

THE COMMUNICATIVE ECOLOGY OF CAREGIVER BURDEN AND THE  
MODERATING EFFECTS OF EMOTIONAL INTELLIGENCE

A

Dissertation

by

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## ABSTRACT

This mixed-method exploratory study examines the communicative ecology of caregiving, which includes interpersonal, clinical, and family communication realms. It also examines whether the trait of emotional intelligence is linked to caregiver burden, and whether emotional intelligence influences the relationships among communication variables and caregiver burden. Three hundred and two respondents participated in this mixed methods study. Hierarchical regressions revealed that emotional intelligence, clinical communication self-efficacy, and disclosure of patient medical information with family members decreased caregiver burden, whereas increased ownership, privacy rules, interpersonal communication competence, and negative interactions with family members increased caregiver burden. Thematic analysis of the exploratory qualitative results revealed that caregivers identify with all three of the communicative environments – interpersonal, clinical, and family – as major challenges within the scope of their caregiver responsibilities.

## DEDICATION

This dissertation is dedicated to the memory of Katherine Dennis Welch and Joel Jacobs Welch, my beloved grandparents, and Dr. Reuben R. McDaniel Jr., my beloved mentor and friend.

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### **Contributors**

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## NOMENCLATURE

CGB	Caregiver Burden
ICC	Interpersonal Communication Competence
PCC	Clinical Communication Self-Efficacy
DSC	Disclosure of Patient Medical Information
PRV	Privacy [Ownership and Rules]
NEG	Negative Interactions with Family Members
TEQ	Trait Emotional Intelligence

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## CHAPTER I

### INTRODUCTION AND LITERATURE REVIEW

#### **Introduction**

As the U.S. population rapidly ages, researchers are focusing more attention on the stresses and needs of family caregivers. While much of the literature focuses on clinical and logistical tasks, other caregiving tasks are critically important, especially those of social and communicative nature. Some of these tasks include interpersonal communication, clinical communication self-efficacy, and disclosure, but have received little empirical attention. This study addresses the gap in research by examining the communicative environment of caregiver burden. Caregiver burden is defined as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotions, social, financial, physical, and spiritual functioning” (Zarit, Todd, & Zarit, 1986, p. 7). The author proposes a model of the communicative environment of caregiving, which includes subsets of caregiving-patient interactions, family communication, and clinical interactions (Figure C1). Specific communicative tasks are performed within each of these areas that have been attributed to caregiver burden, and this study examined the effect of the following communication variables: interpersonal communication competence (with patient), clinical communication self-efficacy (with medical professionals), and disclosure (of medical information with family). This study also examined if emotional intelligence is directly associated with caregiver burden, and how it moderates the relationships of the communication variables with caregiver burden.

## **Caregiver Burden**

According to the National Alliance for Caregiving [NAC] and the American Association for Retired Persons [AARP] (2009), nearly 90% of all at-home long-term care is provided by informal and unpaid family caregivers. An estimated 65 million people (29% of the population) spend approximately 20 hours per week providing care to family members or friends. Among these caregivers, 13% provide assistance 40 hours per week. A 2012 study conducted by the AARP Public Policy Institute and the United Hospital Fund champions the need to support the multiple demands placed on informal family caregivers (AARP, 2012). The level of care that an aging relative needs resides on a spectrum. Depending on the condition of the patient, a family member may simply provide simple caregiving tasks such as housekeeping and grocery shopping, or may need to perform complex medical tasks such as intravenous medications and managing multiple medications.

The detrimental effects of the stress associated with these tasks comprise what is known as caregiver burden. Zarit and colleagues describe caregiver burden as “The extent to which caregivers perceive that caregiving has had an adverse effect on their emotions, social, financial, physical, and spiritual functioning” (Zarit, Todd, & Zarit, 1986, p. 7). Several risk factors for caregiver burden have been identified, including being female, living with the care-recipient, low socio-economic status, low levels of self-care, and less-than full-time or unemployment (Beach et al., 2005). Caregiving contexts that contribute to burden level include number of hours that caregiving is provided, the number and types of Activities of Daily Living [ADLs] and Instrumental Activities of Daily Living [IADLs] provided, financial stress, the level of caregiving efficacy with particular tasks, the ability or inability to maintain employment, and the emotional distress associated with witnessing and experiencing the suffering of the patients

(Beach et al., 2005; Burden & Quite, 2000;). Several adverse outcomes may result from caregiver burden, including caregiver mortality, weight loss, and diminishing self-care (Schulz & Beach, 1999). Poorer psychosocial outcomes may occur as well including depression, social withdrawal, perceived patient distress, and social isolation, anxiety, and even suicide (Pinquart & Sorenson, 2003).

The negative outcomes of caregiver burden are abundant, and have garnered the attention from multiple research disciplines to better understand and mitigate the detrimental effects of this stress epidemic. The following pages will provide a review of the relevant literature to support my proposed model of the Communicative Ecology of Caregiver Burden, which is comprised of three primary realms: Patient Communication, Clinical Communication, and Family Communication. This study proposes that specific tasks and traits within each realm will associate with caregiver burden. Finally, I predict that the personality trait of emotional intelligence [EQ] will be negatively associated with caregiver burden and examine whether EQ moderates the relationship between caregiver burden and communication.

### **Emotional Intelligence & Caregiver Burden**

In all three communicative environments of caregiving – interpersonal, clinical, and family – an enormous body of research reveals that emotional stress is an overwhelming component of caregiver burden. In addition to the aforementioned medical, logistical, relational, and communicative tasks and responsibilities, the caregiver also endures their loved one’s suffering, physical pain, cognitive decline, and in most cases, death (Monin & Schulz, 2009). Many caregivers reported that it was difficult to manage their own emotions and maintain composure when receiving a troublesome medical diagnosis while in the physical presence of the care recipient (Ngwenya, Farquhar, & Ewing, 2015). This psychological impact can manifest as

negative health outcomes such as stress, anxiety, and depression (Convinsky et al., 2003; Cooper, Balamurali, & Livingston, 2007; Schulz & Sherwood, 2008).

There are training programs and interventions for caregivers to mitigate this emotional distress. The topics of the interventions range from performing medical tasks to teaching psychological self-care (Hepburn, Lewis, Sherman, & Tornatore, 2003). For example, one program recommends that caregivers prepare themselves emotionally for the changes that they will witness when caring for patient with dementia (Hepburn, Lewis, Sherman, & Tornatore, 2003). Learning objectives from this program include 1) *making the cognitive shift*, (strategically anticipating the cognitive losses that will occur, and adapting caregiver behavior to these changes and losses); and (2) *developing emotional tolerance* (acknowledge care recipients need for emotional stability and the caregivers responsibility to provide that stability (Hepburn, Lewis, Sherman, & Tornatore, 2003). Results from such interventions indicate positive outcomes such as reduction in caregiver burden, and increased skill and knowledge about tasks (Hepburn, Lewis, Sherman, & Tornatore, 2003)

Intervention literature that addresses emotional strain is abundant, but what seems lacking in the research landscape is how personality traits of the caregiver may affect the perception of (or reaction to) emotional distress. One area of research that may inform our understanding of caregiver burden is emotional intelligence [EQ]. The term emotional intelligence was conceived by Mayer and Salovey in 1990, and is defined as “a subset of social intelligence that involves the ability to monitor one’s own and others’ feelings and emotions, to discriminate among them and to use this information to guide one’s thinking and actions” (Mayer and Salovey, 1990, p. 188). Emotional intelligence has been linked to communication skills and outcomes in a variety of ways, including the link between trait emotional intelligence, conflict communication patterns,

and relationship satisfaction (Smith, Heaven, and Ciarrochi, 2008); the role of emotional intelligence in building interpersonal skills (Petrovici & Dobrescu, 2014), and how nurses use emotional intelligence in conflict management strategies (Baoul & Ozgur, 2016). Surprisingly, very little research is found that uses emotional intelligence as a lens to understanding caregiver burden. Khalaila and Cohen (2016) conducted a study on the effects of emotional suppression and coping strategies on depression, but searches for emotional intelligence in caregiving literature yielded no results.

