relationship if she continues to purposefully ignore her parent's situation. Moreover, because of his refusal to discuss sensitive topics before receiving an invitation to do so, Joe believed something might be wrong with him, but he was relieved when informed that this was a common experience among EoL family caregivers. Chloe [GBM, Child, 35, F-M] further summed up the benefits of opening up:

If you're more open to it, then you can get more help generally. And you will feel better. You'll feel less stressed, less lonely, less depressed, everything. It helps you. Just because I may not do it – I know better, and then that falls back on the, uh, you're an idiot thing. But if you're more open to it, then everybody can be more helpful to you. Because if you keep everything closed off and then you put that out that it's all good – and then you're sitting in the backroom going nuts, well, you're just punishing yourself for no reason, because those people are there to help you, and you're just not letting them.

According to Chloe, caregivers who need support but are disinclined to seek it, are unwittingly sentencing themselves to a overwhelming and distressing existence, when it could be prevented through seemingly simple conversation.

On top of waiting for family and friends to extend an invitation to talk about themselves, EoL family caregivers declined to talk to the care recipient's health care providers about their concerns or experiences unless they were specifically and *sincerely* asked. Take Lacey [ADRD, Child, 39, F-M] for example, who shared, "I don't talk about [my concerns or experiences] with them...I don't. I *could* do it. If they asked me, I would, but I haven't been asked [laughs]." Likewise, Rose [ADRD, Spouse, 72, F-M] stated, "I don't know. Just don't talk about my experience much. [The providers] have to open the door." Despite the fact that caregivers admitted they would benefit from talking about their experience and concerns, EoL family caregivers refused to bring up their own emotions unless someone opened the door for them through a sincere invitation. For family caregivers, this applied not only to friends and family, but also to health care professionals.

Barriers to Obtaining Expert Information and Support in a Clinical Setting

In addition to various tensions that influence caregiver communication burden in personal and social contexts, EoL family caregivers described many barriers that inhibited them from seeking information or support in a clinical setting. The

communication burden with regards to the clinical setting stemmed from the patient's presence and from perceptions that health care providers were unavailable to both the patient and caregiver.

Patient Presence: “You Hate Talking About Her in Front of Her”

As previously discussed, EoL family caregivers were inclined to protect care recipients by focusing on the well being of the patients at their own expense. This tendency extended beyond interpersonal and social contexts and into healthcare contexts. When accompanying care recipients to their clinical visits, family caregivers were reluctant to openly discuss the patient while he/she was in the room because they did not want to induce feelings of guilt, burden, or anger. For example, at the beginning of the interview, when asked to talk about her experience providing care for her father diagnosed with an aggressive form of Frontotemporal dementia, Lacey [ADRD, Child, 39, F-M] explained:

The one big thing that I really think is aggravating with the *whole* process is every time I take him somewhere people just assume you're gonna talk about it *in front* of him. And we don't talk about—I mean, I don't want to go in and say he's not taking care of himself...because he doesn't realize that he's not doing that, and I think that would be very depressing for him to hear me say all these things about him. And that's one thing that I think I've had to say, 'Can I talk to you first?,' because during his visits, they put us both in the room and, “What are you here for today?” and that's just...its very uncomfortable...[The doctor] was asking me questions about him—in front—I wouldn't really answer much because it was a little bit uncomfortable...I will not. I will not hurt his feelings. I will not make him feel like he's a burden.

As illustrated here, the majority of caregivers, and especially those providing for someone with cognitive impairments, chose to protect the care recipient from hearing and learning the truth about their disease. While, family caregivers' needed to ask questions of health providers in order to provide quality care, the presence of the care recipient

hindered open and honest communication with the doctors. Clearly EoL family caregivers experience communication burden within the clinical setting between the innate need to protect the patient from harm versus obtaining information needed to help oneself. For example, Marie [ADRD, Child, 58, F-F] claimed, “Discussing...and that is very hard, too, because if she’s in the room you feel – you know, you hate not... you hate talking about her in front of her.” Like Lacey and Marie, many caregivers yearned for an opportunity to talk with the physician alone to enable unencumbered disclosure and achieve appropriate information based on an accurate depiction of the issues and symptoms.

Several, EoL family caregivers described an inclination to make doctor’s appointments for themselves so they could achieve an accurate expert opinion based on the true facts. Correspondingly, many caregivers disclosed that they would often slip the doctor “a little note” about the situation without the care recipient’s knowledge in order to covertly contribute to the conversation. In addition to avoiding open discussions of the care recipient’s condition, one caregiver became upset when the doctor suggested the experience might be burdensome on the caregiver:

And you know he gave me, the doctor gave me some pamphlets one day about caregivers and you know some numbers that I could call for support and you know so like, ‘Well here’s some...and oh I could of just taken them and slapped them with him [laughing]... You know what I’m saying with [my husband] sitting right there, you know. I just said, ‘Uh-huh, whatever.’ and smiled on.

When asked whether the doctor asked about her own experience, Lane [GBM, Spouse, 65, F-M] declined and illustrated that instead of inquiring, her husband’s doctor provided her information regarding ways she might seek assistance to help relieve the stress of caring for her husband. Although, she admitted that she needed the information, Lane

was angry that it was introduced in front of her husband. Lane was upset because in her mind the doctor inadvertently suggested to the care recipient that providing care for her husband was a burden on her, which could have hindered her efforts to protect her husband. Thus, Lane revealed her communication burden stems from the dualism between needing information and a desire to protect the patient from harm.

In addition to protecting the patient by concealing information, caregivers also noted a reluctance to openly disclose their observations in an effort to avoid making the care recipient angry. For example when asked if she feels comfortable talking openly to the care recipient's doctor, Marjorie [GBM, Sibling, 71, F-F], who provided care for her sister diagnosed with a terminal brain tumor said, "No, because she gets mad...if I talk about [her] memory loss... because she says she doesn't have any memory loss. She doesn't want him to know what's going on so they can figure out how to help her. So she doesn't even want to go to the doctor's appointment." In addition to the difficulties she experienced when coercing her sister to attend her own appointments, Marjorie experienced communication burden because she felt a need to disclose the care recipient's symptoms to the physician, but was unable for fear the disclosure would cause further problems. Similarly, Julia [GBM, Spouse, 38, F-M] explained the difficulties she encountered and the torment she forced herself to endure to avoid making her husband angry:

It's not that I would feel uncomfortable, it's that I don't want to do anything to upset [my husband]. You know, telling his doctor *in front of him* that he has a temper and cusses me out 20 times a day and kicks me out...I mean, it would just make him mad at me, like I told on him you know? After eight months, I finally told the doctor about it, and then he refused to take [the medicine]. Just flat out refused, was not going to happen no way, no how. So, I sneaked. I started out crushing them up and putting them in his sweet tea. And I don't think it was really working as good as it would have, but then after a while, when he started taking a

new blood pressure medicine, I just I threw that [pill] in too and just kind of told him that it's for his blood pressure too. He has no idea; He would be upset. He won't take a Tylenol, he never would...And he doesn't know that I take anything either.

After suffering through her husband's aggression for eight months, Julia decided that making her husband angry in the short-term was worth getting herself some long-term relief, and she finally disclosed the truth about her husband's tumor symptoms to the doctor. Moreover, in an effort to pacify her husband and get relief for them both, Julia began medicating her unsuspecting husband to curtail his mood swings, and herself for depression and anxiety. For Julia, stress surrounding communication tasks emerged not only when disclosing the care recipient's symptoms to the doctor, but later she also described the stress she felt when keeping secrets from her husband. Another bind experienced by EoL caregivers like Julia stemmed from the need to withhold information to protect the care recipient versus revealing information to protect oneself from feeling guilt. EoL family caregivers endured immense stress when preparing and following through with their responsibility to inform health care professionals of the patient's symptoms. Furthermore, caregiver's experienced significant distress when negotiating whether and in what manner to disclose which is caused by a tension between the caregiver's need to be an open and honest advocate for their loved one's wellbeing, and a desire to protect both the patient and themselves from the anticipated outcome.

The presence of the patient was not the only barrier that created stress for family caregivers; caregivers also contended with the care recipient's propensity to mislead the doctor by refusing to admit their symptoms both to themselves and to the doctor. Thus, inhibiting the doctor from providing the best care to alleviate patient symptoms, quality of life, and enhance the wellbeing of the family caregiver. When asked to describe her

experience communicating with her mother's health care providers, Jolene [ADRD, Child, 38, F-F] shared:

Very frustrating. Stressful. Wasted time, inefficient because they can't treat her, or, pay attention to what's going on. The other big thing with the medical is that because my mom lies and she knows that I am *very* big about not being on a lot of medicine, she doesn't tell me what medicine she's on. So, she, I think personally that her reactions to the medicine [the doctor] put her on is because she's on other meds that he doesn't know about... Like she fills her own 'scripts, and when asked she told [the doctor] like these five meds she was on, but then when we to the family doctor I had that list to check and there was like eight or nine.

For Jolene, accompanying her mother to the doctor is a stressful task in itself because her mother kept information from both the doctor and Jolene. In fact, as a result of the example provided, Jolene explained that her mom had a bad reaction to a new medication and stopped taking it, but Jolene's husband who was a doctor, looked at the list of prescriptions and was able to identify that the contraindication resulted from the combination of medications her mother was on. Because the doctor was unaware of the patient's prescriptions, he prescribed a medication that caused undesirable consequences, something that could have been avoided. For caregivers like Jolene, the communication encounter with the doctor and a patient who was not forthcoming became a source of stress due the caregiver's fear of upsetting the patient, which would inhibit the care recipient from obtaining appropriate care.

Like the example above, caregivers portrayed both ADRD and GBM patients as prone to evade questions in order to mislead physicians; however, this more commonly occurred in ADRD patients because an associated behavioral symptom of the disease is a tendency to keep secrets and lie. The presence of the patient caused immense communication burden for EoL caregivers, yet patient presence was necessary because

the appointment was for the wellbeing of the care recipient, which placed caregivers in a difficult and stressful situation.

Availability: “The Reality is that [We] Don’t Have a Lot of Interaction with the Doctor”

Overall, accompanying loved ones to clinical visits was a very stressful and frustrating ordeal for EoL family caregivers. Much of the stress emanated from the fact that providers were simply perceived as being communicatively, emotionally, and physically unavailable to them. The findings of this study revealed that caregivers perceive providers as being unavailable in several ways, including the providers’ verbal and nonverbal communication, perceptions that the provider was not being forthcoming, and because they were too busy.

Communication: “Talking with my mom's...provider is like a toothache.”

EoL family caregivers experienced immense stress when communicating with the care recipient’s health care providers, which largely stemmed from the provider’s communication style, making the caregiver’s goals of obtaining expert advice unachievable. For example, when asked to describe his relationship with his mom’s healthcare providers, David [GBM, Child, 59, M-F] explained:

I try to ask questions so I can understand more about mom's disease and situation, and I can make the best decisions that are going to benefit her as far as her treatment and her quality of life. With our primary care physician, he's a nice man. He's joking and stuff all the time. But sometimes it gets vague – vague answers to questions. Sometimes I think he's already got his mind made up about mom's condition and diagnosis prior to giving the test or doing whatever. That's my perception, and it doesn't necessarily have to be accurate, but that's just my perception...So for me, talking with my mom's primary care provider is like like a toothache...because we're aching for answers and treatment. It makes me feel bad, but at the same time, I know I've got to overcome my feelings and try to be a more effective communicator with him, simply because I need him to give me

answers. So I can't actually be indifferent, aloof, derogatory towards him, because I *need* him.

David portrayed his encounters with his mother's physician as a cumbersome ordeal because of his inability to obtain clear answers to his questions, and the resulting struggle he experienced by trying to carefully frame questions to obtain the required answers. The physician's communication emotionally pained David because he had to be careful not to step on any toes by suppressing his frustration and staying calm because he and his mom needed to remain on good terms for the sake of his mother's wellbeing. David's frustration and communication burden sprang from tension between his desires for clear information and his felt inability openly speak to the doctor because he feared an adverse outcome for his mother's care.

In a similar vein to David's portrayal of communication with his mother's doctor as lacking empathy, Patricia [GBM, Spouse, 47, F-M] explained, "There's nothing really bad about his care, but sometimes it's just that overall feeling, well you know this is just the way it is, and they don't show any sympathy on that." Patricia felt that her husband's physician was nonchalant regarding her husband's terminal brain tumor, and even more she described his demeanor as lacking sympathy, which distressed both she and her husband because they not only sought biomedical care, they required supportive communication to help them cope and move forward, which not available to them.

Likewise, Shirley [GBM, Child, 55, F-F] explained the communication burden derived from the physician's equivocal communication style:

He doesn't really say okay it looks like the tumor...has decreased or it's still there, if it's grown back or it's going to – we don't really know anything and they keep saying, in a little while we're going to do an MRI...but we haven't been scheduled yet...it's kind of confusing and makes it uncertain as to what we need to do you know? How close are we to having to make decisions about what we're

going to do at the house, where we're going to live and all that kind of thing...but I don't want to want to ask those questions in front of her. Because she has a lot of hope that what she's doing is going to give her many years. And they told her fifteen months at diagnosis, and they told her very clearly, "We're not curing we're containing. All we're doing is giving you a little bit more time if you do nothing you've got nine months." And I don't know that really has processed for her, you know?...Honestly, I don't think they want to give you a clear answer because then you can say, "Well you said that she had six or eight more months. And it's two months and she's dead," you know? Because they can't tell you how fast the tumor's going to grow back, they can't tell you if this is going to give her a year or...

Hearing and processing a terminal diagnosis are two very distinct things. The above example illustrated how physician's use of ambiguous language could inflict communication burden upon the caregiver. Shirley's desire to protect her mother overruled her need to prepare for the future. Moreover, because the care recipient was unaware of the actual prognosis, Shirley later explained that her mom was waiting to make important financial, estate, and end-of-life decisions because she believed she had many years to accomplish those tasks.

Moreover, Clara [GBM, Spouse, 52, F-M] felt uncomfortable asking questions of her husband's physician because he communicated in a flippant manner:

He's like, "Well I don't suggest the Ketogenic diet for anyone, but if you want to do it then go ahead." And part of me feels like, and I'm being totally blunt, that he just doesn't give a shit because he thinks [husband's] going to die anyway. You know I don't really particularly like his bedside manner if you want to know the truth. Everybody, out of all the people residents and nurses, everybody included there's two people that I do not like their bedside manner and it's him and [Dr. O] they're both in neuro.

In this example, Clara described the physician's reaction to her doing her own research on things that could potentially slow the growth of her husband's tumor. In fact, the way the physician responded caused her to feel the doctor was uncaring and simply passing time until her husband passed. Later, Clara shared that the communication with her

husband's doctor was good until she asked about changing her husband's diet, in fact she could recall the moment relationship with the doctor changed when she shared a study about the Ketogenic diet:

And he just, he kind of looked over and I mean it was just at that point I just saw a change. Like he was like, it, I had this feeling like, "Here's another one of these people who've looked on the Internet and found something that they think is smarter than me." That is the feeling that I got, you know? And so it's like there's a fine line of do you want your patients to know something or absolutely nothing at all? And if we want to have a logical discussion about something can't we discuss it instead of you making us feel like we're dumb asses. And I'm sorry I don't usually cuss but this is making me bring up these feelings.

This one interaction with the doctor colored Clara's perceptions of the doctor and therefore made it a challenge to engage him, much less ask questions of which she sincerely needed answers. Clara's perceptions of the doctor's dismissive and therefore unavailable communication style caused her to feel immense tension between her need to obtain significant information to protect the patient versus her belief that health providers would prefer caregivers and patients remain in the dark. This tension caused immense communication burden for Clara when negotiating whether to ask the physician questions for which she needed answers.

In addition to communication styles that depict the doctor as unengaged and unavailable, many EoL family caregivers felt as though they were unable to communicate with providers because they were physically unavailable. Caregivers like Natalie [GBM, Spouse, 38, F-M] explained, "the reality is that [we] don't have a lot of interaction with the doctor." Many caregivers shared similar sentiments regarding a desire to obtain more information from the physician, but felt unable in the minimal time given their brief presence. Moreover, the lack of availability caused caregivers to feel unimportant; Patricia [GBM, Spouse, 47, F-M] described feeling as "very much like a number."

Likewise, when explaining her communication burden from interactions with her husband's neuro-oncologist, Nora [ADRD, Spouse, 86, F-M] shared:

[Dr. O] said I'm just going to tell you that this brain tumor is inoperable and I don't remember everything he said, but when I tried to question him about it again he like cut me off...But then we had to go meet [Dr. C], which was the same day that we were seeing [Dr. O] for the follow up. I'm not kidding you [Dr. O] wasn't in the room more than thirty seconds. He came in and he looked at [husband] and he goes, "Looking okay. You doing alright?" "Yeah," "Okay well [Dr. C] will be in in a minute," and he walked out of the room.

The above example illustrates the sentiments of many caregivers who described the care recipients physician as both emotionally and physically unavailable, which caused caregivers to feel immense uncertainty about the care of their loved ones, while negatively impacting the caregiver's inclination to seek future information or support.

In a like manner, Kathleen [GBM, Child, 59, F-F] described the communication burden and frustration she felt when her husband's providers were unavailable:

[My husband] was having an allergic reaction to something and I thought that it was from the Bactrim. And you know they had said how open and accessible they are and stuff and [the Nurse] had given me her contact info, but the only thing I could find at the moment was the email and so I sent an email to her and copied [Dr. C] too and even days later neither one of them wrote me back. He never acknowledged my email.