Because emotional intelligence has been linked to positive communication outcomes (interpersonal relationships, conflict management) which are also desirable in the communicative environment of caregiving, it seems warranted to examine how emotional intelligence affects (a) communication behaviors in the caregiving context and (b) caregiver burden as a whole.

Therefore, the first hypothesis of this study is posed:

*Hypothesis 1: Emotional intelligence is associated with decreased caregiver burden.*

### **Interpersonal Communication Competence**

The relationship between the caregiver and the care recipient is complex, and is the primary source of caregiving burden. The caregiver is most often a spouse or adult daughter (Merrill, 1996; Pillemer & Sutor, 2013; Willyard, et al., 2008), that the care recipient and caregiver are often regarded as an inseparable dyad by medical professionals (Wilder, Oliver, Demiris, and Washington, 2008). While this relationship is an uplifting source of love, affection, and satisfaction (Kramer, 1997; Pinquart & Sorenson, 2003), the tasks, emotional distress, and communication challenges in these relationships can contribute to the overall caregiver burden. Though the relational dynamics between spouse caregiver/spouse recipient and child caregiver/parent recipient may differ, caregivers require certain interpersonal competencies that are both

appropriate and effective in order to achieve relational and caregiving goals (Spitzberg & Cupach, 1984). To navigate through these logistical and relational tasks, caregivers face several challenges such as decision-making, negotiation, problem solving, and managing additional difficulties associated with patients who are experiencing cognitive decline. The following paragraphs will offer a review of various communicative tasks, which are associated with caregiver burden, and then present an overview of how interpersonal communication competence may work to mitigate these challenges.

From an interpersonal standpoint, it is important to take note of the various role changes that occur when a need for caregiving arises. For married couples, the diagnosis of a serious illness and the required care places strains on the relationship, and hence the communication. On one hand, the caregiving recipient is transitioning to a role where his/her independence and autonomy are diminished and he/she no longer is able to perform many activities and tasks; on the other hand, the caregiver is now responsible for additional duties to help the ill partner (Connidis, 2001). In cases when a spouse or partner is unable to provide care for an ill loved one, children are next in line to take responsibility for their parent. Seventy-five percent of American adults believe that it is their responsibility to provide assistance to an elderly parent in need (Pew Research, 2013). Research has shown that one adult child inevitably bears the majority of the caregiving responsibilities (Merrill, 1996; Pillemer & Suitor, 2013; Willyard, et al., 2008), and parent-child communication can be especially difficult during this transitional time. The child has now evolved from a "non-helping offspring" into a "caregiver", and who now must inform, direct, and instruct the care-recipient parent in an effective and considerate manner. When considering this delicate interpersonal interaction, Goldsmith, Wittenberg-Lyles, Ragan, and Nussbaum (2011) argue that younger caregivers should remain mindful of the intergenerational



communication taking place, and to avoid stereotyped expectations and patronizing talk to their elderly family member.

Caregivers must also navigate a wide landscape of negotiations and decision-making with the care recipient, and many of these communicative tasks have been directly associated with caregiving burden. Conversations between spouses or parents and children can include what preferences the parent holds for care, as well as the logistical coordination of who will provide that care (Fowler & Afifi, 2011; Scott & Caughlin, 2014). These conversations are often not previously discussed between the caregiver and the care recipient until the actual care is needed. Research examining eldercare conversations have found that fewer than 40% of adult children have had conversations about care with their parents (Bromley & Blieszner, 1997), and as little as 25% of adult daughters have had explicit discussions with their mothers about the possibility of needing care in the future (Pecchioni, 2001). Many caregivers report that the quantity of communication is problematic in caregiver/recipient relationships. Fried, Bradley, O'Leary, and Byers (2005) found that caregivers who preferred more communication with their care recipients experienced significantly higher levels of burden than caregivers who did not desire more communication.

When important discussions that pertain to care *do* occur, there are often challenges that hinder communication and decision-making, which contribute to caregiver burden. Heid, Zarit, and Van Haitsma (2016) studied how adult daughters who care for parents often resolve conflict and manage differences in care goals. Daughters were found to reason with their parents, and most often make the decisions when a choice pertained to health or safety needs of their parents. When examining conversations that involved caregiving decision-making, Wittenberg-Lyles and colleagues (2012) found that caregivers reported higher levels of caregiver burden when care

recipient's communication is impacted by cognitive decline. Specifically, though a care recipient may still have the ability to communicate, he or she may perceive inaccurate information as being accurate, and therefore cause strain and anxiety in the caregiver when they are trying to accomplish shared decision making about treatment or care (Wittenberg-Lyles et al., 2012).

Savundranayagam, Hummert, and Montgomery (2005) found that communication problems and problem behaviors caused by dementia and loss of cognitive function (such as loss of verbal fluency, speaking too loudly, empty speech, inventing words, and trouble finding words and names), fully mediated the relationship between care-recipient status and caregiver stress burden.

To manage the conversations with care recipients with dementia, caregivers may employ a variety of techniques, strategies, and competencies. Some of these strategies have been empirically supported as effective in improving problematic communication, such as using paraphrased sentences, using nonverbal gestures to emphasize verbal instruction, verbatim repetition, and simple sentences (Small et al., 1997; Tappen et al., 1997; Bourgeois et al, 2002; Gentry & Fisher, 2007). One study with aims similar to this study was conducted by Savundranayagam & Orange (2011), which examined the effect of specific communication strategies on caregiver burden, when care recipients suffered cognitive decline of Alzheimer's disease. The study revealed that when caregivers appraised their communication strategies as being more effective, the result was lower levels of caregiver stress burden (Savundranayagam & Orange, 2011).

It is clear from interdisciplinary research that communication does have an association with caregiver burden, but the overarching concept of interpersonal communication competence (as opposed to specific communication strategies) has yet to be linked to caregiver burden. Interpersonal communication competence (ICC) is defined as a "person's ability to manage

interpersonal relationships in communication settings” (Rubin & Martin, 1994). Instead of relying on a narrow set of specific strategies, a competent communicator possesses a wide variety of communication skills and uses one appropriately for any given situation. Interpersonal scholars refer to communication competence as the ability to balance appropriateness and effectiveness in order to achieve communication goals (Spitzberg & Cupach, 1984); whereas appropriateness is how well an act or behavior fits within a particular situation (Spitzberg, 1983), and effectiveness refers to whether a behavior is goal-oriented (McCroskey, 1982).

Communication competence enables an individual – or a caregiver – to be flexible and adapt to new relational contexts and situations when necessary (Bochner & Kelly, 1974), and is measured with respect to particular skills such as empathy (feeling with the other and understanding another’s perspective); assertiveness (standing up for one’s rights/self without infringing upon the rights of another); interaction management (ability to manage everyday conversation and ritualistic procedures such as taking turns in conversation); supportiveness (confirming the other); and immediacy (being approachable and available for communication) (Rubin & Martin, 1994).

The review of caregiver burden literature lists a multitude of communication challenges associated with relational changes, decision-making, problem solving, lack of communication, and poor communication patterns due to cognitive decline. Interpersonal communication competence is defined as the skill set to “achieve goals in a prosocial fashion” (Spitzberg & Cupach, 1984, p. 68), yet scant literature seems to link interpersonal communication competence to caregiver burden. To address this gap in the literature, I propose the second hypothesis of this study:

*Hypothesis 2: Higher levels of caregiver interpersonal communication competence will predict lower levels of caregiver burden.*

To examine whether emotional intelligence influences the relationship between interpersonal communication competence and caregiver burden, I pose the first research question of the study:

*Research Question 1: Does emotional intelligence moderate the relationship between interpersonal communication competence and caregiver burden?*

### **Clinical Communication Self-Efficacy**

Clinicians and health care teams typically consider the patient and caregiver as an inseparable dyad who work and communicate together to achieve care and treatment goals (Wilder, Oliver, Demiris, and Washington, 2008). The caregiver's role in the clinical setting is critical to the patient's health outcomes, as caregivers often schedule and manage medical appointments, accompany the patient on visits, communicate medical history and patient preferences, receive instructions about medication and treatment, discuss disease progression, and make decisions regarding nearly every aspect of the patient's care (Wittenberg-Lyles et al., 2012). Several studies have identified physician communication with health care providers as the most frequently reported topic of comments – whether positive, negative, favorable, or unfavorable – from patients and family caregivers who have experienced end of life care (Hanson, Danis, and Garrett, 1997; Shield, Wetle, Teno et al., 2005; Singer, Martin, & Kelner, 1999; Teno, Clarridge, Casey et al., 2004). Results from a study that examined patients' and relatives' complaints about health care revealed several examples of why patients and family caregivers were dissatisfied with clinical communication encounters, including not receiving enough information, not having the option to participate in conversations and decision making,

not given an opportunity to discuss treatment, not given privacy for such discussions, not being addressed in a professional manner (including nonchalance and laughing from the physician), and not receiving support (informational, practical) from the medical staff (Jangland et al., 2009).

Poor communication between physician, patient, and caregiver is problematic and can contribute to caregiver and patient dissatisfaction, anxiety, uncertainty, and distress (Capone and Petrillo, 2014) but the communication breakdown is not solely the responsibility (or fault) of the physician. Patients and caregivers alike also share an obligation to engage, ask questions, and share preferences about treatment and care in order to achieve patient centered care and collaborative decision-making (Politi and Street, 2011). A number of researchers have agreed that quality medical decisions require that decisions are (a) based on the quality of clinical advice, (b) involve the patient's preferences and values, (c) include the patient in the decision-making process to the level of the patient's desire for involvement, and (d) are feasible and reasonable to implement (Elwyn, Edwards, Kinnersley, and Grol, 2000; Epstein & Street, 2007; Sepucha, Ozanne, Silvia, Partridge, & Mulley, Jr, 2007; Politi & Street, 2011).

Extant research establishes that quality patient communication requires involvement of both parties, but what seems scant in the current caregiving literature is examination of how a caregiver's communication self-efficacy plays a role when a caregiver is involved in clinical encounters. Self-efficacy is defined as "the belief about what person can do: it refers to subjective judgements of one's capabilities to organize and execute courses of action to attain designated goals" (Capone & Petrillo, 2014, p. 340). In clinical settings, communication self-efficacy has been identified as a predictor of how likely a patient/caregiver is to initiate communication with a physician (Makoul & Roloff, 1998; Capone & Petrillo, 2014). Self-

efficacy has been investigated broadly in caregiving literature with respect to performing medical tasks, but has received very little attention with respect to communication. Given the abundant reports of dissatisfaction and distress that is attributed to poor communication with physicians, and that caregivers also share a responsibility for agency and participation in order to achieve quality medical decisions, it seems reasonable to believe that the more engaged a caregiver is when communicating with doctors, then the more information and support they will receive which in turn can contribute to less burden. Thus, the third hypothesis and second research question of this study are proposed:

*Hypothesis 3: Caregivers who report higher levels of clinical communication self-efficacy with experience lower levels of caregiver burden.*

*Research Question 2: Does emotional intelligence moderate the relationship between clinical communication self-efficacy and caregiver burden?*

### **Caregiver Communication with Family**

Because of the responsibility for caregivers to accompany patients to medical visits, caregivers possess a large amount of medical information about the patient's condition and are the messengers between medical teams and family members. Similar to the relationship between the caregiver and patient, families are a source of both support and stress for caregivers. Caregivers who seek support from family members must navigate myriad communication transactions while doing so.

When a family member becomes ill, a ripple effect begins that impacts the relationships and lives of the entire family. As prominent end of life scholars Goldsmith and colleagues state, "The inclusion of the family is central to the end-of-life experience for the patient, especially as

the family shares in the illness journey of anxiety, depression, and the numerous losses accompanying critical illness" (Goldsmith, Wittenberg-Lyles, Ragan, and & Nussbaum, 2011). Life span scholars argue that transitions are difficult for families and negatively influence communication among family members. Relationships are strained, uncertainty is high, and conversations become challenging and often confrontational (Knobloch & Theiss, 2011; Solomon, Weber, & Steuber, 2010). Many individuals cope with EOL topics by not seeking or sharing any information at all (Goldsmith et al., 2011), and oftentimes avoid communication about the patient or illness in order to "avoid psychological distress" (Duggan, 2006, p. 99). Conversations pertaining to issues of progressing disease or late-stage cancer are particularly difficult (Zhang & Siminoff, 2003), causing some family members to neglect such conversations altogether.

There are several dyadic and small group contexts to consider when examining the context of caregiving communication within the family. Conversational partners and decision makers include spouse/spouse or partner/partner, parent/child, sibling/sibling, grandparent/grandchild, as well as in-laws, close friends, other family members, and interdisciplinary caregiving teams. Research has shown that one adult child inevitably bears the majority of the caregiving responsibilities (Merrill, 1996; Pillemer & Sutor, 2013; Willyard, et al., 2008), but some of the caregiving duties can be distributed among a network of siblings. Sibling communication is prevalent and complex within the caregiving context. Siblings share information and provide social support to each other during these difficult times, but can also be a source of conflict. Shared caregiving and decision-making presents tensions, relational challenges, and conflict. Disagreement arises among siblings regarding issues such as perceived

parental favoritism, division of labor, illness diagnosis, and care provision (Bourgeois, Beach, Schultz, & Burgio, 1996; Semple, 1992; Sutor, Gilligan, Johnson, & Pillemer, 2013).

Social support is also a family resource that can mitigate caregiver burden (Canary, 2008; Fisher, Kobayashi, & Smith, 2011). Social support is viewed positively within the family caregiving context because of its beneficial association with health outcomes and mental well-being (Goldsmith, 2004). Family caregivers generally need three types of support: instrumental, emotional, and informational. Instrumental support for caregivers includes helping with caregiving tasks, providing respite care, running errands, and providing financial assistance (Stone, 2013; Wittenberg-Lyles et al., 2012). Informational support includes providing educational resources for disease stages, illness management, and information regarding financial management of resources (Stone, 2013; Wittenberg-Lyles et al., 2012). Emotional support includes listening to the caregiver, being available for the caregiver, and providing supportive communication. The caregiver in need of support is generally reliant on a social network of family members, friends, and health care professionals to provide the array of assistance needed (Stone, 2013; Wittenberg-Lyles et al., 2013). Social support for caregivers has been directly linked to the level of burden experienced. Miller et al. (2001) found that lower levels of received caregiver emotional support lead to higher reports of caregiver distress.

Moreover, social support has been found to aid caregiving individuals and relationships with well-being, self-esteem, self-worth, and helping with problem solving (Antonucci & Jackson, 1990; Cutrona & Russell, 1990; Krause, Liange, & Yatomi, 1989; Thoits, 1995). Despite the large amount of literature available that links social support to positive caregiver outcomes, very little literature is available that links caregiver burden to various communication



processes that inevitably occur as the caregiver is *seeking and receiving* social support. The following sections will focus specifically on three communicative behaviors that are likely to occur within the family caregiving context: caregiver disclosure of patient medical information, establishing implicit and explicit privacy rules in order to manage that information, and caregiver reports of experiencing negative interactions with family members while seeking and receiving social support.

This study focuses on three communicative processes in particular within the family caregiver communication context and seeks to explain how disclosure of patient medical information, establishing privacy rules, and negative interactions with family members impact caregivers' perceived level of caregiver burden.