The above example illustrated how caregivers like Kathleen felt stress when they were unable to obtain vital information from health providers because they were inaccessible. Not only were there very few opportunities for caregivers, patients, and providers to interact in person, often other modes of communication were ineffective as well, which caused significant stress for the family caregiver, especially when the providers refused to acknowledge or respond.

Distrust: "Don't believe what a doctor tells you...you need to question." Not only did the physician's communication style cause the caregiver and patient to feel

unimportant as illustrated above, but also the communication often caused a sense of distrust in the provider's ability, intentions, and claims. Like in Ronald's [GBM, Spouse, 65, M-F] case:

Yeah. And the last time we was up there when we talked to him I said now we got some questions we want to ask you. And he asked her a couple of questions, and she finally answered them, then he, I believe he got a little aggravated at me at the end. Because he said, 'I think she's doing real good.' He said, 'I see a lot of patients, but she's doing real good.' And I wish that you had to live with her [laughs] because I mean she just, she ain't doing no good at all. She can't remember from one day to next what day it is or nothing.

When physicians withheld information from the patient and caregiver, many EoL caregivers began to lose trust in the information shared by the provider. Moreover, Kenneth's [GBM, Spouse, 56, M-F] experience interacting with his wife's doctors influenced him to recommend, "Don't believe what a doctor tells you. Most of them don't know what they're talking about...when they say one thing; you need to question, because they think they know, but don't." Based on Kenneth's experience trying to get his wife's brain tumor diagnosed which involved several refusals to run necessary diagnostic tests in conjunction with continuous dismissals of trivial diagnoses (e.g., allergies, migraines), Kenneth finally summed up the courage to press for a CAT scan, which was when the tumor was detected. Likewise, Lane [GBM, Spouse, 65, F-M] explained that her distrust of her husband's physicians was a result of the obvious focus on research over the well being of the patient and family:

Well...[laughing]. The doctor doesn't give that much information. And sometimes it doesn't seem like he's on top of his game. I don't know if it's because he's more in to the research part of it than the actual care of the patient...Because at first you know, when he was trying to get [my husband] in to the research program... "He'd just talk and talk and talked about the research program and blah blah blah and this, that, and the other. And then after that didn't work out and he could no longer be in the research program, it seems like conversations got shorter and shorter and shorter. He would come in and I know

the attending you know that come in don't spend that much time, but they come in and just say, "Well how are you doing this morning? Doing alright, that's good" [laughing] you know?

Not only was the doctor's communication evasive, vague, and confusing, Lane attributed the doctor's gradual change in communication quantity and quality to the belief that the doctor was only interested in pursuing and furthering his research than caring for his patients. An immense tension and communication burden stemmed from the caregivers desire to trust the doctor but feelings of distrust as a result of prior encounters with providers.

Too busy: "I know you don't have time to sit and listen." In addition to being emotionally unavailable and vague communication practices, another reason EoL family caregivers were reluctant to talk about their experience and ask questions of physicians was because they appeared to be too busy. Ronald [GBM, Spouse, 65, M-F] explained his frustration with his wife's doctor:

Well see [Dr. C] he won't stay in there long....Well I just feel like [the doctor] don't have time for us. And he has said "I'll be right back" then never come back. Yeah, and I don't like that. I get so mad! Even if I had [my questions] wrote down, he would say, "I'll be right back" and then you'll never see him. He'll send somebody else in there with a prescription or time for the next appointment.

In the above example, the family caregiver explained his significant stress and frustration because the physician was too busy to care about them. The meager face-time he had with the doctor prevented Ronald from asking the important questions he desired. As a result, Ronald later explained that he and his wife discussed finding a different doctor, but have yet to do so, because Dr. C was a top-ranked specialist and because it would be a hassle to locate and begin again with another doctor. Similarly, Peggy [GBM, In-law,

50, F-M] explained why she was not forthcoming with her mother-in-law's care providers:

He'll say, you know, "How are you doing this morning? 'Well fine'" [laughing], you know what else am I supposed to say because I know you don't have time to sit and listen if I would tell him how I was feeling, you know he wouldn't have time.

Here, Peggy revealed feeling unable to be candid because the doctor clearly communicated to her that he was rushed and did not have time to waste. Moreover, when asked if she would disclose her feelings and needs if the doctor used seemingly sincere open-ended questions, she said, "No. I wouldn't have gotten the trust." The sheer fact that her mother-in-law's doctor appeared to be rushed, insincere, and overworked, not only impacted her willingness to be forthcoming, but the minimal interaction they did have was not enough for her to build the trust needed for a truthful disclosure.

In addition to communicating inefficient time through nonverbal communication, doctors who were overbooked and unable to meet with patients caused challenges for family caregivers who were forced to engage in uncomfortable interactions in order to achieve their goals, as illustrated by Lois' [ADRD, Spouse, 77, F-M] depiction of her experience:

We hadn't seen [Dr. K] for a long time. Well, it was longer because we had a problem, and the reason we got to see [Dr. K] this time is because I got rather unpleasant. The physician's assistant was fine. They do an excellent job, but when my husband's status changed, I felt we deserved to see the neurologist, and it wasn't happening for a long time...when the status changes, you need to be able to get back to your neurologist. And it did happen for us, but I had to work hard for it, and that was frustrating.

Lois, who questioned the accuracy of her husband's Alzheimer's diagnosis, was unable to get her husband to see the neurologist when the care recipient started exhibiting signs she believed were associated with aphasia, not Alzheimer's. Unfortunately, after her initial

visit, Lois was only able to see the Physician's Assistant, but to reduce her uncertainty about the official diagnosis she needed to see the neurologist for an expert opinion. After waiting several months to see the neurologist, Lois became frustrated and had to use forceful communication techniques in order to see the doctor, which she described as a quite a hassle to achieve and very out of character.

Table 4.1
Interview Participant Demographics

Caregiver (<i>N</i> = 40)	<i>n</i>	%
Gender		
Female	31	77.5
Male	9	22.5
Age		
20-29	1	2.5
30-39	6	15
40-49	2	5
50-59	12	30
60-69	9	22.5
70-79	8	20
80-89	2	5
Education		
Less than high school	3	7.5
High school / GED	11	27.5
Some college/trade school	7	2.5
Associate's degree	3	7.5
Bachelor's degree	6	15
Master's degree	8	20
Doctoral degree	1	2.5
Professional degree	1	2.5
Employment status		
Full-time	14	35
Part-time	2	5
Retired	17	42.5
Disabled	1	2.5
Not employed	6	15
Race		
American Indian	1	2.5
African American	2	5
Caucasian	37	92.5
Relationship to recipient		
Spouse/partner	22	55
Adult child	13	32.5
Sibling	3	7.5
In-law	1	2.5
Parent	1	2.5

Table 4.1 (continued)

Avg. hrs care/week		
1-5	5	12.5
6-10	2	5
11-20	6	15
21-30	3	7.5
31-40	3	7.5
41-50	3	7.5
Above 50	2	5
24/7	15	37.5
No answer	1	2.5
Caregiver length		
Less than 1 year	9	22.5
1-3 years	17	42.5
4-6 years	8	20
7-10 years	4	10
More than 10 years	2	5
Residence		
With recipient	26	65
Miles from recipient		
1-10 miles	9	22.5
11-30 miles	2	5
31-50 miles	2	5
Over 100 miles	1	2.5

Table 4.2

Interview Participant Demographics and Caregiving Specifics

ADD Caregiver (N = 20)			TBT Caregiver (N = 20)		
	<i>n</i>	%		<i>n</i>	%
Gender			Gender		
Female	17	85	Female	14	70
Male	3	15	Male	6	30
Age			Age		
20-29	1	5	20-29	-	-
30-39	3	15	30-39	3	15
40-49	-	-	40-49	2	10
50-59	6	30	50-59	6	30
60-69	2	10	60-69	7	35
70-79	6	30	70-79	2	10
80-89	2	10	80-89	-	-
Education			Education		
Less than high school	1	5	Less than high school	2	10
High school / GED	3	15	High school	8	40
Some college/trade school	3	15	Some college/trade school	4	20
Associate's degree	1	5	Associate's degree	2	10
Bachelor's degree	5	25	Bachelor's degree	1	5
Master's degree	7	35	Master's degree	1	5
Doctoral degree	-	-	Doctoral degree	1	5
Professional degree	-	-	Professional degree	1	5
Race			Race		
American Indian	-	-	American Indian	1	5
African American	1	5	African American	1	5
Caucasian	19	95	Caucasian	18	90
Relationship to recipient			Relationship to recipient		
Spouse/partner	9	45	Spouse/partner	13	65
Adult child	11	55	Adult child	2	10
Sibling	-	-	Sibling	3	15
In-law	-	-	In-law	1	5
Parent	-	-	Parent	1	5

Table 4.2 (continued)

Avg. hrs care/week			Avg. hrs care/week		
1-5	3	15	1-5	2	10
6-10	1	5	6-10	1	5
11-20	4	20	11-20	2	10
21-30	1	5	21-30	2	10
31-40	-	-	31-40	3	15
41-50	2	10	41-50	1	5
Above 50	2	10	Above 50	-	-
24/7	6	30	24/7	9	45
Declined to answer	1	5	Declined to answer	-	-
Caregiver length			Caregiver length		
Less than 1 year	2	10	Less than 1 year	7	35
1-3 years	6	30	1-3 years	11	55
4-6 years	7	35	4-6 years	1	5
7-10 years	4	20	7-10 years	-	-
More than 10 years	1	5	More than 10 years	1	5
Residence			Residence		
With recipient	9	45	With recipient	17	85
Miles from recipient			Miles from recipient		
1-10 miles	7	35	1-10 miles	2	10
11-30 miles	2	10	11-30 miles	-	-
31-50 miles	1	5	31-50 miles	1	5
Over 100 miles	1	5	Over 100 miles	-	-

Table 4.3

Qualitative Themes

Themes & Subthemes	
1	<p>Symptoms as Communicative Barrier</p> <p>Behavioral Changes: <i>“It’s a constant battle with her these days.”</i></p> <p>Language Barriers: <i>“The communication things are really hard.”</i></p> <p>Fatigue / Apathy: <i>“I get angry [and] resentful...because he’s so low-energy.”</i></p>
2	<p>Perceived Taboo Topics</p> <p>Finances</p> <p>Disease</p> <p>The future</p> <p>Caregiver (oneself)</p>
3	<p>Caregiver as Guardian</p> <p>Protection of the Patient: <i>“My needs is secondary, as long as [he’s] taken care of I’m fine.”</i></p> <p>-Communication barriers: <i>“You don’t want him to feel guilty, but yet he needs to understand.”</i></p> <p>-Withholding: <i>“I keep that information from him...”</i></p> <p>-Optimism: <i>“There’s gotta be a way to be...both really positive but also more accepting of the real possibility of death.”</i></p> <p>-Focus on the patient: <i>“At the expense of...”</i></p> <p>Protection of Others: <i>“This is a lot of responsibility to put on...”</i></p> <p>Self-Protection: <i>“I am fighting my thoughts.”</i></p> <p>-Fear the outcome: <i>“Fear of the unknown is worse than fear of the known.”</i></p> <ul style="list-style-type: none"> • Vulnerability: <i>“Opening that emotional box...there’s not a time for it.”</i> • Vulnerability: <i>“It’s an ordeal...every time.”</i> • Incongruous responses: <i>“Talking with others is the hard part because...”</i> • Intrusive responses: <i>“Stop projecting yourself and your experience onto me.”</i> <p>-Family issues: <i>“We don’t get along the best.”</i></p>
4	<p>Anticipating Instead of Seeking Support</p> <p>Pride: <i>“...Because I like to be self-sufficient.”</i></p> <p>Additional Responsibility: <i>“[It’s] a logistical nightmare!”</i></p> <p>Support Anticipation: <i>“I don’t think you should have to ask.”</i></p>
5	<p>Barriers to Obtaining Expert Information and Support in a Clinical Setting</p> <p>Patient Presence: <i>“You hate talking about her in front of her.”</i></p> <p>Availability: <i>“The reality is that [we] don’t have a lot of interaction with the doctor.”</i></p> <p>-Communication: <i>“Talking with my mom’s...provider is like a toothache.”</i></p> <p>-Distrust: <i>“Don’t believe what a doctor tells you...you need to question.”</i></p> <p>-Too busy: <i>“I know you don’t have time to sit and listen.”</i></p>

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CHAPTER V

Quantitative Method

Instead of collecting the qualitative and quantitative data in two distinct phases, a concurrent triangulation design was employed so the data could be collected and interpreted together to enable a comprehensive understanding of communication burden (Cresswell & Clark, 2011).

Sample and Setting

Eligible survey participants were recruited from outpatient clinics at a major academic medical center and a private hospital in central Kentucky in the following six ways: a) paper surveys were mailed to ADRD current/past caregivers of a large pool of research participants who were affiliated with a local aging research center (surveys were mailed from the center and were accompanied by a personalized letter endorsing the study, signed by the head physician; see Appendix C for cover letter); b) paper surveys were placed in the charts of new patients visiting the chemo infusion unit of a local cancer center; c) at the reception desk in a hematology unit, paper surveys were given to caregivers who were accompanying a loved at a local cancer center; d) recruitment flyers advertising an online Qualtrics version of the survey were placed in relevant health care clinics; e) interview participants who consented to be contacted to take the survey were either mailed paper versions or emailed a Qualtrics link (depending on preference); f) participating caregivers were encouraged to share the Qualtrics study link with other current/past caregivers who might be interested in participating.

A total of 263 surveys provided usable data. Participants were 72 males (27.8%; coded 0) and 187 females (72.2%; coded 1); 152 were ADRD caregivers (58%, coded 1),

103 were oncology caregivers (39%, coded 2), and 8 caregivers provided for other conditions (3%, coded 3). Participants' ages ranged from 19-91 ($M = 63.2$, $SD = 14.4$). The majority of participants were White ($n = 240$), followed by African American ($n = 15$), and other ($n = 7$). While the majority of caregivers completed less than high school to some college ($n = 127$), 70 completed an undergraduate degree, and 66 obtained an advanced degree. In terms of employment status, 97 caregivers were employed full or part-time (coded 1), 125 were retired (coded 2), and 41 were not employed (coded 3). Regarding marital status, 50 were not married (coded 1) and 213 were married (coded 2).

In terms of caregiving characteristics, over half of caregivers reported providing care for a spouse/partner ($n = 152$), while the remainder identified as adult child ($n = 71$), parent ($n = 16$), and other ($n = 22$). The average hours per week spent providing care included the following: 1-10 hours ($n = 69$; coded 1), 11-30 ($n = 56$; coded 2), 31-50 ($n = 18$; coded 3), above 50 ($n = 31$; coded 4), and 24/7 ($n = 78$; coded 5). Participants reported the duration of care provision in years and months as the: 1 day to 1 year ($n = 64$), 1 year/1 month to 5 years ($n = 119$), 5 years/1month to 10 years ($n = 49$), 10 years/1 month to 20 years ($n = 5$), and above 20 years/1 month ($n = 3$). The majority of caregivers had not hired anyone to assist ($n = 194$; coded 0) while 61 had hired outside assistance (coded 1). A minority of caregivers in this sample had no religious affiliation ($n = 45$, coded 0) and 215 reported having a religious affiliation (coded 1). Further, 175 participants were currently providing care (66.5%) and 88 had provided care in the past (33.5%). Care recipients' ages ranged from 19-100 ($M = 71.09$, $SD = 16.69$). Of the 263 survey participants, 17 (6.5%) indicated they were also participants in the interview portion of this study. Finally, while the majority of surveys were completed on paper ($n =$

228, 86.7%), 35 (13.3%) were taken online. See Tables 5.1 and 5.2 for participant demographics and additional caregiving-related information.

Procedure

Upon completing the final version of the CCB scale, institutional review board approval was obtained. Upon receipt of the paper surveys, the author input the survey data into a Qualtrics database identical to the online Qualtrics survey. Additionally, two versions of the survey were distributed, a) one for caregivers currently providing care, and b) one for caregivers who provided past care for a family member. The surveys were identical except for altering the sentence tense and the addition of further to remind past family caregivers to answer based on past experience while providing care. For the corresponding surveys, see Appendix C for current, and Appendix D for past caregivers. Upon completion of the survey, participants were invited to enter into a drawing to win one of eight \$25 gift cards.

Measurement

Because the ACT theoretical framework was used as a guiding lens for this study, the quantitative data collected for the supplementary portion of this project consisted of the caregiver's demographic and background context variables (i.e., age, gender, race, marital status, work status, religion, relationship to patient, caregiving duration, hours per week providing care), caregiver stressors (i.e., caregiver communication burden), and caregiver outcomes (i.e., caregiver burden, quality of life). The corresponding survey can be found in Appendix C. Due to intuitive revelations gained during the in-depth interview process; additional items were added to the caregiver's background context variables (i.e., care recipient diagnosis, previous caregiving experience, caregiver profession, and

relational closeness with the patient, general family, and family helpers) to be assessed as part of the background context variables.