#### *Disclosure of Medical Information*

The benefits of disclosure on health outcomes are well documented in the literature. Disclosure is the act of revealing information to another, and has been linked to physical health, psychological health, and quality of interpersonal relationships (Pennebaker, 1989). Disclosure also builds trust and intimacy among relational partners (Reis & Shaver, 1988) and is recommended as a strategy for improving quality of life and overall well-being (Cameron, Holmes, and Vorauer, 2009). Disclosure is also a mechanism for soliciting or receiving social support from others during a difficult situation – by revealing information that may be emotionally distressing, individuals benefit from counsel, caring, and support from others in response to their disclosure (Laurenceau, Feldman, Barrett, and Pietromonaco, 1998; Laurenceau, Feldman, Barrett, and Rovine, 2005). Family caregivers who accompany their patients to medical visits are often privy to bad news related to the patient's medical condition. Given that this bad news is distressing to the caregiver, it seems warranted

that a caregiver would disclose this information with others in order to (a) process and alleviate the burden of this knowledge and (b) seek a supportive response from whom they have disclosed this information. Despite the logical connection between these two variables, little literature is found that specifically addresses how disclosure of patient's medical information to others may decrease the feelings of caregiver burden. Therefore, I offer the following hypothesis and research question:

*Hypothesis 4: Higher levels of disclosure of medical information to family members will decrease caregiver burden.*

*Research Question 3: Does emotional intelligence moderate the relationship between disclosure and caregiver burden?*

#### *Privacy: Ownership and Rules*

Converse of the notion of disclosure, one area of caregiver communication that seems currently unexplored is how caregivers perceive their ownership of this medical and disease information about the patient, and how they manage that information when choosing to share with other family members. Two important domains of privacy management are Ownership of Information and Privacy rules. Ownership of information refers to the idea that when an individual is privy to a particular piece of information, that he or she "owns" that information and therefore has control over it. As Communication Privacy Management theory posits, "[when] people consider private information something they own, and over which they desire control, they both reveal and conceal the information. Individuals want to be in control because there are risks as to how this information is managed" (Petronio, 2002, p. 9), Privacy rules refer to expectations that are assumed or communicated to others about how they can share that information once they become "co-owners" of that information. Because the caregiver is likely

to accompany the care recipient to physician's appointments, they are not only responsible for managing their "patient" but also responsible for managing the patient's private health information. Once a caregiver/ family member co-owns the private information, he or she will face dilemmas about with whom to share or not to share that information. Individuals who co-own private medical information face several complex privacy decisions and navigate between two intersecting boundary dimensions: (1) the internal sphere, which regulates privacy *within* the family, and (2) the external sphere, which regulates the sharing of information *outside* of the family (Petronio, 2013). The interior boundaries represent how private information is shared or managed between marital partners, parents, children, siblings, and other close family members. Private information within these boundaries may take various forms of confidentiality, including *individual secrets*, which is information kept by only one person, *internal family secrets*, which is information known by at least two family members and kept from others, and *shared family secrets*, which is information known by all members of the family. (Karpel, 1980).

The negotiation of these various circles and secrets are kept in place by privacy rules. Two types of privacy rules exist – (1) *implicit privacy rules*, which are rules inherently known between partners about that information not being shared with others, and (2) *explicit privacy rules*, which a partner will communicate upon disclosure to whom the recipient can share that information, or not at all. Ownership of information is positively related to implicit and explicit privacy rules (Greene & Carpenter, 2016), suggesting that disclosure will decrease as perceived ownership of that information and privacy rules increase. Within the scope of caregiver burden, it seems to follow that an increased feeling of information ownership and tighter rules around privacy would increase caregiver burden. Therefore, I offer the next hypothesis and research question of this study:

*Hypothesis 5: Higher levels of ownership and privacy rules will increase caregiver burden.*

*RQ4: Does emotional intelligence moderate the relationship between privacy and caregiver burden?*

#### *Negative Interactions*

Though social support has been linked to positive effects on caregiver stress, research also reveals that many caregivers perceive some interactions with family members as negative or burdensome. In the family context, social support can become *a source* of stress, which prevents caregivers from interacting with family members (Rodakowski, Skidmore, Rogers, & Schulz, 2012). Primary caregivers avoid conversations and support from family members for a variety of reported reasons. In a study investigating the effect of burdensome social support on caregivers, Wittenberg-Lyles and colleagues (2014) found that there were several negative costs associated with a caregiver seeking, maintaining, and receiving social support, including (1) *perceived relational boundaries* (caregiver not comfortable asking for help because of what it may do to relationship); (2) *being in control* (caregiver wanting to be in total control, resulting in distrust and viewing help as an additional burden); (3) *loss of patient social support* (no longer having the active decision making and social support from the patient and therefore not sure if patient wants additional help), and (4) *family dynamics* (stress and burdens associated with family relationships, including forced co-caring and lack of emotional support). The Wittenberg-Lyles et al. (2014) study strongly suggests that involving and asking for additional support with a patient adds to the level of existing level of stress associated with caregiving and hence many just avoid seeking support altogether.

A caregiver who discloses private medical information about the patient with other family members may in turn receive wanted or unwanted social support. If the social support is

unwanted, then the interaction with family members will likely be perceived by the caregiver as burdensome. To add to the current body of literature and examine whether a link exists between negative interactions and caregiving burden, I offer the following hypothesis and research questions:

*Hypothesis 6: Higher levels of negative interactions with family members will increase caregiver burden.*

*Research Question 5: Does emotional intelligence moderate the relationship between negative interactions and caregiver burden?*

Finally, I examine two other research questions. Of particular interest is the relative importance of the three family communication variables in predicting caregiver burden.

*Research Question 6: Which of the family communication variables (disclosure, privacy, or negative interactions) serve as the strongest predictor of caregiver burden?*

Because each caregiving situation is unique and challenging, it seems warranted to take an iterative approach to this topic and allow for challenges to emerge from our participants. To add contextual richness to the study and examine unique, additional stressors that may contribute to caregiver burden, and reveal potential paths for future research, we pose a final, exploratory research question of this study:

*Research Question 7: What unique characteristics or experiences in caregiving have yet to be examined by communication researchers that can be improved in areas of family, clinical, interpersonal, or intervention contexts?*

## CHAPTER II

### METHOD

#### **Participant Recruitment**

Participants for this study were recruited via social media to the researcher's personal contacts and posts on caregiver support forums. The targeted number of participants was 300. Inclusion criteria included adults aged 18 years or older who are currently providing care for a family member or friend at least 20 hours per week. Caregiver tasks may include assisting with (a) Activities of Daily Living [ADLs], such as bathing, eating, toileting, or dressing and (b) Instrumental Activities of Daily Living [IADLs] such as housekeeping, managing finances. Once IRB approval was received to begin collecting data, the first step was to post the Qualtrics survey link on the researcher's personal Facebook page, with an accompanying message that asked personal friends to take the survey if they fit the criteria, or to share the link on their personal pages with friends or family members who may qualify. The post was also shared on the Texas A&M University Communication Graduate Students Facebook group, asking colleagues to share the link, as this was data collection portion of dissertation study. Finally, the survey link and post was shared on two Caregiver Support Facebook groups, one of which had approximately 11,000 followers.

#### **Procedure**

All subjects were invited to participate in the online survey administered through Qualtrics. The survey was distributed via social media on the researcher's personal page, which included a request to share with those who fit the criteria of caring for someone at least 20 hours per week. Respondents were offered a compensation for completing the survey, in the form of a \$10 Amazon electronic gift card that was delivered electronically to the recipient. Participants

who wished to receive an electronic gift card from Amazon were asked to email the completion code that is randomly generated to [tamucaregiverstudy@gmail.com](mailto:tamucaregiverstudy@gmail.com). Upon receipt of that code, the researcher replied with the code for compensation of completing the study. The study was reviewed and approved through the Institutional Review Board of Texas A&M University.

### **Measures**

Demographic and caregiving context measures. In the demographic section, respondents were asked to provide demographic information such as age, sex, race, education, employment status, and income level. Respondents were also be asked to provide non-identifying and non-medical information about the care recipient, such as whether the care recipient is a spouse, child, parent, other relative, or friend/non family member. Participants were also asked about how many hours per week they spend providing care, as well as which specific Activities of Daily Living (bathing, feeding, dressing, etc.) and Instrumental Activities of Daily Living (managing finances, grocery shopping, etc.). Participants were asked to provide additional information with regard to their caregiving duties, including:

- how long they have been providing care to the relative;
- whether anyone else is helping them provide care; and
- whether the health condition of the relative is chronic or acute.