Quality of Life

Another outcome identified in the ACT model is quality of life, which was assessed using the revised measure of Caregiver Quality of Life (CQLI-R). The CQLI-R is a reliable and valid 4-item self reporting instrument designed specifically for EoL caregivers that measures caregiver quality of life (QoL) on four dimensions: emotional, social, financial, and physical (McMillan & Mahon, 1994). Higher scores indicate better quality of life. Caregiver QoL instrument reviews have recommended the CQLI as a psychometrically acceptable measure in the clinical setting, due to its brevity, reliability, and validity (McMillan & Mahon, 1994). The original CQLI measured each dimension using a 100-mm visual analog scale anchored with 0 to indicate “lowest quality” and 100 to indicate “highest quality.” The maximum score for each dimension is 100, with a total maximum score of 400. Cronbach’s alpha coefficients for the original CQLI range from .76 to .88. The total measure and each individual dimension show strong content, convergent, and discriminate validity (Edwards & Ung, 2002). The original CQLI has been used successfully with elderly EoL caregivers (Straton, 2003). The original CQLI instrument was revised for use in oral interviews using 0 and 10 for anchors in place of the visual analog scale (Courtney, Demiris, Parker Oliver, & Porock 2005). Cronbach’s alpha for the revised instrument (CQLI-R) was 0.769, and test-retest reliability was supported ($r_s = 0.912$, $p < 0.001$). The CQLI-R has been used successfully within the context of EoL care (Demiris, Parker Oliver, Courtney, & Day, 2007). In the present study, although several participants skipped one or all of the CQLI-R items, cronbach’s

alpha scores of revealed good internal consistency for the aggregate CQLI-R measure ($M = 27.23$, $SD = 8.07$, Cronbach $\alpha = .83$). See Table 5.3 for CQLI-R items, means, standard deviations, and response options.

Caregiver Burden

To assess caregiver burden as an outcome variable, the Caregiver Reaction Assessment (CRA) was used. The CRA is a 24-item multidimensional scale that measures positive and negative reactions to family caregiving. The measurement consists of a five-point Likert-type scale, wherein each item is presented as a statement and rated on a range of “strongly disagree” to “strongly agree”. The CRA measures five distinct unidimensional subscales that include: a) *impact on schedule*, impact of caregiving in terms of activity interruption, activity elimination, and relaxation interference (5 items); b) *caregiver esteem*, value or worth ascribed to caregiving perceived as rewarding or fueling resentment (7 items); c) *lack of family support*, perceptions of bearing the brunt of responsibility or receiving family support (5 items); d) *impact on health*, physical capacity to provide care and energy levels (4 items); e) *impact on finances*, financial aspects of adequacy, difficulty, and strain on the caregiver and family (3 items). The CRA can be computed as individual scores (Given et al., 1992) by calculating the mean item scores for each dimension ranging from 1.0-5.0, higher scores reflect burden for each dimension; or an aggregate burden score (Groo et al., 2006), wherein higher scores reflect high burden and lower scores indicate low burden. The CRA has been cited as having strong psychometric properties in terms of reliability and validity (Misawa, Miyashita, Kawa, Abe, Abe, Nakayama, & Given, 2009). Past research revealed good internal consistency based upon Cronbach’s alpha scores aggregate CRA measure and

each of the five dimensions (see Given et al., 1992; Grov et al., 2006; Misawa et al., 2009). Lastly, in order to increase clarity and sensitivity to the vulnerable caregiver population, the stems of the CRA items were slightly modified to include “for my loved one” in place of “for _____”. See Table 5.4 for CRA items, means, standard deviations, and response categories.

Cronbach’s alpha scores revealed good internal consistency for the aggregate measure of caregiver burden ($\alpha = .79$), and each of the five CRA dimensions: impact on schedule ($\alpha = .78$), caregiver esteem ($\alpha = .83$), lack of family support ($\alpha = .84$), impact on health ($\alpha = .74$), impact on finances ($\alpha = .84$). Further, in the current study, a principal components analysis of the CRA confirms each factor as distinct unidimensional sub-dimensions of caregiver burden.

Communication Burden

Because communication burden is a newly identified and defined construct, prior to the current study, only one measure of communication burden exists which was developed through a small pilot study ($n=36$) of a convenience sample of the general caregiver population and later re-tested within a small population of oncology caregiver ($n=27$) and patient ($n=30$) pairs (Shaunfield, Reno, & Iannarino, 2013).

Pilot scale development. In order to gain insight into communication related caregiver burden, I utilized Goldsmith and Baxter’s (1996) Revised Taxonomy of Interpersonal Speech Events [RTISE], a framework that highlights the constitutive function of communication exchange and outlines the topics of everyday conversation. The RTISE was used to guide the development of the pilot communication burden

measure which was intended to supplement Given and colleague's (1992) Caregiver Reaction Assessment (CRA), a common measure of caregiver burden.

The development of the pilot measure of communication burden began with a thorough review of the extant caregiver burden literature (DeVellis, 2011). Next, because item germination, whenever possible, should be guided by theory (DeVellis, 2011), the items were created using eight of the original 29 speech events presented in Goldsmith and Baxter's (1996) RTISE that encapsulated the five categories of caregiver communication burden identified in the literature at that time (*Note, since the pilot study, two additional categories have been identified and were incorporated in the literature review above and in the current investigation): 1) *inability to communicate with patients in advanced stages of illness*; 2) *seeking support and information from health care professionals*). The eight RTISE speech events that encapsulated the five categories of communication burden from the literature and number of items investigated in the pilot study, included the following: a) *recapping the days events* (2 items), b) *conflict* (2 items), c) *serious conversation* (3 items), d) *talking about problems* (2 items), e) *breaking bad news* (2 items), f) *complaining* (2 items), g) *decision-making conversation* (3 items), and h) *asking a favor* (2 items).

The construct of family caregiver communication burden was clearly conceptualized and item development was guided by theory. Moreover, the preliminary measure consisted of 18 items to reduce the chance of participant fatigue. In order to increase the content validity of the measure, once developed, the item pool was reviewed by two experts who provided minor suggestions, which were settled and changed (DeVellis, 2011). Study participants of the pilot scale development study consisted of a

small convenience sample of 36 family caregivers who provided care for a variety of patient conditions.

Principal components analysis using varimax rotation revealed a multidimensional scale with two factors and seven items. The preliminary 18-item scale was paired down using standard factor loading criteria. The first factor included four items that together represented *Family Conversation* (eigenvalue = 3.77, 35.16% variance explained). The second factor included three items that assessed *Family Collaboration* (eigenvalue = 1.15, 35.1% variance explained). Thus, the final composite scale contained two dimensions (i.e., family conversation, family collaboration) that accounted for 70.24% of the total variance in communication burden (Shaunfield et al., 2013). An assessment of the reliability for the pilot measure was computed using Cronbach's coefficient alpha, which revealed the preliminary scale as potentially reliable ($\alpha = .086$). Participants' scores were summed and averaged ($M = 2.67$, $SD = .88$, min = 1, max = 4.9); the higher scores indicated increased levels of communication burden.

Convergent validity of the pilot communication burden measure was assessed using a one-tailed Pearson Correlation between pilot measure and the five CRA dimensions. Aside from caregiver esteem ($r = -.13$, $p = .23$), the results revealed significant positive correlations with the remaining sub dimensions of the CRA: impact on schedule ($r = .45$, $p = .003$), lack of family support ($r = .62$, $p = .000.$), impact on health ($r = .52$, $p = .001$), impact on finances ($r = .45$, $p = .003$). Although, caregiver esteem did not reveal a positive correlation, the sub-dimension is positively valenced and therefore intended to inversely correlate with measures of caregiver burden. Nevertheless, the correlation was not significant. Although based on a small convenience sample, the

seven-item measure of communication burden developed in the pilot study, revealed high convergent validity as the scale correlated the four CRA dimensions that measure negative aspects of caregiver burden.

Of the five identified in the literature (at the time), only three of the categories were represented within the two extracted dimensions: family conversation and family collaboration dimensions (i.e., informing and involving other family member in care decisions and end-of-life discussions, expressing feelings of stress and exhaustion from caregiving tasks, communicating about sensitive issues and care decisions with others) of caregiver communication burden identified in the literature were represented in retained items following factor analysis. This was likely due to the small sample ($n=36$), which precluded the opportunity for a more realistic representation of the various categories of communication burden as reported in the literature above. Further, two additional categories were later identified which were not tested in the initial pilot study. To review, the seven categories of caregiver communication burden revealed in the literature, to date, include: (a) informing and involving other family member in care decisions and end-of-life discussions (Houts et al., 1996; Waldrop et al., 2005); (b) expressing feelings of stress and exhaustion from caregiving tasks (Wilks & Croom, 2008); (c) communicating about sensitive issues and care decisions with others (Roscoe et al., 2006; Waldrop et al., 2005); (d) disclosing to family and friends a need for assistance with care duties (Wittenberg-Lyles et al., 2014); (e) communicating with the patient about his/her own care preferences (Fried et al., 2005; Gillespie et al., 2010); (f) inability to communicate with patients in advanced stages of illness (Savundranayagam et al. 2005); and (g) seeking support and information from health care professionals (Casarette et al.,

2005; Kutner, 2009). The overall goal of this project was to conduct a comprehensive exploration the variety of communication stressors experienced by family caregivers, which is supplemented by the development of a comprehensive measure of communication burden based on a sufficient sample size, and an introductory investigation into the relationship among communication burden and the effects of EoL caregiving (i.e., caregiver burden, quality of life).

CCBs scale development. Overall, item development for the Caregiver Communication Burden scale (CCBs) was guided by extant research, theory, and insights gained through in-depth interviews, caregiver feedback, and an informal expert review. The process of developing the CCBs was conducted in six steps, which are detailed below.

First, because the construct of family caregiver communication burden was clearly conceptualized and initial item development was guided by extant research, theory, and expert review (DeVellis, 2011), the original 18 items from the pilot scale development were used as a point of initiation for the scale development presented in this dissertation (see, Shaunfield et al., 2013). Second, after interviewing 30 caregivers (i.e., 75% of interview participants), the author began modifying original 18-item measure of communication burden. During this phase of scale development, significant revisions were implemented (e.g., item additions, deletions, word alterations) based on the notes regarding the author's enlightened understanding of communication stressors made throughout the interview process. In order to reduce the chance of participant fatigue, the final item pool was kept at a maximum of 25 items (Devellis, 2011). The new communication burden items were created in accordance with the seven categories of

communication burden identified in the literature and confirmed in the interviews: a) *informing and involving family members about prognosis and disease progression* (3 items); b) *expressing feelings of caregiver stress and exhaustion* (3 items); c) *disclosing to family and friends a need for assistance* (3 items); d) *communicating with others about sensitive issues and care decisions* (4 items); e) *communicating with the patient about his/her own illness and care preferences* (5 items); f) *inability to communicate with patients in advanced stages of illness* (3 items); and g) *seeking information and support from medical staff* (4 items).

Third, to enhance face validity, after compiling the measure of communication burden, five family caregivers reviewed the item pool and provided feedback and suggestions. After which, modifications were made to wording and format on the basis of the suggestions made by family caregivers. Next, four experts (i.e., health care professionals: 2 social workers, 2 neurologists) conducted an informal review and provided minor suggestions, which were discussed and changed for the final version of the CCB. Afterwards, once established, the items were transformed into a five-point Likert-type scale (“strongly disagree” to “strongly agree”) to correspond with the CRA in order to aid in clarity and decrease respondent confusion (DeVellis, 2011). Finally, to minimize response error, seven items were reverse coded (DeVellis, 2011).

Data Management and Analysis

Data were analyzed using SPSS software version 22. Upon examination, the data showed no problems with multicollinearity or violation of the assumptions of homoscedasticity independence, or linearity.

Table 5.1
Demographic Characteristics of Sample Population

Caregivers (<i>N</i> = 263)	<i>n</i>	(%)
Age		
18-30	7	2.7
31-40	13	4.9
41-50	19	7.2
51-60	66	25.1
61-70	71	27
71-80	57	21.7
81-91	26	9.9
Declined to answer	4	1.5
Gender		
Male	72	27.4
Female	187	71.1
Declined to answer	4	1.5
Marital Status		
Never married	14	5.3
Married	209	79.5
Separated	3	1.1
Divorced	20	7.6
Widowed	14	5.3
Other (please specify)	3	1.1
Education		
Less than High School	6	2.3
High School / GED	50	19
Some College/trade school	68	25.9
Undergraduate degree	68	25.9
Other (please specify)	7	2.7
Masters Degree	41	15.6
Doctoral Degree	12	4.6
Professional Degree (JD, MD)	11	4.2
Race		
White/Caucasian	240	91.3
Black or African American	15	5.7
Hispanic/Latino	1	0.4
Asian	4	1.5
American Indian/Alaska Native	1	0.4
More than one race	1	0.4
Other	1	0.4

Table 5.1 (continued)

Employment Status		
Not employed	32	12.2
Employed part time	24	9.1
Retired	122	46.4
Employed full time	66	25.1
Other	19	7.2
Relationship to CR		
Spouse/partner	152	57.8
Sibling	10	3.8
Adult child	71	27
Parent	16	6.1
In-law	2	0.8
Friend	3	1.1
Other	7	2.7
Declined to answer	2	0.8
Hired Assistance		
Yes	61	23.2
No	194	73.8
Declined to answer	8	3
Hours/wk Providing Care		
1-5	37	14.1
6-10	32	12.2
11-20	34	12.9
21-30	22	8.4
31-40	12	4.6
41-50	6	2.3
24/7	78	29.7
Above 50	31	11.8
Declined to answer	11	4.2
Religion		
Yes	215	81.7
No	45	17.1
Declined to answer	3	1.1

Table 5.2
Caregiving Characteristics of the Sample Population

Caregivers (<i>N</i> = 263)	<i>N</i>	(%)
Care Recipient Diagnosis		
ADRD	152	57.8
Cancer	103	39.2
Other	8	3
Care Recipient Age		
18-30	7	2.7
31-40	10	3.8
41-50	11	4.2
51-60	27	10.3
61-70	42	16
71-80	76	28.9
81-90	64	24.3
91-100	16	6.1
Declined to answer	10	3.8
Caregiver Status		
Current Caregiver	175	66.5
Past Caregiver	88	33.5
First-Time Caregiver		
Yes	178	67.7
No	81	30.8
Declined to answer	4	1.5
Live with Care Recipient		
Yes	184	70
No	79	30
Miles from Care Recipient		
1 to 10 miles	53	20.2
11 to 20 miles	6	2.3
25 to 35 miles	8	3
60 to 1100 miles	12	4.6
Care Recipient's Living Arrangements		
Apartment	12	4.6
Home	32	12.2
Nursing Home	10	3.8
Assisted Living Facility	8	3
Aging-in-Place Facility	5	1.9
Other	12	4.6

Table 5.2 (continued)

Caregiver Employment Change		
CG Employment Change	30	11.4
Give less to your job	32	12.2
Reduce hours	35	13.3
Change jobs	2	0.8

Table 5.3

CQLI-R: Items, Means, Standard Deviation, and Response Options

Item	Response Type	M	SD	(n)
1. Please rate your emotional quality of life.	1 = lowest quality applies to someone who is depressed, anxious, insecure, alienated and lonely. 10 = highest quality applies to someone who is emotionally comfortable with self, others, and the environment.	7.02	2.34	252
2. Please rate your social quality of life.	1 = lowest quality applies to someone whose social relationships are unsatisfactory, or poor quality, or few: help from family and friends is not even available occasionally. 10 = highest quality applies to someone whose social relationships are very satisfactory, high quality and many; help from family and friends is often available.	6.49	2.64	255
3. Please rate your financial quality of life.	1 = lowest quality describes someone who is constantly worried about medical costs and present and future living expenses. 10 = highest quality describes someone who feels confident of his or her financial status now and in the future.	6.94	2.64	254
4. Please rate your physical quality of life.	1 = lowest quality describes someone who has no energy or is physically ill and feels unable to maintain normal activities. 10 = highest quality describes someone who is energetic, in good physical health, and is maintaining normal activity levels.	6.83	2.22	255

^aInstructions are as follows: For each question, please indicate from 1 to 10 which score best describes you at the present time (today). Mark your answers on the blank to the right of the question.

**Note.* Several participants skipped either one or all CQLI-R items.

Table 5.4

CRA: Means, Standard Deviation, and Response Options (N=263)

	Item	Mean	SD
1.	I feel privileged to care for my loved one.	4.17	0.83
2.	Others have dumped caring for my loved one onto me.	2.18	1.08
3.	*My financial resources are adequate to pay for things that are required for caregiving.	3.43	1.05
4.	My activities are centered around care for my loved one.	3.72	1.02
5.	Since caring for my loved one, it seems like I'm tired all of the time.	3.16	1.09
6.	It is very difficult to get help from my family in taking care of my loved one.	2.60	1.12
7.	*I resent having to take care of my loved one.	1.74	0.86
8.	I have to stop in the middle of my work.	2.59	1.04
9.	I really want to care for my loved one.	4.28	0.78
10.	My health has gotten worse since I've been caring for my loved one.	2.63	1.14
11.	I visit family and friends less since I have been caring for my loved one.	3.35	1.09
12.	I will never be able to do enough caregiving to repay my loved one.	3.29	1.11
13.	*My family works together at caring for my loved one.	3.37	1.14
14.	I have eliminated things from my schedule since caring for my loved one.	3.65	.95
15.	*I have enough physical strength to care for my loved one.	3.65	.89
16.	Since caring for my loved one, I feel my family has abandoned me.	1.94	.82
17.	Caring for my loved one makes me feel good.	3.83	.83
18.	The constant interruptions make it difficult to find time for relaxation.	3.03	1.07
19.	*I am healthy enough to care for my loved one.	3.95	.69

Table 5.4 (continued)

20.	Caring for my loved one is important to me.	4.38	.62
21.	Caring for my loved one has put a financial strain on the family.	2.47	1.03
22.	My family (brothers, sisters, children) left me alone to care for my loved one.	2.38	1.07
23.	I enjoy caring for my loved one.	3.94	.86
24.	It's difficult to pay for my loved one's health needs and services.	2.42	1.05

^aCodes are as follows: 1 = strongly disagree, 2 = disagree, 3 = neither agree or disagree, 4 = agree, 5 = strongly agree

CHAPTER VI

Quantitative Results

Research Question 2

The second research question posed in this study asked whether a reliable and valid measure of caregiver communication burden could be developed in a sample of EoL family caregivers.

Reliability

The reliability of the initial subscales was examined using internal consistency, inter-item correlations, and item-total correlations. Homogeneity of the CCBs was investigated by examining item-total correlations and inter-item correlations. Correlation coefficients between .30 and .70 were considered acceptable, while coefficients below .30 were non-contributory and above .70 were deemed redundant (Ferketich, 1991).

Validity Testing

In order to investigate whether the seven categories of communication burden identified in the literature could be empirically tested, a principal components analysis of the 25-item measure was conducted using varimax rotation. The analysis revealed a scale with six factors (eigenvalue > 1.0) and 25-items (see table 6.1 for CCBs means, standard deviations, and factor loadings). While the six factors were not clean due to item cross loading, further reduction of the 25-item measure led to greater confusion and exclusion of items representing significant attributes of communication burden.

In the context of EoL family caregiver communication burden, there are advantages to both multidimensional and unidimensional measures. First, the development of a multidimensional measure of communication burden would be

advantageous for use in clinical settings to identify EoL caregivers in need of tailored interventions. The presence of different dimensions would enable providers to identify specific communication stressors and needs, thus enabling targeted service provision. Second, scale reduction yields parsimony, which would be of great benefit in present context, as fewer items would produce less burden for an already overtaxed population. When a multidimensional measure consists of coherent and clear dimensions there are many advantages to dimensionality.

While there are benefits to multi-dimensional measures, in the present study and context, a unidimensional scale was decidedly more valuable for a two reasons. First, further reduction through factor analysis led to factors that did not cleanly correspond to any of the seven categories identified in the literature. Thus, further reduction of the CCBs would require force-fitting the results to correspond with the extant caregiving literature, which is in stark contrast with DeVellis' (2011) declaration that scale development is best served when extant research and theory guide scale development processes. Second, further reduction would preclude the assessment of various communication burden categories, which will be of great value to practitioners who wish to conduct comprehensive communication burden assessments. Consequently, a decision was made in favor of maintaining a one-dimensional scale with all 25-items that together represent the seven communication burden categories (see Table 6.2 for CCBs items, means, and standard deviations). Although there are pros and cons associated with unidimensional and multidimensional scales, in the current study, a unidimensional measure was considered the best conceptual fit for the construct of communication burden.

The reliability assessment using Cronbach's coefficient alpha revealed the 25-item Caregiver Communication Burden scale (CCBs) as a reliable ($\alpha = .89$) measure that accounts for 60.42% of the total variance. Participants' scores were summed and averaged ($M = 68.85$, $SD = 14.46$, $\text{min} = 25$, $\text{max} = 111$); the higher scores indicate increased levels of communication burden (see Table 6.3 for CCBs inter-item correlation matrix).

Hypotheses

Hierarchical regression analyses were used to examine the contribution of communication burden to explaining caregiver outcomes (Hypotheses 1, 2, and 3). Seven of the background context variables identified in the ACT model (age, gender, marital status, employment status, hours/week providing care, religion, and hired assistance) and diagnosis correlated with caregiver burden and quality of life. Therefore, age, gender, marital status, employment status, hours/week providing care, religion, hired assistance, and diagnosis were accounted for in the hierarchical regression analyses. The correlations for all variables included in this study are summarized in Appendix F.

Caregiver Burden

Variables entered on the first step (age, gender, marital status, employment status, hours/week providing care, religion, hired assistance, and care recipient diagnosis) accounted for 14.9% of the variance ($R = .39$, $p < .001$). Age ($\beta = -.12$, $p < .05$) and hours per week providing care ($\beta = 1.65$, $p < .001$) was significantly associated with caregiver burden. After caregiver communication burden was entered, the final equation accounted for 48.5% of the total variance in caregiver burden. Significant contributors in the final equation include the following: Gender ($\beta = 2.20$, $p < .01$), hours per week providing care

($\beta = 1.54, p < .001$), diagnosis ($\beta = 3.15, p < .05$), and communication burden ($\beta = .40, p < .001$), $R = .70$, $R^2 = .49$ $F(9, 233) = 24.43, p < .001$. These results support Hypothesis 1. Consistent with the future research recommendations of prior research referenced earlier and Hypothesis 1, caregiver communication is associated with caregiver burden when controlling for caregiver background context variables. These results indicate that communication burden is significantly associated with caregiver burden. Further, the results suggest that confounding variables associated with increased levels of caregiver and communication burden include the following: female gender, elevated amounts of time providing care per week, care recipient diagnosis, and high levels of communication burden. See Table 6.4 for a summary of the final results when regressing communication burden on caregiver burden.

Quality of Life

Age, gender, marital status, employment, hours per week providing care, religion, hired assistance, and care recipient diagnosis accounted for 19.7% of the variance on quality of life when entered on the first step ($R = .44, p < .001$). Age ($\beta = .13, p < .01$), marital status ($\beta = 3.40, p < .05$), and hours per week providing care ($\beta = -1.46, p < .001$) were significantly associated with caregiver quality of life. Upon entering communication burden to the model, the significant contributors were the following: Marital status ($\beta = 3.37, p < .01$), weekly hours providing care ($\beta = -1.34, p < .001$), care recipient diagnosis ($\beta = -2.82, p < .01$) and communication burden ($\beta = -.31, p < .001$). Thus, the final equation accounted for 47.9% of the variance, $R = .69$, $R^2 = .48$, $F(9, 224) = 22.93, p < .001$. Together, marital status, hours/week providing care, care recipient diagnosis, and communication burden account for a significant portion of the variance in EoL caregiver

quality of life. Caregiver communication burden is significantly associated with caregiver quality of life, thus Hypothesis 2 was supported. Accordingly, the results indicate the following background context variables associated with increased caregiver quality of life: married caregivers, less time spent providing care per week, care recipient diagnosis, and smaller degrees of communication burden. See Table 6.5 for a summary of the final results when regressing communication burden on quality of life.

A final hierarchical regression analysis was used to examine the contribution of communication burden for explaining caregiver quality of life beyond caregiver burden (Hypothesis 3). Again, caregiver background context variables and care recipient diagnosis were entered on the first step to control for any variance they might contribute, caregiver burden was added on the second step, and the final step included caregiver communication burden. Variables entered on the first step (age, gender, marital status, employment status, hours/week providing care, religion, hired assistance, and care recipient diagnosis) accounted for 19.7% of the variance ($R = .44, p < .001$). Age ($\beta = .13, p < .01$), marital status ($\beta = 3.39, p < .05$), and hours per week providing care ($\beta = -1.46, p < .001$) were significantly associated with caregiver quality of life. After caregiver burden was entered, the second equation accounted for 49.8% of the total variance in quality of life. Significant contributors in the second step include the following: Age ($\beta = .07, p < .05$), marital status ($\beta = 2.50, p < .05$), hours per week providing care ($\beta = -.64, p < .05$), and caregiver burden ($\beta = -.50, p < .001$). In the final step, upon entering communication burden to the model, the significant contributors were the following: Marital status ($\beta = 2.8, p < .01$), weekly hours providing care ($\beta = -.89, p = .001$), care recipient diagnosis ($\beta = -2.07, p < .05$), caregiver burden ($\beta = -.33, p < .001$), and

communication burden ($\beta = -.18, p < .001$). Thus, the final equation accounted for 55.6% of the variance, $R = .75, R^2 = .56, F(10, 223) = 27.96, p < .001$. Together, marital status, hours/week providing care, care recipient diagnosis, caregiver burden, and communication burden account for a significant portion of the variance in EoL caregiver quality of life. Thus the answer to Hypothesis 3 revealed that caregiver communication burden explains additional variance in quality of life over and beyond that explained by caregiver burden. Accordingly, the results indicate the following background context variables associated with increased caregiver quality of life: married caregivers, less time spent providing care per week, care recipient diagnosis, and smaller degrees of caregiver communication burden. See Table 6.6 for a summary of the final results when regressing communication burden on quality of life when controlling for caregiver burden.

Table 6.1

Means, Standard Deviations, and Factor Loadings for Items in Caregiver Communication Burden Scale (N=263)

Item	M	SD	1	2	3	4	5	6
Factor 1								
1	7.62	1.20	.79	-.10	.15	.20	.01	.03
2	7.45	1.03	.75	-.00	.06	.23	-.09	-.15
3	7.89	1.3	.69	.30	.16	-.13	-.14	.01
4	5.88	.99	.62	.41	-.05	.04	-.19	.01
5	8.28	1.14	-.54	-.11	-.04	.20	.29	.35
6	30.03	1.05	.51	.15	.25	.21	.13	-.23
7	7.56	.98	.47	.14	.36	.17	-.25	.38
8	5.58	1.01	.39	-.06	0.3	.26	-.26	.31
Factor 2								
9	7.90	1.35	-.02	.85	.11	.14	.07	-.02
10	5.73	1.18	.05	.83	.03	.19	-.05	-.07
11	7.80	1.11	.17	.72	-.04	.12	-.10	-.02
12	7.77	1.20	.21	.51	.30	.21	-.12	.01
13	6.10	1.07	.44	.45	.18	.04	-.02	.26
Factor 3								
14	5.71	1.02	-.06	-.03	-.81	-.07	.03	.07
15	5.59	1.01	-.06	.00	-.69	.03	.32	-.07
16	8.17	1.09	-.18	-.15	-.69	-.17	.09	.24
17	7.89	1.19	.37	.21	.54	.44	.14	.08
18	7.98	1.23	.46	.17	.50	.37	.26	.09
Factor 4								
19	5.25	1.07	.12	.22	.01	.74	-.16	.05
20	5.42	1.10	-.04	.26	.07	.71	-.18	.00
21	6.22	.97	-.14	-.05	-.20	-.64	.15	.15
22	7.49	1.06	.51	.14	.13	.53	.22	-.05
Factor 5								
23	9.01	.75	-.04	-.04	-.12	-.19	.73	.07
24	5.30	.99	.26	.24	.21	.32	-.52	.04
Factor 6								
25	7.76	1.02	-.13	-.03	-.16	-.13	.07	.78
Eigenvalue			7.27	2.18	1.79	1.38	1.27	1.22
Proportion of variance (%)			16.0	12.05	11.05	10.57	5.81	4.92

^aCodes are as follows: 1 = strongly disagree, 2 = disagree, 3 = neither agree or disagree,

4 = agree, 5 = strongly agree

Cronbach's alpha for the 25-item scale is .89

The total proportion of variance explained by CCBs is 60.42%

Table 6.2

CCBs: Items, Means, Standard Deviation, and Response Options (N=263)

	Item	M	SD
1.	I find it hard to discuss future preparations (funeral arrangements, division of finances and belongings) that need to be made with my family.	7.62	1.20
2.	I find it difficult to discuss important healthcare decisions (advance directives, will, living will) for my loved one with family.	7.45	1.03
3.	It is hard for me to have conversations with my loved one about his/her end-of-life preferences and wishes	7.89	1.30
4.	I wish I knew how to bring up sensitive topics (illness/disease progression; end-of-life care preferences; estate planning) with my loved one because that would help me feel more confident and prepared for whatever the future may bring.	5.88	.99
5.	*I have no problem discussing end-of-life care preferences and decisions (advance directives, will, living will) with my loved one	8.28	1.14
6.	It is hard to be the one to report unfavorable news regarding my loved one's condition to our family and friends	30.03	1.05
7.	I rarely tell others about the difficulties I face when providing care for my loved one because voicing that would make me feel incapable	7.56	.98
8.	I rarely ask others for help with my daily chores and caregiving duties because I fear they would think I'm weak.	5.58	1.01
9.	I have a hard time communicating with my loved one because the illness/disease has reduced his/her ability to fully understand and participate	7.9	1.35
10.	I wish I could have conversations with my loved one about his/her care preferences and wishes, but the illness-related symptoms have reduced our ability to communicate effectively	5.73	1.18
11.	I often second-guess myself when trying to discern my loved one's needs because he/she is unable to clearly communicate them to me	7.8	1.11
12.	I find it difficult to discuss my caregiving related issues and concerns with my loved one's health care providers while he/she is in the room	7.77	1.20
13.	When talking with my loved one, I avoid topics related to the illness/disease progression because it is more important that he/she remains positive	6.1	1.07

Table 6.2 (continued)

14.	*I always tell family when I feel overwhelmed from my many responsibilities involved in providing care	5.71	1.02
15.	*I always tell my loved one's healthcare providers when I feel stressed and overwhelmed.	5.59	1.01
16.	*I have no problem asking others for assistance when I am overwhelmed and need help to provide care	8.17	1.09
17.	I have a hard time asking family for assistance when I need help providing care	7.89	1.19
18.	I have a hard time talking with family about the stress I experience providing care for my loved one	7.98	1.23
19.	It seems like I have had more disagreements with family since I have been caring for my loved one	5.25	1.07
20.	It seems like my loved one and I have had more disagreements since I have been providing care for him/her.	5.42	1.10
21.	*My family and I always agree when discussing the care of my loved one	6.22	.97
22.	In addition to my other caregiving responsibilities, I find it difficult to continuously update my family of my loved one's condition	7.49	1.06
23.	*I am always forthcoming and honest when discussing my concerns and needs with my loved one's health care providers	9.01	.75
24.	I find it difficult to fully discuss important issues regarding my loved one's care with his/her healthcare providers because they don't seem to have much time	5.3	.99
25.	*Being the one responsible for keeping family and friends updated and responding to their inquiries is an effortless task	7.76	1.02

^aCodes are as follows: 1 = strongly disagree, 2 = disagree, 3 = neither agree or disagree, 4 = agree, 5 = strongly agree

Note. * Indicates reverse coding.

Table 6.3
Inter-Item Correlation Matrix for CCBs

Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	
1 I find it hard to discuss future preparations...	1.00																									
2 I find it difficult to discuss important health	.62**	1.00																								
3 It is hard for me to have conversations with...	.51**	.42**	1.00																							
4 I wish I knew how to bring up sensitive to...	.36**	.37**	.52**	1.00																						
5 I have no problem discussing end-of-life c...	-.28**	-.039**	-.38**	-.34**	1.00																					
6 It is hard to be the one to report unfavorabl...	.38**	.42**	.34**	.37**	-.21**	1.00																				
7 I rarely tell others about the difficulties I fa...	.40**	.38**	.36**	.35**	-.21**	.30**	1.00																			
8 I rarely ask others for help with my daily...	.37**	.32**	.25**	.29**	-.13*	.26**	.49**	1.00																		
9 I have a hard time communicating with my...	.01	0.09	.24**	.24**	-.04	.16**	.18**	.06	1.00																	
10 I wish I could have conversations with my...	.04	0.12	.24**	.37**	-.15*	.20**	.19**	.07	.67**	1.00																
11 I often second-guess myself when trying to...	.12*	.20**	.27**	.39**	-.11	.26**	.25**	.14*	.56**	.54**	1.00															
12 I find it difficult to discuss my caregiving r...	.22**	.31**	.30**	.29**	-.16**	.28**	.34**	.21**	.45**	.37**	.33**	1.00														
13 When talking with my loved one, I avoid t...	.33**	.31**	.44**	.44**	-.19**	.23**	.33*	.18**	.31**	.35**	.27**	.41**	1.00													
14 I always tell family when I feel overwhelmed...	-.20**	-.14*	-.17**	-.12	.08	-.28**	-.27**	-.23**	-.11	-.08	-.05	-.23**	-.16*	1.00												
15 I always tell my loved one's healthcare pro...	-.18**	-.011	-.29**	-.09	.14*	-.11	-.27**	-.24**	-.04	-.05	-.03	-.18**	-.17**	.49**	1.00											
16 I have no problem asking others for assist...	-.25**	-.25**	-.23**	-.15*	.26**	-.36**	-.31**	-.31**	-.20**	-.20**	-.12*	-.37**	-.21**	.43**	.34**	1.00										
17 I have a hard time asking family for assist...	.42**	.40**	.30**	.29**	-.14*	.35**	.50**	.39**	.29**	.26**	.28**	.37**	.37**	-.40**	-.25**	-.55**	1.00									
18 I have a hard time talking with family abo...	.45**	.39**	.34**	.31**	-.14*	.42**	.42**	.31**	.24**	.25**	.18**	.36**	.41**	-.40**	-.25**	-.43**	.66**	1.00								
19 It seems like I have had more disagreement...	.22**	.22**	.15*	.24**	-.09	.18**	.22**	.27**	.27**	.33**	.25**	.29**	.21**	-.08	-.18**	-.18**	.37**	.32**	1.00							
20 It seems like my loved one and I have ha...	.08	.14*	.08	.17**	.00	.18**	.22**	.18**	.25**	.34**	.23**	.32**	.17**	-.15	-.08	-.23**	.35**	.26**	.51**	1.00						
21 My family and I always agree when discus...	-.27**	-.32**	-.12*	-.16**	.09	-.27**	-.20**	-.21**	-.16**	-.23**	-.14*	-.26**	-.21**	.28**	.27**	.24**	-.32**	-.29**	-.49**	-.36**	1.00					
22 In addition to my other caregiving responsi...	.45**	.40**	.34**	.36**	-.13*	.41**	.31**	.24**	.24**	.21**	.21**	.29**	.28**	-.17**	-.07	-.27**	.51**	.57**	.36**	.31**	-.32**	1.00				
23 I am always forthcoming and honest when...	-.10	-.16**	.012	-.16*	.10	-.11	-.23**	-.15*	-.006	-.08	-.15*	-.20**	-.11	.18**	.15*	.20**	-.12	-.08	-.12*	-.24**	.19**	-.10	1.00			
24 I find it difficult to fully discuss important...	.29**	.28**	.29**	.34**	-.19**	.22**	.35**	.29**	.24**	.31**	.25**	.32**	.29**	-.19**	-.28**	-.36**	.34**	.33**	.36**	.30**	-.26**	.33**	-.40**	1.00		
25 Being the one responsible for keeping fami...	-.14*	-.15*	-.13*	-.13*	.19**	-.17**	.02	-.04	-.06	-.08	-.09	-.011	0.03	.15*	.09	.25**	-.16*	-.010	-.009	-.10	.18**	-.15*	.11	-.12*	1.00	

* $p < .05$ ** $p < .01$

Table 6.4

Summary of Final Results When Regressing Caregiver Communication Burden on Caregiver Burden (n = 244)

Variables	Unstandardized β	Standardized β	<i>p</i> value	R ² change	R ² for full model
Step 1				.15***	
Age	-.02	-.02	.70		
Gender	3.15	.15	<.01		
Marital status	-1.64	-.07	.19		
Employment status	-1.29	-.09	.06		
Hrs./week providing care	1.54	.26	<.001		
Religion	1.56	.06	.23		
Hired assistance	1.29	.06	.027		
Diagnosis	2.20	.13	<.05		
Step 2				.34***	.49***
Communication burden	.04	.60	<.001		

Note. *** p <.001.