For a complete overview of the demographic and caregiving items measured in this study, please see Appendix A.

### *Caregiver Burden*

To measure caregiver burden, respondents answered questions adapted from the short version of the Zarit Burden Interview (ZBI, Zarit, Orr, & Zarit, 1985), which consists of 12 items ( $\alpha = .92$ ) (Bedard et al., 2001). Items from the shortened ZBI (Appendix A) were presented and

respondents will be instructed to indicate the frequency with which they believe they agree with each of the items presented on a 5-point Likert-type scale with 1= “never”, 2= “rarely” 3 = “sometimes”, 4 = “quite frequently”, and 5 = “nearly always” Example items from the Zarit Burden Interview include “Do you feel that because of the time you spend with your [patient] that you don’t have enough time for yourself?”, “Do you feel angry when you’re around your [patient]?”, “Do you feel that your health has suffered because of your involvement with your patient?”, and “Do you feel that your social life has suffered because you are caring for your relative?” Appropriate items were reversed when cleaning data, and lower scores for CGB in the results indicate a lower level of caregiver burden.

### *Emotional Intelligence*

To measure caregiver’s emotional intelligence, respondents will answer questions adapted from the Trait Emotional Intelligence Questionnaire- Short Form (Petrides & Furnham, 2006), a 30-item questionnaire ( $\alpha = .78$ ). Items were presented and respondents were be instructed to indicate the level with which they agree with each statement on a 5-point Likert-type scale with 1= “strongly disagree”, 2 = “disagree”, 3 = ‘neither agree nor disagree’, 4 = “agree”, and 5 = “strongly agree”. Examples of items include “I’m usually able to control my emotions when I want to”. For a complete overview of the Trait Emotional Intelligence Questionnaire- Short Form (Petrides & Furnham, 2006), please see Appendix A.

### *Interpersonal Communication Competence*

To measure caregiver’s perceptions of their interpersonal communication competence, respondents answered questions adapted from the Interpersonal Communication Competence Scale (Rubin & Martin, 1994). The measure taps into different dimensions of competence including empathy, assertiveness, interaction management, supportiveness, immediacy, and



environmental control. Only 8 of the 30 items of the ICC scale were included in the survey ( $\alpha = .71$ ), which represented the subscales of empathy, assertiveness, interaction management, and environmental control. Respondents were instructed to indicate the frequency with which they communicate in agreement with each statement on a 5-point Likert-type scale with 1 = "almost never", 2 = "seldom", 3 = "sometimes", 4 = "often", and 5 = "almost always". Examples of items include: "I allow friends to see who I really am", "I am comfortable in social situations", and "In conversations with friends, I perceive not only what they say but also what they do not say" (see Appendix A for ICC items used in the survey). Appropriate items were reversed when cleaning data, and lower scores for ICC in the results indicate a lower level of interpersonal communication competence.

#### *Clinical Communication Self-Efficacy*

To measure caregiver's communication self-efficacy with healthcare providers, respondents answered questions adapted from the Patient's Communication Perceived Self-Efficacy Scale (PCSS, Capone & Petrillo, 2014), which consists of 12 total items ( $\alpha = .77$ ) assessing abilities to provide and collect information, express concerns and doubts, and verify information when interacting with clinicians. Respondents were instructed to indicate the level which they agree with each statement on a 5-point Likert-type scale with 1 = "strongly disagree", 2 = "disagree", 3 = "neither agree nor disagree", 4 = "agree", and 5 = "strongly agree". Since caregivers are often present at medical appointments for the patients, items from this measure were adapted to indicate that the caregiver's self-efficacy in communicating with clinicians. Sample items from the *provide and collect information* subscale include "I can ask my patient's doctor to explain a new and complicated therapy in a simple way" and "I can tell my patient's doctor what my patient liked/disliked about the treatment". Example items from the *express*

*concerns and doubts* subscale include “I can claim my patient’s doctor’s attention if he/she looks distracted” and “I can express my disagreement to the doctor who behaves arrogantly.” Example items from the *verify information* subscale include “I can repeat in my own words to the doctor the information he/she just gave to me” and “I can express my perplexity when my doctor speaks to me about the course of my patient’s disease with long words”. Appropriate items were reversed when cleaning data, and lower scores for PCC in the results indicate a lower level of clinical communication self-efficacy.

### *Disclosure of Medical Information*

To measure caregiver’s depth, breadth, and frequency of disclosure about patient medical information, respondents answered questions adapted from the Patterns of Disclosure about a Health Condition (PDHC, Checton and Greene, 2012). The PDHC is a 12-item self-report measure ( $\alpha = .64$ ) that assesses patterns of disclosure of health information along dimensions of breadth, depth, and frequency of disclosing health information with family. Each dimension consisted of 4 items and the individual items were adapted to fit the caregiving context. For example, questions that originally read “ I discuss a wide variety of issues about my health condition” were adjusted to read “I discuss a wide variety of issues about my patient’s health condition” Items from each subscale were presented and respondents were instructed to indicate the level with which they agree with each statement on a 5-point Likert-type scale with 1=“strongly disagree”, 2 = “disagree”, 3 = ‘neither agree nor disagree’, 4 = “agree”, and 5 = “strongly agree”. Examples of items on the PDHC include “I discuss a wide variety of issues about [my patient’s] health condition” and “There are some areas related to [my patient’s] health condition that I avoid discussing. For a complete overview of the Patterns of Disclosure about a Health Condition measure (PDHC, Checton and Greene, 2012), please see Appendix A.

### *Privacy: Ownership and Rules*

To measure the extent with which a caregiver feels as though he/she owns their patient's information, and establishes implicit or explicit privacy rules for the management of that information, we used the Venetis et al. (2012) Privacy Rule measure. This tool is a 10-item measure ( $\alpha = .69$ ) that assesses perception of ownership (2 items), explicit privacy rules (6 items) and implicit privacy rules (2 items). Items from all three dimensions were presented and respondents were instructed to indicate the level with which they agree with each statement on a 5-point Likert-type scale with 1 = "strongly disagree", 2 = "disagree", 3 = "neither agree nor disagree", 4 = "agree", and 5 = "strongly agree". Example items from the Privacy Rules measure include "I feel that I 'own' [my patient's] health information" (perception of ownership), "After I shared the health information with this person, I asked him/her not to share the information with anyone" (explicit privacy rules), and "Although I did not ask this person not to, s/he knows not to tell others" (implicit privacy rules). For a complete overview of the Privacy Rules (Venetis et al., 2012) measure, please see Appendix A.

### *Negative Interactions*

To measure negative interactions with caregiver's family members, we adapted items from the Social Support Behavior Code (Cutrona & Suhr, 1992) and included six items in the survey ( $\alpha = .85$ ). Items were presented and respondents were instructed to indicate the level with which they agree with each statement on a 5-point Likert-type scale with 1 = "strongly disagree", 2 = "disagree", 3 = "neither agree nor disagree", 4 = "agree", and 5 = "strongly agree". Examples of items measuring negative interactions include statements such as "When I am seeking support from my family members, they are often sarcastic with me when we are discussing my care recipient", and "When I am seeking support from my family members, they

often criticize me when we are discussing my care recipient”. For a complete overview of the adapted Negative Interactions measure, please see Appendix A.

### *Unique Caregiver Experiences and Challenges*

To gather data regarding unique challenges or experiences, the survey contained a short series of questions which asked the respondent to comment on their biggest challenges of caregiving. Questions for this portion of the study included:

1. What are some of your most difficult challenges as a caregiver?
2. What caregiving events and tasks did you feel that you were prepared for?
3. What caregiving events and tasks were surprises for you?
4. Please share some final thoughts with us. Every caregiving situation is unique. Will you please share a story, and example, or an anecdote about your caregiving experience that illustrates what is unique and special about your situation?