Table 6.5

Summary of Final Results When Regressing Caregiver Communication Burden on Quality of Life (n = 235)

Variables	Unstandardized β	Standardized β	<i>p</i> value	R ² change	R ² for full model
Step 1				.197***	
Age	0.05	0.08	0.2		
Gender	-.16	-.01	0.87		
Marital status	3.37	0.16	<.01		
Employment status	-.16	-.01	0.79		
Hrs./week providing care	-1.34	-.27	<.001		
Religion	0.24	0.01	0.83		
Hired assistance	-1.46	-.08	0.15		
Diagnosis	-2.82	-.19	<.01		
Step 2				.28***	.48***
Communication burden	-.31	-.55	<.001		

Note. *** p <.001.

Table 6.6

Summary of Final Results When Regressing Communication Burden on Caregiver Burden and Quality of Life (n = 235)

Variables	Unstandardized β	Standardized β	<i>p</i> value	R ² change	R ² for full model
Step 1				.19***	
Age	0.04	0.08	0.21		
Gender	0.89	0.05	0.32		
Marital status	2.8	0.13	<.01		
Employment status	-.52	-.04	0.34		
Hrs./week providing care	-.89	-.17	=.001		
Religion	0.71	0.03	0.49		
Hired assistance	-.95	-.05	0.32		
Diagnosis	-2.07	-.14	<.05		
Step 2				.30***	
Caregiver burden	-.33	-.39	<.001		
Step 3				.06***	.56***
Communication burden	-.18	-.32	<.001		

Note. ****p*<.001.

CHAPTER VII

Discussion

Family caregiving in the United States is becoming more prevalent as the aging population continues to increase as a result of life sustaining advances in technology that have enabled a significant rise in the average life expectancy. In America more than 65 million individuals have assumed the family caregiver role (NAC, 2009). However, the burdens, stresses, and responsibilities that caregivers experience often negatively influence caregiver health outcomes (Sharpe et al., 2005). Although the family caregiving literature reveals and alludes to many communication tasks and responsibilities that are difficult for the caregiver (Fried et al., 2005; Pruncho, Burant, & Peters 1997; Savundranayagam et al. 2005; Wittenberg-Lyles et al., 2012), the findings from this study suggest that communication in of itself is a burden for EoL family caregivers. Not only does communication burden exist, the current study reveals that EoL family caregivers experience immense tension and communication stressors regarding a variety of relational contexts when communicating with the care recipient, others (family, friends), and even clinicians. Further, the results of the study presented here, illustrate that communication burden stems from the caregiver's attempt to negotiate between two opposing extremes: a desire to protect the patient and others versus a need to protect oneself when contemplating whether and how to engage others, and then again when following through. Added insight into communication burden was provided through a scale development study which revealed communication burden as significantly associated with caregiver burden and quality of life.

Summary of Qualitative Results

The construct of caregiver communication burden is in line with Donovan-Kicken, Tollison, and Goins' (2012) findings regarding the communication work of cancer patients. Like caregiver communication burden, the communication work of oncology patients is a demanding task that involves: disclosing the diagnosis, informing others about treatment decisions, plans, and implications, difficulties experienced when seeking and receiving support, and being responsible for updating friends, family, and co-workers (Donovan-Kicken et al., 2012). Although the communication work of cancer patients presents some of the issues identified as caregiver communication burden, the construct of communication burden extends prior work on oncology patients to EoL family caregivers in particular, and suggests communication burden may be an additional dimension of caregiver burden that should be investigated by health care professionals when tailoring interventions. The communication needs of cancer patients and their caregivers often go unmet, resulting in psychological distress (Siminoff et al., 2008), the findings presented here indicate communication burden is strongly associated with enhanced caregiver burden and reduced quality of life. Future research should investigate caregiver communication burden in tandem with the communication work of patients in order to achieve a holistic view of the complexities inherent in a variety of EoL family caregiving contexts. A necessary step for developing tailored interventions that support both members of the patient-caregiver unit.

EoL family caregivers live a largely dualistic existence that emanates from tensions experienced when attempting to maintain a focus on life in the present, meanwhile acknowledging the uncertainty surrounding the certain future—death. The

dualistic existence begins after the care recipient receives a terminal diagnosis, after which, family caregivers become constrained to a seeming binary existence between life and death. The interplay between polar needs and desires influence communication burden as a result of the caregiver's attempts to negotiate the tension within various communication encounters. The dualisms predominately emanate from the strain felt from attempting to live life in the present and a simultaneous yet contradictory demand to prepare oneself for the loved one's impending death and the caregiver's ongoing future. The inherent centrifugal force between life and death therefore influences communication as the caregiver struggles to find equilibrium in the midst of chaos—continually striving to achieve a balance between the caregiver's goal to provide quality patient care versus attending to one's own needs. The results revealed that caregiver communication burden emerges from stress and frustration felt when both preparing to and actually engaging in sensitive conversations with the care recipient, others, and health care professionals.

The finding that care recipients' symptoms serve as a communication barrier that enhances communication burden is supported by previous findings that ADRD wives reported difficult and effortful attempts to interpret the care recipient's needs due to cognitive, behavioral, and language barriers (Baxter et al., 2002). Further, the authors illustrated a certainty-uncertainty contradiction experienced by ADRD caregivers regarding the care recipient's absence yet occasional presence of lucidity, in which the caregivers regained certainty by through glimpses into the husband's true self (Baxter et al., 2002). The push and pull between certainty and uncertainty caused caregivers immense frustration when communicating with the care recipient. Like the present study, ADRD caregivers made conscious efforts to reframe the behavior of their loved ones by

continuously reminding themselves the behavior was a result of the disease rather than care recipient (Baxter et al., 2002). Baxter and colleagues' (2002) findings support the results that communication burden ensues as a result of the disease symptomology and associated communication barriers.

In support of previous findings, EoL family caregivers experience stress when unable to assess the care recipient's pain and symptom management needs (Mitrani et al., 2005; Savundranayagam et al., 2005; Wittenberg-Lyles et al., 2014). However, the results of this study, extend prior findings by suggesting that EoL family caregivers' continued failed efforts to assess the patient needs is not only stressful, but a significant source of communication burden. This communication task, in particular, was directly related to the caregiver's ability to protect the care recipient, thus the inability to accurately conduct needs assessments creates a tension that works against the caregiver's intent to protect and safeguard the patient. Circumstances in which the patient's cognition becomes impaired, hinders family caregivers from achieving the ultimate goal—protecting the patient at all costs, which causes caregivers significant communication burden, and according to the findings of the supplemental study may in turn heighten the caregivers' overall sense of burden and reduce quality of life.

Caregiver communication burden is further influenced by the EoL family caregiver's response to the patient's symptoms and whether the caregiver attributes the symptoms to the disease or the patient. Caregiver attribution is significantly related to the disease-type, the specific symptoms impeding the caregiver's communication efforts, and whether the caregiver accurately understands and knows what to expect regarding the disease-type, prognosis, and associated symptomology. Symptoms such as memory loss,

language deficits, and deteriorating function are more palpable than largely imperceptible symptoms like fatigue, depression, apathy, and behavioral misconduct. Conversely, obscure symptoms cause significant frustration for EoL caregivers, because unlike detectible symptoms, clearly associated with cognitive and functional decline, caregivers have a tendency to attribute the more indiscernible symptoms to the patient as a person, rather than the disease. For example, to EoL caregivers if the patient is suffering from symptoms such as apathy or fatigue, the symptoms may be perceived as an unwillingness of the patient to engage in previously enjoyed activities, which is an affront to the caregiver's protection work and guardian role. Unfortunately, when symptoms are attributed to the person rather than the disease, resentment and a loss of relational intimacy between the patient and caregiver may result.

In the current study, the care recipients were diagnosed with dementia or terminal brain cancer. ADRD diagnoses are significantly more common than GBM, thus ADRD caregivers are more likely have at least some prior knowledge of the disease, and therefore anticipate symptoms related to cognitive, communication, and functional deterioration. Conversely, GMB caregivers do not know what to expect because the associated symptoms are much more vague (Schubart, Kinzie, & Farace, 2008). The aggressiveness of this particular brain tumor inhibits physicians from knowing and thus preparing the caregiver for the associated symptoms because it is unknown where the finger-like tentacles of the tumor will invade and therefore affect (ABTA, 2014). As a result, GBM caregivers may be more likely than ADRD caregivers to attribute the symptoms to the person rather than the disease.

EoL family caregivers experience immense communication burden that stems from the necessity to overcome the patient's unyielding symptoms associated with their disease. As a result, EoL family caregivers engage in an perpetual internal battle to remind themselves that the discontentment and strain they are experiencing is due to the disease symptomology and not the fault or intention of the care recipient. In addition to their internal battles, the ways in which EoL caregiver's respond to the presenting disease symptoms can precipitate a barrier that impedes the caregiver's efforts to achieve the goal of protecting the patient by seeking compliance, assessing the patient's needs, and making the care recipient comfortable and content.

In line with prior research, EoL family caregiver's naturally assume the responsibility to protect the patient from harm (Hilton et al., 2000; Stajduhar, Martin, & Cairns, 2010; Zhang & Siminoff, 2003), however these findings provide further insight into the communication burden experienced as a result of protection efforts. For example, in addition to managing the unceasing interplay between contrary tendencies, EoL family caregiver's must also remain vigilant in managing the content, outlook, and tone of their conversations to protect the patient, others, and themselves, which heightens the stresses associated with communication tasks. Like the findings of the current study, Baxter et al. (2002) identified an openness-closedness contradiction that emerged for ADRD wives due to opposing desires to withhold information and hide their emotions to protect the care recipient from feeling anger, or sadness, thus inducing immense feelings of caregiver guilt (Baxter et al., 2002). Likewise, when uncertain of the appropriate amount of information to share with care recipients, EoL caregivers opted for discretion above candor causing significant guilt. Which strongly supports the EoL family caregiver

tendency to withhold information to protect the care recipient at the caregiver's own expense.

The current findings are further supported by a variety of studies, conducted in specific disease and/or relational contexts that report the caregiver's need to protect the patient by avoiding taboo topics. EoL family caregivers strive to avoid the following taboo topics: disease and/or prognosis (Badr & Taylor, 2006; Lobchuck, 2006), death (Bachner & Carmel, 2009; Bachner et al., 2009; Gardner & Kramer, 2009) and advanced care planning (Gallagher-Thompson, Solano, Coon, & Arean, 2003) in an attempt to remain hope (Imes et al., 2011). However, the current findings extend prior research on taboo topics not only by providing insight into the various reasons why such topics are perceived as difficult and avoided, but also a comprehensive look into a potential reason for and implications of topic avoidance: communication burden, caregiver burden, and reduced quality life quality.

Another notable finding revealed that in addition to previously known taboo topics, EoL family caregivers also consider conversations about the future and the caregivers themselves as forbidden topics of conversation. An interesting finding given that these topics of conversation are common within a healthy context. EoL family caregivers were averse to discussing the future because of the need to negotiate the uncertainty-certainty contradiction. For example, caregivers were reluctant to discuss uncertainty regarding their own future because that would force them out of the certain present to consider an uncertain future without the care recipient. This finding contrasted with a previous report that oncology couples engage in conversations about future plans as a distraction and to maintain hope (Badr & Taylor, 2006). In light of prior research, the

findings presented here suggest that in an EoL context, in particular, family caregivers avoid conversations about the future. Second, oneself (the caregiver) was also revealed as a taboo topic, as EoL family caregivers avoided discussing their own experiences, concerns, and fears. Given the qualitative findings, caregivers likely avoid talking about themselves as a result of the need to protect the patient and others above themselves.

EoL family caregivers tend to privilege remaining optimistic at the expense of future preparedness, which results in anguish and communication burden. This finding is supplemented by prior research findings that suggest AD/DRD spousal caregivers experience a past-present contradiction due to feelings that the person they loved was in the past, while living with a physically present spouse who is cognitively and emotionally absent (Baxter et al., 2002). The results of this study add to the past-present contradiction by suggesting that EoL family caregivers also negotiate an additional temporal contradiction: present-future.

In addition to a desire to protect the care recipient, caregivers also take it upon themselves to protect others (friends, family; especially children and grandchildren), a priority that ensues significant costs to the caregiver's openness to attend to one's own needs, thus resulting in communication burden and consequential resentment and emotional distress. Although EoL family caregivers attempt to safeguard both the care recipient and others at their own expense, they are further caught in a bind due to a need to protect themselves from becoming vulnerable. The findings associated with caregiver avoidance as a means of self-protection are in line with Neufeld and Harrison's (2003) claims that women caregivers experience negative and non-supportive interactions (with family in particular) including, disparaging comments, conflict over the care recipient's

health and treatment plan, criticism of the caregiver's efforts, and spillover from longstanding family issues. Moreover, the findings of this study suggest that immense exhaustion and overwhelming feelings of burden due to an immensely distressing situation, may cause EoL family caregivers to be more sensitive to what others say as a result of inner conflicts resulting from the admittance of information perceived as taboo, thus causing the caregiver to reject the response due to his/her own discomfort. Moreover, supportive others are also dealing with their own concerns and anxiety when determining how to respond to the caregiver's initiation of dialogue regarding topics that are taboo and generally avoided.

As a result of the numerous contradictions and tensions revealed above, caregivers tend to anticipate rather than seek support. While prior research has revealed family caregivers are reluctant to ask for support or admit emotional need due to a sense of pride and responsibility (Coe & Neufeld, 1999; Hilton et al., 2000), these results demonstrate that EoL family caregivers are prone to anticipate rather than seek support. Recently, Wittenberg-Lyles and colleagues (2014) suggested that hospice caregivers are reluctant to seek support because it would be too burdensome. However, the findings presented here indicate that while that may be true in some cases, EoL family caregivers not only acknowledge a need for support, they are open to receiving and even desire support. Thus, the burden associated with obtaining support may instead be a result of caregiver communication burden. Communication burden emanates from a tension between contradictory and opposing needs: to safeguard the care recipient, others, and oneself versus a desire for support, which is why caregivers anticipate rather than openly seek support. Moreover, the findings presented here, further suggest that caregivers who

report obtaining support as a burden rather than relief (see Wittenberg-Lyles et al., 2014) may voice those opinions due to the communication burden that stems from the caregiver's need to protect oneself from becoming emotionally vulnerable—a potential result of verbalizing and acknowledging a lack of support.

Instead of openly discussing their concerns, needs, and fears to obtain support, EoL family caregivers anticipate supportive offers. These findings enhance social support literature in the context of EoL family caregiving by revealing caregivers—even male caregivers who are least likely to seek support due to pride and family responsibility (Coe & Neufeld, 1999; Hilton, Crawford, & Tarko, 2000)—may be more accepting of specific supportive offers. Vague and general offers of support influence caregiver communication burden that stems from the caregiver's need for support versus the fear of overstepping relational boundaries. The findings presented here further indicate that the provision of specific supportive offers framed to put the caregiver at ease are more acceptable than vague offers. This finding is a significant contribution to the caregiving literature and for the development of tailored caregiver and family interventions. For example, one way to translate this finding into practice could involve holding a family meeting between a social worker, family caregiver, and social network members following a terminal diagnosis, to educate both the family caregiver and support network about the ways in which they can help and optimal ways to present support offers. Further, a meeting between family and support network would likely reduce caregiver communication burden by opening the door for caregivers to talk openly about their experiences and needs.