## **Data Analysis**

### *Quantitative Analysis*

Descriptive statistics (mean, standard deviation, median and range for continuous variables, frequency and percentage for categorical variables) were used to summarize caregiver demographics (age, gender, income, etc.) and caregiving context characteristics (relation to patient, chronic or acute condition, length of time providing care). Bivariate correlation analysis were run to determine if significant relationships existed among demographic or caregiver characteristics with the communication variables and caregiver burden outcome variable to identify potential covariates that needed to be controlled in regression analysis. Variables that were significant at the  $p < .05$  were kept in the final models.

Each of the control variables were entered into step one of the regression analysis as covariates. For Hypothesis 1, which examined whether higher levels of emotional intelligence predicted caregiver burden, a mean-centered emotional intelligence variable was added in step two. For the remainder of the hypotheses (hypotheses 2-6), which stated that communication variables would predict higher or lower levels of caregiver burden, only the single specific mean-centered communication variable was included in step 2. These included, respectively, interpersonal communication competence, clinical communication self-efficacy, disclosure, privacy, and negative interactions. To answer research questions 1-5, which questioned whether emotional intelligence moderates the relationships between communication variables and caregiver burden, step 3 involved adding the mean-centered emotional intelligence variable and also adding the interaction term of [communication variable] X emotional intelligence. To answer research question 6, a regression test was run with step two containing three of the family variables (disclosure, privacy, and negative interactions) to determine which of the three variables served as the strongest predictor of caregiver burden.

### *Qualitative Analysis*

Data for the exploratory, qualitative component of this study was collected via Qualtrics in the form of open-ended questions at the end of the survey. The data was isolated from the quantitative results and exported in to an excel spreadsheet in order to clean up the data. After removing responses that simply included “No” or N/A, the author printed the spreadsheet for analysis, which amounted to 24 pages of 9-point font data. A total of 230 participants provided analyzable responses.

The analysis of the data was performed solely by the researcher, who performed several series of manual coding operations and created multiple visual displays during the data immersion phase of analysis. Categories, themes, and subthemes were identified and defined as they emerged, utilizing the constant-comparative method and approach (Lincoln & Guba, 1985). Moreover, the researcher maintained phronetic, iterative approach to analyzing the data (Tracy, 2013), which enabled reflection and refinement of identified themes as the data is continually visited and revisited using the constant comparative method

The content analysis of the qualitative responses was conducted in two steps. First, the author reviewed and color-coded all responses with respect to the three communicative ecology themes that were examined in the quantitative portion: (1) interpersonal communication with the patient, (2) clinical communication with physicians and medical teams, and (3) communication with family members. Once the responses were coded into the three primary ecological categories, a subsequent content analysis was then performed to glean any additional themes emerged extraneous of the primary categories. For more examples of participant responses categorized by communicative ecology variable, see Table B14. After identifying responses that aligned with the three primary themes, the author examined the data again in order to identify additional themes that emerged from the responses which were more specifically categorized. The author scoured the responses and manually color coded once themes began to emerge. During the secondary stage of content analysis, four additional categories were identified: (1) Lack of support from family; (2) Importance of [caregiver] self-care, (3) Duty to family, and (4) Disparities in medical skills training.

## CHAPTER III

### QUANTITATIVE RESULTS

#### Caregiver Characteristics

The final sample consisted of 302 participants, ( $M_{\text{age}} = 34.6$  years, age range 23-67 years), the majority of which served as the sole, primary caregiver ( $n = 188$ , 62%). Characteristics of the sample are included in Table B1. Most participants were female ( $n = 202$ , male  $n = 100$ ), Caucasian ( $n = 167$ , Hispanic  $n = 76$ , African American  $n = 29$ , Other  $n = 30$ ). Most of the participants had a college degree or had attended some college (four-year degree  $n = 113$ , master's degree  $n = 21$ , doctoral degree  $n = 6$ , two-year degree  $n = 79$ , some college  $n = 64$ , HS diploma/ GED  $n = 13$ , did not graduate HS  $n = 6$ ). Additionally, most of the participants were employed full-time ( $n = 158$ , part-time  $n = 79$ , unemployed  $n = 50$ , student  $n = 6$ , "other  $n = 9$ ). Annual income of participants was less than \$30,000 ( $n = 13$ ), \$30,001 - \$49,999 ( $n = 42$ ), \$50,000 - \$74,999 ( $n = 80$ ), \$75,000 - \$99,999 ( $n = 99$ ), \$100,000 or more ( $n = 68$ ).

Some caregivers shared duties with only one other person ( $n = 80$ ), and a small amount split the caregiving duties with two or more others ( $n = 34$ ). Most of the participants provided care for less than 40 hours per week ( $n = 276$ ; more than 40 hours per week,  $n = 26$ ).

Approximately two-thirds of the participants reported providing care for an individual with an acute condition (a short-term, treatable, curable disease,  $n = 194$ ), as opposed to chronic (a long-term condition, often not curable,  $n = 108$ ). Nearly 75% of respondents had cared for their patient for a year or less ( $n = 223$ ; 12-24 months,  $n = 53$ ; more than 24 months,  $n = 26$ ). An overview of the caregiver characteristics are provided in Table B2.

Means and standard deviations for the EQ and communication variables are reported in Table B3. Because EQ was skewed toward the high, the EQ variables was recoded as “high” at 3.1 and above and “low” below 3.1 for subsequent analyses.

### **Covariates Related to Caregiver Burden**

Tables B4, B5, and B6 present correlations among the variables used in the study. Covariates included in the regression models predicting caregiver burden included (number in parentheses represent the correlation between that measure and caregiver burden) relationship of patient to caregiver [REL\_NEW] ( $p < .001$ ); Sharing caregiving duties with another [CareShare],  $p < .001$ ); time per week spent caregiving [CareTime], ( $p < .001$ ); condition of patient, whether acute or chronic [Condition], ( $p < .001$ ); length of caregiving in months [CareLength],  $p < .001$ ); employment,  $p < .001$ ); and income, ( $p < .01$ ).

Several bivariate relationships existed between communication variables and caregiver burden as well. Emotional intelligence, clinical communication self-efficacy, and disclosure were all significantly negatively correlated with caregiver burden ( $p < .01$ ), while interpersonal communication competence and negative interactions were significantly positively correlated with caregiver burden (Table B6).

### **Multiple Regression Analysis**

#### *Caregiver Context and Emotional Intelligence*

Hypothesis 1 predicted that high levels of emotional intelligence would decrease caregiver burden. To test this hypothesis, a hierarchical regression analysis was run with relationship to patient [REL\_NEW], sharing caregiving duties with another [CareShare], time per week spent caregiving [CareTime], condition of patient [Condition], length of caregiving [CareLength], employment, and income as controls in step 1. Emotional intelligence was added



in step 2. The model was significant in step 1 (adjusted  $R^2 = .31$ ,  $F(7, 294) = 20.06$ ,  $p < .001$ ) with significant covariates including CareShare, ( $p < .001$ ); Condition, ( $p < .001$ ); and CareLength ( $p < .001$ ), and Employment, ( $p = .013$ ). The model was also significant in step 2 (adjusted  $R^2 = .39$ ,  $F(8, 293) = 25.19$ ,  $p < .001$ ). Emotional intelligence emerged as a significant predictor in step 2, ( $\beta = -.32$ ,  $p < .001$ ), and thus hypothesis 1 is supported. Model statistics for all tests of H1 can be found in Table B7.