This study provides new insight behind the interactions caregivers engage with the care recipients' health care professionals. Although, caregivers claim they could open up to the care recipient's health practitioners if specifically asked, they were still reluctant to disclose due to the belief that the care recipient's visits are solely patient-focused, and because of the caregiver's need to protect the patient by ensuring all attention remains on them. Although EoL caregivers have good intentions by maintaining focus on the care recipient's wellbeing, family caregivers are often referred to as "secondary patients," meaning they deserve guidance and protection and therefore should be assessed, treated, and cared for in conjunction with the primary patient (Reinhard, Given, Petlick, & Bemis, 2008; Wittenberg-Lyles, Demiris, Oliver, & Burt, 2011). EoL family caregiver reluctance to discuss one's own concerns, difficulties, and needs during clinical visits inhibits the caregiver from obtaining important information and support, to enhance their own wellbeing and therefore that of the care recipient – but this is a foreign concept to EoL caregivers. Caregivers are critical to the patient's plan of care and therefore should be educated on the influence of their health and wellbeing on the care recipient's health (Reinhard et al., 2008; Siminoff, Wilson-Genderson, & Baker, 2010).

In addition to maintaining a focus on the care recipient, EoL family caregivers revealed much of their communication burden in the clinical setting stems from the fact that the care recipient's providers, physicians in particular, are perceived by caregivers as communicatively, emotionally, and physically unavailable. The perceived unavailability of the care recipient's health professionals not only influenced caregivers to withhold vital information, but also caused caregivers to lose trust in the providers, thus further impeding the caregiver from truthfully disclosing their observations, needs, concerns, and

questions—which is vital to the caregiver’s ability to provide quality patient care.

Because EoL family caregivers receive inadequate information, resources, and support to prepare them for the requirements involved in family caregiving (Hudson et al., 2008), they feel unable and unwilling to seek information, advice, and support from health care providers. The caregivers in this study report a need for direct and open communication rather than implied (as experienced) with providers regarding the patient’s condition.

Extant research reveals that open communication with providers helps to reduce caregiver anxiety (Edwards et al., 2012) and enables caregivers to make informed EoL decisions that are critical to ensuring a good patient death (Deschepper et al., 2008). The apparent disconnect between caregiver needs and actions reveals that health care professionals should facilitate caregiver, patient, and family involvement based on their wishes in order to reduce the stress, burden (Andershed, 2006), and communication burden.

Another salient contribution of this study is due to the finding that a tension exists between the caregiver’s desires and need to talk freely with the care recipient’s providers, but the disinclination to do so because the patient is in the room. The results presented here reveal that the tension emanates from the caregiver’s all-consuming need to protect the patient, which takes precedence over the need to disclose their own observations, needs, concerns, and ask questions—although caregivers admit communicating with the doctor would contribute to enhanced care provision. To my knowledge this is the first study to suggest that patient presence inhibits EoL family caregivers from disclosing their concerns and asking questions of providers.

Family caregivers play vital role in influencing the patient's health and well being (Andershed, 2006, Reinhard et al., 2008)—when clinicians solely rely on patients to initiate discussion of psychosocial problems, significant issues often go unaddressed (Taylor et al., 2011). Inadequate attention to family caregivers by health practitioners is a significant gap that must be overcome in order to fully achieve quality patient care (Reinhard et al., 2008). The findings of this study suggest that health care professionals must also understand that even when asked about their own wellbeing, caregivers tend to respond disingenuously because of an inherent need to protect the patient.

Overall, the qualitative results reveal that caregiver communication burden stems from a crucial dilemma faced by caregivers: an incessant internal competition among opposing goals thus forcing the caregiver to choose between one of two extremes—a need to seek and obtain support for themselves to provide quality care versus caregiver perceptions of having no one with whom to talk. These findings further reveal that EoL family caregivers may indeed have access to available support, yet they are reluctant to look for an outlet or create one to purge their thoughts and obtain relief. This predicament was revealed in a variety of opposing dualisms that simultaneously affect EoL family caregivers' willingness to seek support, all of which stemmed from the caregiver's need to protect the patient and others above oneself.

Summary of Quantitative Results

Given that little is known about communication as a potential stressor that influences caregiver outcomes, the comprehensive qualitative investigation into communication burden was supplemented with a quantitative investigation to explore which of the seven communication burden categories identified in the literature can be

measured empirically and to determine whether communication burden is associated with caregiver outcomes.

The results of this study demonstrated the reliability and validity of the CCBs and support the use of the CCBs to measure caregiver communication burden. The results of reliability and validity tests (i.e., factor analysis, hypothesis testing) provided support for a 25-item unidimensional measure with high reliability. Initial factor analysis revealed six dimensions several items were cross-loaded; however, further reduction led to greater confusion and the exclusion of items that represent valuable facets of EoL caregiver communication burden.

Based upon conceptual and theoretical considerations, the 25-item unidimensional measure was identified the best fit for the construct of communication burden as represents all seven communication burden categories previously discussed. A possible reason the seven dimensions were not cleanly extracted through factor analysis may be due to the fact that the measure was developed prior to the inductive analysis that revealed the dualistic tensions from which we now know communication burden emanates. Future work is needed to further develop the CCBs so that the items reflect the contradictions inherent in communicating at the end of life. Further development of the CCBs will enhance the measure for the development of holistic communication burden assessments to aid in identifying caregivers in need of specific services.

Hypothesis 1 predicted an association between communication burden and caregiver burden. Hypothesis 2 predicted that communication burden would be significantly associated with caregiver quality of life. Hypothesis 3 predicted that communication burden would be significantly associated with quality of life over and

beyond caregiver burden. Three different regression analyses were conducted to test the three hypotheses. The results revealed that caregiver communication burden is significantly associated with both caregiver burden and quality of life when controlling for background context variables (i.e., age, gender, marital status, employment status, hours/week providing care, religion, hired assistance) and care recipient diagnosis. These results corroborate prior research that suggests communication problems may significantly influence caregiver outcomes (Bachner et al., 2006; Braun & Beyth, 2008; Braun et al., 2010; Savundranayagam et al., 2005), and therefore support all three hypotheses.

The results of Hypothesis 1 suggest that heightened caregiver communication burden is associated greater caregiver burden. Further, the results revealed several factors associated with increased caregiver burden. First, unlike prior research that suggests older age is associated with increased levels of burden as a result of poor health and fewer support resources (NAC, 2009; Pinquart & Sörensen, 2007), the younger caregivers in this sample reported heightened caregiver burden. Next, consistent with prior caregiver burden research, female caregivers experienced enhanced burden as compared to males (Barusch, 1989; Gallicchio et al., 2002; Kramer & Kipnis, 1995; Martinez-Martin, 2005; Pinquart & Sorensen, 2006). Third, family caregivers who reported increased time spent providing care each week were more likely to report caregiver burden, which is consistent with the caregiving literature (NAC, 2009). Fourth, the care recipient's diagnosis is a significant contributor to heightened caregiver burden. Finally, the research presented here confirms previous speculations that caregiver communication experiences could have an impact on burden (Bachner et al., 2006; Braun & Beyth, 2008; Braun et al.,

2010; Fried et al., 2005; Savundranayagam et al., 2005). Thus, caregivers who report high levels of communication burden are also likely to suffer from overwhelming caregiver burden.

Although the finding that younger caregivers experienced heightened levels of burden is inconsistent with prior research, these results makes conceptual sense given the fact that more time spent providing care was also associated with burden. Thus it may be that the younger caregivers in this study were concurrently employed, while also spending increased time providing care, which likely influenced higher reports of caregiver burden. These findings may be due to the different caregiving populations (ADRD and oncology), as ADRD caregivers were mostly retired and older than oncology caregivers, which could have influenced the contrary finding presented here. However, the results do suggest that further research regarding factors associated with caregiver burden is needed because as time goes on the demographics and experiences of family caregivers will continue to change.

The results of Hypothesis 2 and 3 suggest that increased levels of communication burden are also associated with reduced caregiver life quality above and beyond caregiver burden. Although prior reports suggest older caregivers report reduced quality of life (NAC, 2009), these results revealed that younger caregivers reported reduced quality of life. Next, single caregivers also reported reduced quality of life, which is supported by previous research (Kramer & Kipnis, 1995). Likewise, these results support prior research reports that caregivers who spend more time providing care experience low quality of life (FCA, 2015). Interestingly, when communication burden was entered into the model, care recipient diagnosis became a significant contributor to quality of life.

Future research should investigate whether the communication burden of ADRD or oncology caregivers yields reduced quality of life. Finally, the results further suggest that increased caregiver communication burden is associated with reduced caregiver quality of life above and beyond caregiver burden, which to my knowledge has yet to be hypothesized or investigated in the context of EoL family caregiving.

Although unexpected, numerous caregivers who completed the paper survey provided hand-written notes throughout, including suggestions for item revision and qualifications for answers given. Although comments were made by both ADRD and oncology caregivers, the ADRD caregivers recruited through the local aging research center were already highly invested in the center, having participated in prior research studies, and having received a personalized letter (addressing the caregiver by name) endorsing the study, and signed by the beloved physician. As a result, ADRD caregivers made the most substantive comments, and future analysis of the qualitative comments made specifically regarding the CCBs items will enhance future endeavors to further develop the CCBs. See Appendix G for CCBs items and corresponding samples of caregiver comments.

Theoretical Implications

To my knowledge, little research has been conducted that investigates the contradictions and tensions inherent in communication within the context of end of life care and family caregiving. The qualitative findings presented here, support recommendations to consider contradictions as existing beyond simple isolated binary tensions in favor of recognizing that the opposing forces occur within a network of co-existing juxtapositions (Montgomery & Baxter, 1998). Analyzing the binary

contradictions together provides validation of the depth and complexity of communication burden that EoL family caregivers must negotiate on a daily basis. Research is needed that further explores the EoL caregiving experience by investigating the network of internal tensions by which the contradictions and resulting communication burden are constituted. Further, the qualitative investigation was conducted using a grounded theory approach, which revealed various dualisms and competing goals inherent in the caregiving and communication experience. Thus, the results provide significant support for the existence and significance of tensions and contradictions within the EoL care context. Given these findings, it is surprising that a paucity of research has examined the experiences inherent in EoL communication, in which caregivers, patients, and family members attempt to cope with competing forces when communicatively managing the liminal experience between life and death (for existing studies, see Baxter et al., 2002; Considine & Miller, 2010; McGuire, Dougherty, & Atkinson, 2006).

As previously discussed, the stressors delineated within the ACT theoretical framework do not specifically outline caregiver communication burden as part of the three different stressor types. The numerous dualisms and contradictions inductively identified suggest that caregiver communication burden may mostly occupy intrapsychic stressors (i.e., caregiver's thoughts, feelings, and awareness of the caregiving role) and secondary stressors (i.e., personal impacts of performing caregiving tasks), as opposed to primary stressors (i.e., performing caregiving tasks; Demiris et al., 2009). Further, the finding that communication burden is significantly associated with caregiver outcomes (caregiver burden, quality of life) support prior recommendations that communication

should be assessed as a stressor when implementing the ACT theoretical model for EoL caregiver assessment.

The research presented here, revealed communication burden as a stressor that influences caregiver burden and quality of life when the caregiver's background context variables and diagnosis are controlled. Future research, should extend these findings to determine the ways in which communication burden is mediated by coping style, support network, social support, and hospice care as recommended in the ACT theoretical framework (Demeris et al., 2009). Further investigations of communication burden and caregiver outcomes should include anxiety, depression, perceptions of patient outcomes, and health care satisfaction (see Demeris et al., 2009). Gaining comprehensive insight into caregiver communication will enable health care practitioners to conduct a more holistic needs assessment. Future research is needed that tests caregiver communication burden as part of the complete ACT model, to further investigate whether communication burden is an additional dimension of caregiver burden or if it is truly a predictor as suggested by the results of the current study. By conducting further investigations of communication burden using the ACT theoretical framework as a lens for inquiry, health professionals will be able to more easily identify and ameliorate the communication burden that influences caregiver and potentially patient outcomes through tailored interventions

Implications for Practice

In addition to the theoretical implications of this study, the results offer noteworthy applications for health care professionals and EoL family caregivers. The findings presented here reveal the complexities and tensions inherent in EoL family

caregiving as caregivers attempt to manage the numerous contradictions through preparatory and enacted communication. Insight gained into the complex nature of communication at the end of life and knowledge of the various contradictions could be beneficial for the family caregiver, patient, family, and health care provider.

The implications that EoL family caregivers are inhibited by the presence of the patient are a significant contribution to medical practice. By understanding the communication burden associated with achieving one's goals of informing and obtaining information from the provider in the presence of the care recipient, contrasts with the caregiver's most prominent goal—to protect their loved one at all costs. Gaining insight into this particular contradiction could enable health practitioners to structure clinic visits in a way that unencumbers the caregiver and promotes openness. For example, during a clinical visit, the nurse could take the care recipient to get his/her vitals checked, meanwhile the physician talks privately with the caregiver to assess observations, concerns, and information needs in private. Structuring clinic visits such a manner, would promote more open caregiver-provider discussions, which could ultimately enhance patient and caregiver outcomes. Additionally, by meeting with the caregiver first, the clinician can obtain information the patient may otherwise withhold, and therefore cue the provider into ways of leading conversations with the patient to obtain the necessary information to provide adequate care.

Further, this research presents the first steps in developing a reliable and valid measure of caregiver communication burden. Such an instrument would be of value to researchers and clinicians, as no such instrument currently exists. The results of this study illustrate the significant affects of communication burden on caregiver burden and quality

of life. Therefore, it would be of great benefit for providers to administer the CCBs to identify caregivers in need of tailored interventions to assuage burden and enhance outcomes of both the caregiver and patient. Clinicians can use knowledge of caregiver communication burden to provide education targeted to the individual needs of EoL family caregivers to identify ways of coping and overcoming the barriers inherent in communicating in an EoL context. Further, these results provide a further step in legitimizing the field of communication in the eyes of health practitioners by revealing communication as significantly associated with health outcomes (i.e., caregiver burden, quality of life).

Limitations

In light of the theoretical and practical implications of this study, there are several limitations and directions for future research that should be recognized. First, the sample for this study was almost universally Caucasian and lived in the same state, which cannot represent the experiences of EoL family caregivers from different cultural and regional backgrounds. Second, the participants were disproportionately female, however this circumstance, while not representative, is not uncommon since 66% of family members who provide informal care are female (FCA, 2015).

Third, instead of providing a comprehensive understanding of the data as intended, the concurrent triangulation design may have inhibited the development of items that truly reflect the caregiver communication burden experience. For example, if questions had been crafted in a manner that reflects the contradictions later revealed through the inductive qualitative analysis, distinct and clean dimensions may have been extracted in the final measure. Fourth, the imbalance between ADRD and oncology

caregiver survey participants may have skewed the data. The fact that over half of survey participants were AD/RD caregivers may have influenced the factor analysis. Fifth, another limitation of this study was the inability to determine survey participation rate, which may affect the generalizability of the findings. Participation rate was not able to be determined because clinic staff distributed the majority of surveys. Next, future research should eliminate caregivers recruited through caregiver referrals in order to obtain data from a strict clinic sample. Finally, participant responses may have been biased as a result of clinical interview referrals and survey distribution. Given the distrust EoL family caregivers feel and their need to protect the care recipient from harm, participants may not have answered openly for fear their answers could impact the care of their loved one.

Future Research

Overall, this study provided a foundation for future studies on EoL family caregiving and communication burden. While caregiver communication burden is generated by a perpetual bind created when negotiating between opposing needs and goals, the findings of this study further suggest that caregivers are unwittingly shaping their own experience, caregiver burden, and life quality through their protection attempts. For example, although EoL family caregivers believe they should not need to ask for support because others should offer, likely generates a tension for potential supporters who may desire to help, but wait for the caregiver to ask in order to protect the caregiver through an attempt to avoid stepping on the caregiver's toes or harm the caregiver's pride. Future research should investigate caregiver communication burden from a dyadic approach in order to gain insight into the perception of the caregiver in conjunction with

the support network members to gain a more holistic picture of the communication context.

Further research is also needed that concurrently investigates caregiver communication burden and the communication work of patients (see Donovan-Kicken et al., 2012) to gain comprehensive insight into the complexities of communication within the context of EoL care. Moreover, research is needed regarding the ways in which caregivers and patients manage information between one another and the resulting effects on communication burden and outcomes. The ways in which individuals accomplish the communicative act of family caregiving is important for care recipient health outcomes (Sparks et al., 2012). Therefore, future research should investigate the relationship between caregiver communication burden and care recipient outcomes.

In addition to investigating the communication burden of support networks and providers, future research should explore the communication burden from the provider's perspective. The potential communication burden of health care providers should be investigated in relation to burnout. Future qualitative research is also needed in regards to caregiver communication burden, beyond ADRD and GBM caregiver experiences. It is possible that caregivers providing for persons with heart failure or other terminal illnesses may experience different or additional tensions and communication burden. Finally, qualitative research that investigates caregiver communication burden from the bereaved caregiver's perspective would be beneficial for obtaining new insights. For example, caregivers interviewed five years after the care recipient passes would likely have more clarity and awareness into the communication burden they experienced, which may shed further light on the reasons for and the results of caregiver communication burden.

Conclusion

Family caregivers are the foundation of the U.S. long-term care system. Even so, end-of-life caregivers lack the resources and support to overcome the overwhelming burdens associated with providing informal care for a family member. In addition to caregiver burden, findings from this study suggest that EoL family caregivers experience immense contradictions from communication that stems from the need to attend to opposing goals: the goal to protect the care recipient versus a need to protect oneself. These results illustrate that EoL family caregivers privilege the needs of the patient and others above themselves, which enhances stress and distress associated with completing necessary communication tasks, a construct that has now been coined communication burden. Further, the results of this study reveal communication burden as a valid construct and something that has a significant impact on caregiver burden and quality of life. More work is necessary to ensure that EoL family caregivers have strategies for seeking support and have available resources to ensure their needs are met as they tackle the difficult task of encountering and overcoming communication burden and the additional burdens associated with family caregiving.

Change in employment status – did being the primary caregiver cause you to (check all that apply):

- Leave your job? Give less to your job
 Reduce your time at your job? No
 Switch jobs?

If any of these items are true, what was the % reduction in household income? _____

Relationship to care recipient

- Spouse/partner In-law
 Adult child
 Sibling
 Parent
 Other relative (please specify) _____

Impact to caregiver

Have you hired anyone to assist you with caring for (patient)? Yes No

On average, approximately how many hours per week do you spend providing care?

- 1-5 41-50
 6-10 above 50
 11-20 24/7
 21-30
 31-40

What is your loved one's condition/diagnosis? _____

How long has it been since your loved one was diagnosed? (years/months) _____

How long have you been a caregiver? (years/months) _____

Have you ever been a caregiver for another family member or friend? _____

What was your relation? _____

What was his/her condition/diagnosis? _____

How long were you a caregiver? _____

APPENDIX B
Interview Protocol for End-of-Life Family Caregivers

Family Caregiving and Communication Overview

I'd like to start by asking about your experience as a family caregiver.

1. Would you mind telling me the story of how you became a caregiver?
2. Can you tell me a bit about the kind of things you typically do for your loved one, in terms of providing care?
3. What's your relationship like with members of your family (i.e., close, distant)?
 - a. Can you tell me about how things work between you and other family members who may be assisting with care?
4. What's your relationship with the patient like? (i.e., close, distant)?...Can you explain why?
5. What has your experience been like providing care for a family member?...Can you explain why?

Caregiving Stressors

Many family caregivers who provide care for a loved describe their experience as both difficult and rewarding. For the next set of questions I am going to ask whether you experience the following feelings as a result of your caregiving responsibilities.

6. Have you ever felt _____ as a result of providing care for your loved one?
[check all that apply & prompt for details]
 - stress
 - fatigue/physical exhaustion
 - uncertainty (unsure/doubtful) about illness/disease progression
 - uncertainty (unsure/doubtful) about what the future holds
 - concern (fearful/anxious/worried) over illness/disease progression
 - concern (fearful/anxious/worried) over what the future holds
 - like you don't have time to take care of your own needs (medical, social, privacy)
 - like you interact with friends and family less
 - lonely (alone, depressed)
 - worried about your finances
 - like you're not doing enough
 - Rewards of caregiving
 - Is there anything you have experienced that wasn't on the list?

Now I'd like to further discuss the feelings you report experiencing as a caregiver.

[Questions only asked about checked items]

7. Looking at your list of checked items [hand list to caregiver], can you tell me which of those are easy to talk about with others, in general? (Probe: Why? Example?)
8. Again looking at the checked items, which of those things are difficult to talk about with others? (Probe: Why? Example?)

9. With whom (e.g., patient, family, health care professionals) do you discuss these [checked] issues related to your caregiving experience? (Probe: Why?)
 - a. Is there anyone that you avoid/refuse to discuss these issues with? (Probe: Why?)
10. Can you tell me about your experience talking with family members about _____. Do you discuss _____? (Probe: Why/why not?) [ask for checked items]
 - a. Would you like to be able to talk about some of these things? Beneficial?
 - b. Please complete this sentence; talking with my family about my experience providing care is like...? Can you explain why?
11. Next, I'd like to know how you talk about your caregiving experience with your loved one (i.e., patient)? Do you talk about any of these checked items? (Probe: Which items? Are there certain things you avoid? Why/why not?)
 - a. Would you like to be able to talk about some of these things? Beneficial?
 - b. Please complete this sentence, talking with my loved one about my experience providing care is like...? Can you explain why? How does that make you feel?
12. How would you describe your relationship with your loved one's health care providers?
 - a. Finally, please complete the sentence, talking with health care professionals about my experience providing care is like ...? Can you explain why? How does that make you feel?
 - b. If don't discuss: Why? Under what circumstances would you talk about these issues? Do you feel you need permission?

In-Depth Caregiving Communication Experience

Now I'd like to ask more about your experience communicating with family, your loved one, and his/her health care providers.

Primary

13. *Big moments*: Can you tell me about the time when you told family members about your loved one's illness?
 - a. Probe: Who did you tell? Was it easy/difficult?; Why? Example (when/how)?
 - b. Probe: Was there anyone you chose not to tell? (Who/why? Example?)
14. Can give me a few examples of times you have had to make some big decisions as a caregiver?
 - a. Who did you talk to (i.e., HCPs, family, friends, others)?
 - b. Were there other family members involved in the decision-making?
15. Can you tell me about a time when you talked to health care professionals to obtain information for caregiving or support? (Probe: Was it easy/difficult? Why? Example?)
 - a. How did you ask for information?
 - b. Did you feel comfortable asking?
 - c.

Secondary

16. Have you ever discussed decisions related to EoL care, things like advanced directives, living will, DNR orders, etc. with the patient and members of your family?
- a. (Probe: What did you talk about? Was it easy/difficult? Why?)
 - i. If yes, did you discuss these things before/after diagnosis?
 - ii. Would you mind telling me a little more about your feelings, thoughts, experiences leading up to those conversations?
17. Do you ever wish you had more help with caregiving?
- a. What types of care duties do you feel comfortable asking for help with?
 - iii. Are there people you feel more comfortable asking than others?
 - b. What types of care tasks do you feel uncomfortable asking for help with?
 - iv. Who do you not feel comfortable (avoid) asking for help with those things? (Probe: Why?)
 - c. Do you avoid asking for help b/c you don't want to upset your loved one (patient)?

Intrapsychic

18. Many family caregivers talk about experiencing major life and role changes as a result of becoming a caregiver...What family or life changes did you experience when you became a caregiver?
- a. Can you tell me about a specific time when you realized things felt different?
 - b. Have you ever talked with your loved one about the changes you just discussed? (Probe: Was it easy/difficult? Why?)
19. Have you ever negotiated (or tried to) care responsibilities with others? (Probe: Was it easy/difficult? Why? Example?)
20. Has there ever been a time when you felt you weren't able to help your loved one (e.g., pain and symptom management needs)?
- a. Can you give me an example/tell me about it?
 - b. How did that make you feel? (Probe: Why?)

Final Thoughts

We have just a few questions left.

21. What advice would you give other family caregivers who are in a similar situation, in terms of communicating with _____,?
- a. the care recipient (a loved one diagnosed with _____)
 - b. family
 - c. health care professionals
22. A lot of times, people will recommend that caregivers should be open in talking to others about care related issues like the ones we've talked about today. What does "being open" or having "open communication" regarding your experience and needs as a caregiver mean to you?
23. Is there anything else you'd like to share before we end the interview?

APPENDIX C
Study Endorsement Letter



Date

Sanders-Brown Center on Aging
800 South Limestone Street
Lexington, KY 40506-0230
www.mc.uky.edu/coa/

Dear XXXXXXXX,

Thank you for your current and past support of the research programs at the Sanders-Brown Center on Aging and the University of Kentucky Alzheimer's Disease Center. We are writing to request that you complete the attached questionnaire on behalf of the person whom you are caring for in our research program. This survey may be of significant importance in helping health care providers to better understand the caregiving experience. Several research studies have been designed to look at the experiences of caregivers; however, no current research has investigated the impact of communication tasks and responsibilities on caregiver well-being. This information could lead to the development tailored services and resources designed to meet the unique needs of family caregivers.

You are under no obligation to complete the survey, and you will lose no rights in terms of your ongoing healthcare or research participation if you decide not to participate. At the end of the survey, you can opt-in to be included in a \$25 gift card drawing, and it will cost you nothing but the time needed to answer the questions. We have enclosed a stamped self-addressed envelope to return your survey. We will also send you a copy of the final data when published so you can see how your contribution helped advance our understanding on this topic.

All responses will be kept confidential, so aside from the gift card entry at the end, we ask that you do not sign your name, label, or mark the survey with any identifying information.

If have any questions or concerns, please call Sara Shaunfield at (###) ###-###. I would like to personally thank you for taking the time to help us with this extremely important research study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Gregory A. Jicha'.

Gregory A. Jicha, M.D., Ph.D.

Relationship to care recipient

- Spouse/partner In-law
 Adult child Friend
 Sibling
 Parent
 Other relative (please specify) _____

Age of Care Recipient _____

Have you hired anyone to assist you with caregiving? Yes No

On average, approximately how many hours per week do you spend providing care?

- 1-5 31-40
 6-10 41-50
 11-20 above 50
 21-30 24/7

What is your loved one's condition/diagnosis? _____

How long has it been since your loved one was diagnosed? (years/months) _____

How long have you been a caregiver? (years/months) _____

Have you ever been an unpaid caregiver for another family member Yes No

Do you have a religious affiliation? Yes No

If yes, what is your affiliation? _____

On a scale of 1-10 (1 being the lowest, 10 being the highest), how close are you with members of your family? _____

On a scale of 1-10 (1 being the lowest, 10 being the highest), how close are you with members of your family who are assisting with care? _____

On a scale of 1-10 (1 being the lowest, 10 being the highest), how close are you with the care recipient? _____

Were you one of the 40 family caregivers who recently participated in an interview with Sara Shaunfield (PhD student) about your caregiving and communication experience? Yes No

Caregiving and Communication

The following questions ask about your experience with caregiving-related communication tasks and responsibilities. Please indicate whether you agree with each statement by selecting one of the following response choices:

Strongly disagree, Disagree, Neither agree or disagree, Agree, Strongly agree

1. In addition to my other caregiving responsibilities, I find it difficult to continuously update my family of my loved one's condition.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
2. I have a hard time talking with family about the stress I experience providing care for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
3. I have a hard time asking family for assistance when I need help providing care.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
4. I find it hard to discuss future preparations (funeral arrangements, division of finances and belongings) that need to be made with my family.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
5. It is hard for me to have conversations with my loved one about his/her end-of-life preferences and wishes.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
6. I have a hard time communicating with my loved one because the illness/disease has reduced his/her ability to fully understand and participate.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
7. I find it difficult to discuss my caregiving related issues and concerns with my loved one's health care providers while he/she is in the room.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
8. Being the one responsible for keeping family and friends updated and responding to their inquiries is an effortless task.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
9. I rarely tell others about the difficulties I face when providing care for my loved one because voicing that would make me feel incapable.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
10. I have no problem asking others for assistance when I am overwhelmed and need help to provide care.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

11. I find it difficult to discuss important healthcare decisions (advance directives, will, living will) for my loved one with family.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

12. I have no problem discussing end-of-life care preferences and decisions (advance directives, will, living will) with my loved one.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

13. I often second-guess myself when trying to discern my loved one's needs because he/she is unable to clearly communicate them to me.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

14. I am always forthcoming and honest when discussing my concerns and needs with my loved one's health care providers.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

15. It is hard to be the one to report unfavorable news regarding my loved one's condition to our family and friends.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

16. I always tell family when I feel overwhelmed from my many responsibilities involved in providing care.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

17. I rarely ask others for help with my daily chores and caregiving duties because I fear they would think I'm weak.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

18. It seems like I have had more disagreements with family since I have been caring for my loved one.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

19. It seems like my loved one and I have had more disagreements since I have been providing care for him/her.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

20. I wish I could have conversations with my loved one about his/her care preferences and wishes, but the illness-related symptoms have reduced our ability to communicate effectively.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

21. I find it difficult to fully discuss important issues regarding my loved one's care with his/her healthcare providers because they don't seem to have much time.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

22. When talking with my loved one, I avoid topics related to the illness/disease progression because it is more important that he/she remains positive.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
23. I always tell my loved one's healthcare providers when I feel stressed and overwhelmed.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
24. My family and I always agree when discussing the care of my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
25. I wish I knew how to bring up sensitive topics (illness/disease progression; end-of-life care preferences; estate planning) with my loved one because that would help me feel more confident and prepared for whatever the future may bring.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

Caregiver Reaction Assessment

The next set of questions asks about your experience as a caregiver. Please indicate whether you agree with each statement by selecting one of the following response choices:

Strongly disagree, Disagree, Neither agree or disagree, Agree, Strongly agree

1. I feel privileged to care for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
2. Others have dumped caring for my loved one onto me.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
3. My financial resources are adequate to pay for things that are required for caregiving.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
4. My activities are centered around care for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
5. Since caring for my loved one, it seems like I'm tired all of the time.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
6. It is very difficult to get help from my family in taking care of my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
7. I resent having to take care of my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
8. I have to stop in the middle of work.

- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
9. I really want to care for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
10. My health has gotten worse since I've been caring for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
11. I visit family and friends less since I have been caring for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
12. I will never be able to do enough caregiving to repay my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
13. My family works together at caring for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
14. I have eliminated things from my schedule since caring for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
15. I have enough physical strength to care for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
16. Since caring for my loved one, I feel my family has abandoned me.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
17. Caring for my loved one makes me feel good.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
18. The constant interruptions make it difficult to find time for relaxation.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
19. I am healthy enough to care for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
20. Caring for my loved one is important to me.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
21. Caring for my loved one has put a financial strain on the family.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
22. My family (brothers, sisters, children) left me alone to care for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
23. I enjoy caring for my loved one.
- Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

24. It's difficult to pay for my loved one 's health needs and services.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

Caregiver Quality of Life

The next set of questions asks about your life quality. For each question, please indicate from 1 to 10 which score best describes you at the present time (today). Mark your answers on the blank to the right of the question.

1. Please rate your emotional quality of life. _____

1= lowest quality applies to someone who is depressed, anxious, insecure, alienated and lonely.

10=highest quality applies to someone who is emotionally comfortable with self, others and the environment.

2. Please rate your social quality of life. _____

1= lowest quality applies to someone whose social relationships are unsatisfactory, or poor quality, or few: help from family and friends is not even available occasionally.

10=highest quality applies to someone whose social relationships are very satisfactory, high quality and many; help from family and friends is often available.

3. Please rate your financial quality of life. _____

1= lowest quality describes someone who is constantly worried about medical costs and present and future living expenses.

10=highest quality describes someone who feels confident of his or her financial status now and in the future.

4. Please rate your physical quality of life. _____

1= lowest quality describes someone who has no energy or is physically ill and feels unable to maintain normal activities.

10=highest quality describes someone who is energetic, in good physical health, and is maintaining normal activity levels.

General Health

This last set of questions asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Please answer every question by [circling one answer]. If you are unsure about how to answer, please do the best you can.

1. In general, would you say your health is:

- a. Excellent b. Very good c. Good d. Fair

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
- a. Yes, Limited A Lot b. Yes, Limited a little c. No, Not limited at all
3. Climbing several flights of stairs
- a. Yes, Limited A Lot b. Yes, Limited a little c. No, Not limited at all

During the past 4 weeks, have you had any of the following problems with your daily activities as a result of your physical health?

4. Accomplished less than you would like
- a. Yes b. No
5. Were limited in the kind of work or other activities
- a. Yes b. No

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like
- a. Yes b. No
7. Didn't do work or other activities as carefully as usual
- a. Yes b. No
8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
- a. Not at all b. A little bit c. Moderately d. Quite a bit

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

9. Have you felt calm and peaceful?
- a. All of the Time b. Most of the Time c. A Good Bit of the Time
d. Some of the Time e. A Little of the Time f. None of the Time
10. Did you have a lot of energy?
- a. All of the Time b. Most of the Time c. A Good Bit of the Time
d. Some of the Time e. A Little of the Time f. None of the Time

11. Have you felt downhearted and blue?
- a. All of the Time
 - b. Most of the Time
 - c. A Good Bit of the Time
 - d. Some of the Time
 - e. A Little of the Time
 - f. None of the Time
12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
- a. All of the Time
 - b. Most of the Time
 - c. A Good Bit of the Time
 - b. Some of the Time
 - e. A Little of the Time
 - f. None of the Time

Thank you for completing our survey!

If you would like be entered into the drawing to win a \$25 gift card complete the gift card entry on the next page.