### *Interpersonal Communication Competence*

Hypothesis 2 stated that higher levels of caregiver interpersonal communication competence would predict decreased caregiver burden. Research question 2 asked whether this effect would be moderated by emotional intelligence. To test this hypothesis, a hierarchical regression analysis was run with covariate controls in step 1. Interpersonal communication competence was entered in step 2. To test the research question, emotional intelligence and the interaction term of emotional intelligence X interpersonal communication competence was entered in step 3. The model was significant in all three steps. Introducing the interpersonal communication competence variable to the controls in step 2 explained an additional 24% of the variance (in adjusted  $R^2 = .55$ ,  $F(8, 293) = 47.72$ ,  $p < .001$ ), and the change in  $R^2$  was significant ( $\Delta R^2 = .24$ ,  $F(8, 293) = 47.72$ ,  $p < .001$ ). However, contrary to predictions, the coefficient was positive ( $\beta = .53$ ) indicating that higher levels of interpersonal communication competence predict *higher* levels of caregiver burden, thus Hypothesis 2 is not supported. RQ1 asked if emotional intelligence will moderate the relationship between interpersonal communication competence and caregiver burden. The interaction term, emotional intelligence X interpersonal communication competence, was significant in step 3 ( $\beta = -.27$ ,  $p < .001$ ), indicating that emotional intelligence does moderate the relationship between interpersonal communication

competence and caregiver burden, and that emotional intelligence dampens the positive relationship between interpersonal communication competence and caregiver burden (Figure C2). Model statistics for all tests of H2 and RQ1 can be found in Table B8.

### *Clinical Communication Self-Efficacy*

Hypothesis 3 stated that higher levels of clinical communication self-efficacy would predict lower levels of caregiver burden. Research question 2 asked whether this relationship would be moderated by emotional intelligence. To test this hypothesis, a hierarchical regression analysis was run with covariate controls in step 1. Clinical communication self-efficacy was entered in step 2. To test the research question, emotional intelligence and the interaction term of emotional intelligence X clinical communication self efficacy was entered in step 3. The model was significant in all three steps. Introducing the clinical communication self-efficacy variable to the controls in step 2 explained an additional 1.6% of the variance (in adjusted  $R^2 = .32$ ,  $F(8, 293) = 18.83$ ,  $p < .001$ ), and the change in  $R^2$  was significant ( $\Delta R^2 = .016$ ,  $F(8, 293) = 18.83$ ,  $p < .001$ ). Clinical communication self-efficacy emerged as a significant predictor in step 2 ( $\beta = -.14$ ,  $p = .008$ ), indicating that higher levels of clinical communication self-efficacy does decrease caregiver burden and thus hypothesis 3 is supported. RQ2 asked if emotional intelligence will moderate the relationship between clinical communication self-efficacy and caregiver burden. The interaction term, emotional intelligence X clinical communication self-efficacy was significant in step 3 ( $\beta = -.12$ ,  $p = .012$ ), indicating that emotional intelligence does moderate the relationship between clinical communication self-efficacy and caregiver burden, and that emotional intelligence strengthens the negative relationship between clinical communication self-efficacy and caregiver burden (Figure C3). Model statistics for all tests of H3 and RQ2 can be found in Table B9.

### *Disclosure of Medical Information*

Hypothesis 4 stated that higher levels of caregiver disclosure of patient medical information would predict lower levels of caregiver burden. Research question 3 asked whether this relationship would be moderated by emotional intelligence. To test this hypothesis, a hierarchical regression analysis was run with covariate controls in step 1. Caregiver disclosure of medical information was entered in step 2. To test the research question, emotional intelligence and the interaction term of emotional intelligence X disclosure of medical information was entered in step 3. The model was significant in all three steps. Introducing the disclosure variable to the controls in step 2 explained an additional 3.9% of the variance (in adjusted  $R^2 = .35$ ,  $F(8, 293) = 20.82$ ,  $p < .001$ ), and the change in  $R^2$  was significant ( $\Delta R^2 = .039$ ,  $F(8, 293) = 20.82$ ,  $p < .001$ ). Disclosure emerged as a significant predictor in step 2 ( $\beta = -.22$ ,  $p < .001$ ), indicating that higher levels of disclosure of patient medical information does decrease caregiver burden and thus hypothesis 4 is supported. RQ3 asked if emotional intelligence will moderate the relationship between clinical communication self-efficacy and caregiver burden. The interaction term, emotional intelligence X clinical communication self-efficacy was not significant in step 3 ( $\beta = -.03$ ,  $p = .84$ ), indicating that emotional intelligence does not moderate the relationship between disclosure of patient medical information and caregiver burden. Model statistics for all tests of H4 and RQ3 can be found in Table B10.

### *Privacy ownership and rules*

Hypothesis 5 stated that higher levels of caregiver ownership of information and privacy rules regarding that information would predict higher levels of caregiver burden. Research question 4 asked whether this relationship would be moderated by emotional intelligence. To

test this hypothesis, a hierarchical regression analysis was run with covariate controls in step 1. The ownership and privacy rules variable was entered in step 2. To test the research question, emotional intelligence and the interaction term of emotional intelligence X ownership and privacy rules was entered in step 3. The model was significant in all three steps. Introducing the privacy variable to the controls in step 2 explained an additional 1% of the variance (in adjusted  $R^2 = .31$ ,  $F(8, 293) = 18.30$ ,  $p < .001$ ), and the change in  $R^2$  was significant ( $\Delta R^2 = .01$ ,  $F(8, 293) = 18.30$ ,  $p < .001$ ). The privacy variable emerged as a significant predictor in step 2 ( $\beta = .104$ ,  $p = .037$ ), indicating that higher levels of ownership and privacy rules does increase caregiver burden and thus hypothesis 5 is supported. RQ4 asked if emotional intelligence will moderate the relationship between the privacy variable and caregiver burden. The interaction term, emotional intelligence X privacy was not significant in step 3 ( $\beta = -.16$ ,  $p = .27$ ), indicating that emotional intelligence does not moderate the relationship between ownership and privacy rules and caregiver burden. Model statistics for all tests of H5 and RQ4 can be found in Table B11.

#### *Negative interactions*

Hypothesis 6 stated that higher levels of negative interactions with family members would predict higher levels of caregiver burden. Research question 5 asked whether this relationship would be moderated by emotional intelligence. To test this hypothesis, a hierarchical regression analysis was run with covariate controls in step 1. The negative interaction variable was entered in step 2. To test the research question, emotional intelligence and the interaction term of emotional intelligence X negative interactions was entered in step 3. The model was significant in all three steps. Introducing the negative interaction variable to the controls in step 2 explained an additional 10% of the variance (in adjusted  $R^2 = .42$ ,  $F(8, 293) =$

27.87,  $p < .001$ ), and the change in  $R^2$  was significant ( $\Delta R^2 = .10$ ,  $F(8, 293) = 27.87$ ,  $p < .001$ ).

The negative interaction variable emerged as a significant predictor in step 2 ( $\beta = .36$ ,  $p < .001$ ), indicating that higher levels of negative interactions does increase caregiver burden and thus hypothesis 6 is supported. RQ4 asked if emotional intelligence will moderate the relationship between the negative interaction variable and caregiver burden. The interaction term, emotional intelligence X negative interactions was not significant in step 3 ( $\beta = -.18$ ,  $p = .09$ ), indicating that emotional intelligence does not moderate the relationship between negative interactions and caregiver burden. Model statistics for all tests of H6 and RQ5 can be found in Table B12.

RQ6 asked which of the family communication variables, disclosure, privacy rules, or negative interactions with family members, would have the strongest relationship or serve as the greatest predictor of caregiver burden. To test this research question, a hierarchical regression analysis was run with covariate controls in step 1. The three family communication variables, disclosure, privacy, and negative interactions were entered in step 2. The model was significant in both steps. The negative interaction variable emerged as the most significant predictor in step 2 ( $\beta = .32$ ,  $p < .001$ ), followed by disclosure ( $\beta = -.315$ ,  $p = .003$ ). Model statistics for all tests of RQ6 can be found in Table B13.

## CHAPTER IV

### QUALITATIVE RESULTS

RQ7 asked if any unique characteristics or experiences in caregiving have yet to be examined by communication researchers that can be improved in areas of family and clinical, communication contexts. A short series on the survey asked the following four questions: (1) What are your most difficult challenges as a caregiver? (2) What tasks were you most prepared for? (3) What surprised you? (4) Please share a unique experience or tell us about your caregiving situation. A total of 230 participants provided analyzable responses (i.e., answered the question with responses other than ‘No’ or ‘N/A’).