Gift Card Entry

If you would like be entered into the drawing to win a \$25 gift card, please provide your contact information below:

Full name:

Phone number:

Mailing address:

APPENDIX E
Past Caregiver Communication Burden and Outcomes Survey

Caregiver Age _____ **Gender (please check one)** Female Male

Residence (where you lived the majority of time while caregiving)

Lived with care recipient or Lived ____ miles (number) from care recipient

Care recipient's living arrangements (please check one)

- | | |
|---|--|
| <input type="checkbox"/> Apartment | <input type="checkbox"/> Home |
| <input type="checkbox"/> Assisting Living Facility | <input type="checkbox"/> Aging-in-Place Facility |
| <input type="checkbox"/> Hospice Facility | <input type="checkbox"/> Nursing Home |
| <input type="checkbox"/> Other (please specify) _____ | |

Caregiver marital status (please check one)

- | | |
|--|---|
| <input type="checkbox"/> Never married | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Married | <input type="checkbox"/> Widowed |
| <input type="checkbox"/> Separated | <input type="checkbox"/> Other (please specify) _____ |

Caregiver education (please check one)

- | | |
|---|---|
| <input type="checkbox"/> Less than high school | <input type="checkbox"/> Professional degree (JD, MD) |
| <input type="checkbox"/> High school/GED | <input type="checkbox"/> Master's degree |
| <input type="checkbox"/> Some college/trade school | <input type="checkbox"/> Doctoral degree |
| <input type="checkbox"/> Undergraduate degree | |
| <input type="checkbox"/> Other (please specify) _____ | |

Caregiver race (please check one)

- | | |
|--|---|
| <input type="checkbox"/> American Indian/Alaska Native | <input type="checkbox"/> Asian |
| <input type="checkbox"/> Native Hawaiian or Other Pacific Islander | <input type="checkbox"/> Black or African American |
| <input type="checkbox"/> White/Caucasian | <input type="checkbox"/> More than one race |
| <input type="checkbox"/> Hispanic/Latino | <input type="checkbox"/> Other (please specify) _____ |

Caregiver employment status

- | | |
|---|---|
| <input type="checkbox"/> Not employed | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Employed part time | <input type="checkbox"/> Employed full time |
| <input type="checkbox"/> Volunteer | <input type="checkbox"/> Other (please specify) _____ |

What is/was your profession? _____

Caregiving and Communication

The following questions ask about your experiences with caregiving-related communication tasks and responsibilities when you were a caregiver. Please indicate whether you agree with each statement by selecting one of the following response choices:

Strongly disagree, Disagree, Neither agree or disagree, Agree, Strongly agree

1. In addition to my other caregiving responsibilities, I found it difficult to continuously update my family of my loved one's condition.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
2. I had a hard time talking with family about the stress I experienced providing care for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
3. I had a hard time asking family for assistance when I needed help providing care.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
4. I found it hard to discuss future preparations (funeral arrangements, division of finances and belongings) that needed to be made with my family.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
5. It was hard for me to have conversations with my loved one about his/her end-of-life preferences and wishes.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
6. I had a hard time communicating with my loved one because the illness/disease had reduced his/her ability to fully understand and participate.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
7. I found it difficult to discuss my caregiving related issues and concerns with my loved one's health care providers while he/she was in the room.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
8. Being the one responsible for keeping family and friends updated and responding to their inquiries was an effortless task.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
9. I rarely told others about the difficulties I faced when providing care for my loved one because voicing that would make me feel incapable.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
10. I had no problem asking others for assistance when I was overwhelmed and needed help to provide care.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

11. I found it difficult to discuss important healthcare decisions (advance directives, will, living will) for my loved one with family.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
12. I had no problem discussing end-of-life care preferences and decisions (advance directives, will, living will) with my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
13. I often second-guessed myself when trying to discern my loved one's needs because he/she was unable to clearly communicate them to me.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
14. I was always forthcoming and honest when discussing my concerns and needs with my loved one's health care providers.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
15. It was hard to be the one to report unfavorable news regarding my loved one's condition to our family and friends.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
16. I always told family when I felt overwhelmed from my many responsibilities involved in providing care.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
17. I rarely asked others for help with my daily chores and caregiving duties because I feared they would think I was weak.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
18. It seemed like I had more disagreements with family when caring for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
19. It seemed like my loved one and I had more disagreements when I was providing care for him/her.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
20. I wish I could have had conversations with my loved one about his/her care preferences and wishes, but the illness-related symptoms reduced our ability to communicate effectively.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
21. I found it difficult to fully discuss important issues regarding my loved one's care with his/her healthcare providers because they didn't seem to have much time.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

22. When talking with my loved one, I avoided topics related to the illness/disease progression because it was more important that he/she remain positive.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
23. I always told my loved one's healthcare providers when I felt stressed and overwhelmed.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
24. My family and I always agreed when discussing the care of my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
25. I wish I would have known how to bring up sensitive topics (illness/disease progression; end-of-life care preferences; estate planning) with my loved one because that would have helped me feel more confident and prepared for the future.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

Caregiver Reaction Assessment

The next set of questions asks about your experience when you were a caregiver. Please indicate whether you agree with each statement by selecting one of the following response choices: Strongly disagree, Disagree, Neither agree or disagree, Agree, Strongly agree

1. I felt privileged to care for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
2. Others dumped caring for my loved one onto me.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
3. My financial resources were adequate to pay for things that were required for caregiving.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
4. My activities were centered around care for my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
5. While caring for my loved one, it seemed like I was tired all of the time.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
6. It was very difficult to get help from my family in taking care of my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
7. I resented having to take care of my loved one.
Strongly disagree Disagree Neither agree or disagree Agree Strongly agree
8. I had to stop in the middle of work.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
9. I really wanted to care for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
10. My health became worse while I was caring for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
11. I visited family and friends less when I was caring for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
12. I was never able to do enough caregiving to repay my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
13. My family worked together at caring for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
14. I eliminated things from my schedule when caring for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
15. I had enough physical strength to care for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
16. When caring for my loved one, I felt my family had abandoned me.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
17. Caring for my loved one made me feel good.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
18. The constant interruptions made it difficult to find time for relaxation.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
19. I was healthy enough to care for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
20. Caring for my loved one was important to me.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
21. Caring for my loved one put a financial strain on the family.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
22. My family (brothers, sisters, children) left me alone to care for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
23. I enjoyed caring for my loved one.				
Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree

24. It was difficult to pay for my loved one 's health needs and services.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

Caregiver Quality of Life

The next set of questions asks about your life quality. For each question, please indicate from 1 to 10 which score best describes how you felt while you were providing care for your loved one. Mark your answers on the blank to the right of the question.

1. Please rate your emotional quality of life. _____

1= lowest quality applies to someone who was depressed, anxious, insecure, alienated and lonely.

10=highest quality applies to someone who was emotionally comfortable with self, others and the environment.

2. Please rate your social quality of life. _____

1= lowest quality applies to someone whose social relationships were unsatisfactory, or poor quality, or few: help from family and friends was not even available occasionally.

10=highest quality applies to someone whose social relationships were very satisfactory, high quality and many; help from family and friends was often available.

3. Please rate your financial quality of life. _____

1= lowest quality describes someone who was constantly worried about medical costs and present and future living expenses.

10=highest quality describes someone who felt confident of his or her financial status back then and in the future.

4. Please rate your physical quality of life. _____

1= lowest quality describes someone who had no energy or was physically ill and felt unable to maintain normal activities.

10=highest quality describes someone who was energetic, in good physical health, and was maintaining normal activity levels.

General Health

This last set of questions asks for your views about your health when you were providing care. Please answer every question by [circling one answer]. If you are unsure about how to answer, please do the best you can.

1. In general, would you say your health was:

a. Excellent b. Very good c. Good d. Fair

The following items are about activities you might do during a typical day. Back when you were caregiving, did your health limit you in these activities? If so, how much?

2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

b. Yes, Limited A Lot b. Yes, Limited a little c. No, Not limited at all

3. Climbing several flights of stairs

b. Yes, Limited A Lot b. Yes, Limited a little c. No, Not limited at all

Did you have any of the following problems with your daily activities as a result of your physical health?

4. Accomplished less than you would like

a. Yes b. No

5. Were limited in the kind of work or other activities

a. Yes b. No

Did you have any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like

a. Yes b. No

7. Didn't do work or other activities as carefully as usual

a. Yes b. No

8. When you were caregiving, how much did pain interfere with your normal work (including both work outside the home and housework)?

b. Not at all b. A little bit c. Moderately d. Quite a bit

These questions are about how you felt and how things were while you were providing care. For each question, please give the one answer that comes closest to the way you felt.

9. Did you feel calm and peaceful?

a. All of the Time b. Most of the Time c. A Good Bit of the Time
d. Some of the Time e. A Little of the Time f. None of the Time

11. Did you have a lot of energy?

a. All of the Time b. Most of the Time c. A Good Bit of the Time
b. Some of the Time e. A Little of the Time f. None of the Time

13. Did you feel downhearted and blue?
- a. All of the Time
 - b. Most of the Time
 - c. A Good Bit of the Time
 - b. Some of the Time
 - e. A Little of the Time
 - f. None of the Time
12. While you were providing care, how much of the time did your physical health or emotional problems interfere with your social activities (like visiting with friends, relatives, etc.)?
- a. All of the Time
 - b. Most of the Time
 - c. Some of the Time
 - d. A Little of the Time
 - e. None of the Time
 - f. None of the Time

Thank you for completing our survey!

If you would like to be entered into the drawing to win a \$25 gift card complete the gift card entry on the next page.

Gift Card Entry

If you would like be entered into the drawing to win a \$25 gift card, please provide your contact information below:

Full name:

Phone number:

Mailing address:

APPENDIX F

Correlation Matrix of Major Variables in the Study

Variables	1	2	3	4	5	6	7	8	9	10	11
1 Age	1.00										
2 Gender	-.27***	1.00									
3 Marital Status	.31***	-.09	1.00								
4 Employment	.18**	-.03	.15*	1.00							
5 Hrs./week caregiving	.14*	.04	.12	.12	1.00						
6 Religious	.27***	.04	.12	.02	.05	1.00					
7 Hired Assistance	.19**	.01	-.04	-.10	.06	.03	1.00				
8 Diagnosis	-.51***	.07	-.10	-.02	-.15*	-.26***	-.33***	1.00			
9 Caregiver Burden	-.21**	.16**	-.14*	-.12	.24***	-.03	.03	.20	1.00		
10 Quality of life	.27***	-.06	.23***	.02	-.23***	.12	-.00	-.18**	-.65***	1.00	
11 Communication Burden	-.20**	.02	-.08	-.06	.02	-.09	.03	.01	.61***	-.57***	1.00

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

APPENDIX G

CCBs Items and Corresponding Caregiver Comments

Item & Notes	
1	In addition to my other caregiving responsibilities, I find it difficult to continuously update my family of my loved one's condition. - "Not <u>continuously</u> ."
2	I have a hard time talking with family about the stress I experience providing care for my loved one. - "Not really stressful." - "I haven't recognized it like other people – even then, I think I'm fine. She is after all the only mother I have." - "Spouse."
3	I have a hard time asking family for assistance when I need help providing care. - "Don't need help." - "Every one helped."
4	I find it hard to discuss future preparations (funeral arrangements, division of finances and belongings) that need to be made with my family. - "I know, now I'm just procrastinating." - "When my mother was having trouble balancing her checkbook I told my younger sister who [worked at a bank]. She told with my mom and took over all finance need including settle up late finance help from family's." - "Had already made arrangements."
5	It is hard for me to have conversations with my loved one about his/her end-of-life preferences and wishes. - "Have not had the discussion." - "I'm just procrastinating." - "SHE CAN'T COMMUNICATE." - "Discussed very openly early..." - "We had already made arrangements."
6	I have a hard time communicating with my loved one because the illness/disease has reduced his/her ability to fully understand and participate. - "She could have the discussion." - "I know, now I'm just procrastinating." - "True [in] last year."
7	I find it difficult to discuss my caregiving related issues and concerns with my loved one's health care providers while he/she is in the room. - "Provider too busy."
8	Being the one responsible for keeping family and friends updated and responding to their inquiries is an effortless task. - " <u>Depends</u> ."

APPENDIX G (continued)

- 9 I rarely tell others about the difficulties I face when providing care for my loved one because voicing that would make me feel incapable.
- [Not incapable, because] "...I don't want to complain. We all have adversities."
 - “In some areas—I feel incapable. But overall it's neither agree or disagree."
 - "Or more because of their response!"
 - “Spouse ONLY”
- 10 I have no problem asking others for assistance when I am overwhelmed and need help to provide care.
- “Family members were not living nearby so they were not able to help.”
 - "I never felt overwhelmed."
- 11 I find it difficult to discuss important healthcare decisions (advance directives, will, living will) for my loved one with family.
- “Need to do it.”
 - "Not applicable."
- 12 I have no problem discussing end-of-life care preferences and decisions (advance directives, will, living will) with my loved one.
- "I need to do this.”
 - "Will = done. In general I know [her preferences], but she's recently changed her mind when asked by the foundation.”
 - “Discussed prior to illness. – During illness then strongly disagree.”
 - “When she was capable.”
 - “This was decided with drafting our wills. Also, when we prearranged our funerals.”
- 13 I often second-guess myself when trying to discern my loved one's needs because he/she is unable to clearly communicate them to me.
- “Have not tried to do it.”
 - “Very difficult in last year.”
- 14 I am always forthcoming and honest when discussing my concerns and needs with my loved one's health care providers.
- “Provider has no time.”
- 15 It is hard to be the one to report unfavorable news regarding my loved one's condition to our family and friends.
- 16 I always tell family when I feel overwhelmed from my many responsibilities involved in providing care.
- “Don't feel overwhelmed. Not that bad yet.”
 - “Not always.”
 - “I seldom felt overwhelmed.”

APPENDIX G (continued)

- 17 I rarely ask others for help with my daily chores and caregiving duties because I fear they would think I'm weak.
-[Not for fear they would think I'm weak, but because] "...I know they, too have responsibilities of their own."
-"I was the care giver!"
-"Recipient in continuous care facility."
-"All were distant geographically."
- 18 It seems like I have had more disagreements with family since I have been caring for my loved one.
-"With one sibling – Disagree. Other sibling – Strongly agree."
- 19 It seems like my loved one and I have had more disagreements since I have been providing care for him/her.
- 20 I wish I could have conversations with my loved one about his/her care preferences and wishes, but the illness-related symptoms have reduced our ability to communicate effectively.
-"We made plans while she could communicate."
- 21 I find it difficult to fully discuss important issues regarding my loved one's care with his/her healthcare providers because they don't seem to have much time.
-"I have made apt. with MD 2X. APNP will come to apt."
- 22 When talking with my loved one, I avoid topics related to the illness/disease progression because it is more important that he/she remains positive.
-"She keeps all of any negative anything a word and uses it over and over, but anything trying to convince her of the good health she still has or abilities she still possesses is null."
- 23 I always tell my loved one's healthcare providers when I feel stressed and overwhelmed.
-"I have unintentionally & she's tried to help me by folding clothes or washing dishes."
-"Didn't feel stressed – Sad."
- 24 My family and I always agree when discussing the care of my loved one.
-"Have not needed to discuss."
-[Crossed out always]: "Usually"
- 25 I wish I knew how to bring up sensitive topics (illness/disease progression; end-of-life care preferences; estate planning) with my loved one because that would help me feel more confident and prepared for whatever the future may bring.
-"We had those discussion early on: cremation, etc."
-"Other topics discussed prior to illness."
-"We did discuss a lot. My mother was prepared; living will & financial preferences made before she got confused."

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VITA

Education

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- B.A.** **Communication**, University of North Texas (August 2009)

Certificates

Spring 2013 Health Communication, University of Kentucky

Academic Appointments

- 2015** **Assistant Research Professor**
Department of Medical Social Sciences
Northwestern University, Feinberg School of Medicine
- 2014-2015** **Dissertation Year Fellow**
The Graduate School, University of Kentucky
- 2012-2014** **Graduate Teaching Assistant**
Department of Communication, University of Kentucky
- 2011-2013** **Graduate Research Assistant**
Markey Cancer Center/Department of Communication,
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- 2009-2011** **Graduate Teaching Assistant**
Department of Communication, University of North Texas
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Fellowships

- 2015** *Health Communication Research Fellowship*,
Department of Communication University of Kentucky
- 2014-2015** *Dissertation Year Fellowship*, The Graduate School
University of Kentucky, \$20,000

- 2014 *Dissertation Enhancement Award*, Department of Communication
University of Kentucky, \$1,100
- 2014 *Dorothy M. Carozza Memorial Fellowship*,
Department of Communication, University of Kentucky, \$800
- 2013 *Health Communication Research Fellowship*,
Department of Communication, University of Kentucky
- 2012-2013 *Martha and Howard Sypher Memorial Graduate Scholarship for
Excellence in Health Communication Research*,
Department of Communication, University of Kentucky, \$500

Honors and Awards

- 2013 *Top Student Paper*, DCHC Health Communication Conference
- 2012 *Top Paper in Applied Communication*,
Southern States Communication Association
- 2011 *Thesis of the Year*,
Department of Communication, University of North Texas
- 2011 *Outstanding Graduate Student*,
Department of Communication, University of North Texas
- 2010 *Phi Kappa Phi*, University of North Texas
- 2008 *Lambda Pi Eta*, University of North Texas

Peer-Reviewed Publications

Cohen, E. L., Scott, A. M., Record, R., **Shaunfield, S.**, Jones, C., & Collins, T. (2015, in press). Using communication to manage uncertainty about cervical cancer screening guideline adherence among Appalachian women. *Journal of Applied Communication Research*.

Shaunfield, S., Wittenberg-Lyles, E., Parker Oliver, D., & Demiris, G. (2014). Virtual fieldtrips for long-term care residents: A feasibility study. *Activities, Adaptation & Aging*, 38(4), 237–247. doi: 10.1080/01924788.2014.935911

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