The thematic analysis of the qualitative responses was conducted in two steps. First, I reviewed and color-coded all responses with respect to the three communicative ecology themes that were examined in the quantitative portion: (1) interpersonal communication with the patient, (2) clinical communication with physicians and medical teams, and (3) communication with family members. I coded 65 examples of interpersonal communication with the patient, 39 examples of clinical communication content, and 54 examples of communication with the family. Examples of the interpersonal communication with patient responses revealed various challenges that caregivers experiences with their patients, and included comments such as, “It is very important to treat my mom as an adult, she is 85 and often acts like a child. I try to remember to allow her to make her own decisions, just manage the outcomes.” Many caregivers commented on the mood and temperament of their patients with comments such as, “The patient is too demanding and difficult to cope with”, and “My mother in law cries if I go out without her and when I return she refuses to speak with me”.

Clinical communication was mentioned 39 times; examples of clinical communication responses include, "My mom was diagnosed with multiple myeloma and it deposited in her kidneys causing them to fail. I am not trained to perform hemodialysis at home", and "I want to know more about the patient's psychology in the future, so it is good for better treatment". Communication with family members was mentioned 54 times; examples family communication responses included "[I wish I knew more about] keys to sibling harmony with caring for parents", and "I'm not giving all [medical] details because I want to protect [patient's] privacy, and I think they would start to treat him differently". Once the responses were coded into the three primary ecological categories, a subsequent content analysis was then performed to glean any additional themes emerged extraneous of the primary categories. For more examples of participant responses categorized by communicative ecology variable, see Table B11.

During the secondary stage of content analysis, four additional categories were identified: (1) Lack of support from family; (2) Importance of [caregiver] self-care, (3) Duty to family, and (4) Disparities in Medical Skills Training.

### **Lack of Support from Family**

Examples of failure of others include responses such as "siblings are the worst and are selfish and "a general lack of support from other family members." One subset of this category that emerged was that several caregivers mentioned that their patient had been in the care of someone else who had either (a) neglected the symptoms of physical or cognitive decline and/or (b) did not have the resources to take care of that patient. As one respondent pointed out, "This is ridiculous, but no one in the family, except me, will face the fact that my stepfather is suffering from Alzheimer's" and "My friend just died prematurely and alone because her spouse was incompetent. He ignored physical symptoms she had and did not

get medical care for her until she was critically ill. I urged him for a month to take her to a physician. Others did, as well”. The responses of this nature seemed to suggest that many caregivers experienced frustration and distress when family members do not recognize or understand that patient is suffering from cognitive decline or an otherwise deteriorating health condition.

### **Importance of [Caregiver] Self-Care**

Examples of the Self-Care theme include responses such as “Rest is very important. A caregiver should try to rest when his or her patient is sleeping or watching TV. We must remain patient”, “get help and receive help in whatever form it arrives”, and “Keep a part of yourself. You “give up so much but try to keep something that is just about you- a hobby, an interest, a friendship.” The notion of self-care was not just represented positively in all cases, however. The caregiver responses also included dozens of examples of "I am so tired", "I do not get enough sleep", " I am losing weight / getting thinner" and "I am having suicidal thoughts". The range of responses indicated that many caregivers were suffering from the stresses of caregiving, while many others were aware of the positive benefits of coping mechanisms and self-care.

### **Duty to Family**

Examples of the duty theme include statements such as “It is my duty to take care of my husband”, “It is my duty to take care of my parents, they took care of me when I was a child” and “Take care of each other, that is what I need to do. My child will learn from me”, and “I love to take care of my wife. It’s my duty”. Most of the responses evoked a theme multi-generational piety that seemed to be a tradition in the family: parents take care of young children, children take care of aging parents, grandchildren learn from parents and grandparents what is expected in the family.



### **Disparities in Medical Training**

Examples of this category include statements such as “caregivers are also left with performing professional duties without the requisite skills”, “How invisible and unsupported [caregiving] is”, “How utterly screwed up the health care system is”, and “Caregivers often don’t get the help they need. And that’s because getting outside help is expensive, hard to find, and hard to arrange”. These responses seemed to suggest an overwhelming need for training, education, and support, which will be further addressed in the following discussion section.

## CHAPTER V

### DISCUSSION AND LIMITATIONS

This study examined the relationships between communication and caregiver burden, and the effect of emotional intelligence as a both a predictor of caregiver burden and a moderator of communication-caregiver burden relationships. Several noteworthy results were found in this study, which have practical implications for future research, clinical training, and caregiver interventions.

#### **Discussion**

##### *Emotional Intelligence*

Hypothesis 1 predicted that emotional intelligence would decrease caregiver burden. Results from our analysis revealed that higher levels of emotional intelligence predict lower levels of caregiver burden, as we predicted. Emotional intelligence is defined as “a subset of social intelligence that involves the ability to monitor one’s own and others’ feelings and emotions, to discriminate among them and to use this information to guide one’s thinking and actions” (Mayer and Salovey, 1990, p. 188). Our findings align with existing literature that links emotional intelligence to positive communication skills and outcomes, including the link between trait emotional intelligence, conflict communication patterns, and relationship satisfaction (Smith, Heaven, and Ciarrochi, 2008); the role of emotional intelligence in building interpersonal skills (Petrovici & Dobrescu, 2014), and how nurses use emotional intelligence in conflict management strategies (Basogul & Ozgur, 2016). The current study adds to this body of research by establishing a direct link between trait emotional intelligence as a predictor of reduced caregiver burden. There are several implications for this finding. First, it offers an avenue for interdisciplinary research for communication scholars who are interested in the

psychosocial aspects of caregiving. Second, it provides an additional area of training in caregiver intervention programs that are not found to be currently offered. Many caregiver intervention trainings focus on managing expectations for caregiving, but it seems that no training or assessment currently exist that include the element of emotional intelligence.

### *Interpersonal Communication Competence*

Interpersonal communication competence is defined as the ability to balance appropriateness and effectiveness in order to achieve communication goals (Spitzberg & Cupach, 1984). Communication competence is thought to empower an individual to be flexible and adapt to new relational context and situations, and is constructed with respect to specific communicative skills such as empathy, assertiveness, interaction management, supportiveness, and immediacy (Rubin & Martin, 1994). Hypothesis two predicted that interpersonal communication competence would be negatively related to caregiver burden. Our results indicated the opposite – that interpersonal competence predicts higher levels of caregiver burden. We posed this hypothesis based on previous literature which (a) linked specific communication interactions to caregiver burden, such as decision making, conflict resolution, conversation management (cite), and (b) linked specific communication skills and deficiencies to caregiver burden such as lack of communication between patient and caregiver and using focused communication strategies with patients who suffer from cognitive decline (cite).

One potential explanation of this finding may relate to the level of expectation and sensitivity that a caregiver may possess for accomplishing communicative goals for a patient. In other words, if a caregiver with high interpersonal communication competence is accustomed to achieving communication goals, and expects to do so in a caregiving situation, then not accomplishing these goals may in turn lead to caregiver burden. The qualitative results

mentioning interpersonal communication between the caregiver and patient also speak to these burdensome interactions. Interpersonal mentions dominated the results, and caregivers seemed overwhelmingly distressed by the communication environment with their patients. One respondent commented that the most distressing aspect of caregiving was “especially dealing with the altered perceptions of reality that my mom experiences and her interactions with other people (thinking people stole from her, violent outbursts, etc.).” Comments like this suggest that the declining nature of the interpersonal communication between the patient and caregiver is not the only distressor – caregivers are also burdened by observing their patient or loved one have troublesome communication events with others. Because this finding is opposite the prediction, further investigations should seek to replicate these findings and be tuned to explore reasons why higher levels of communication competence lead to higher levels of caregiver burden.

#### *Clinical Communication Self-Efficacy*

Hypothesis three predicted that higher levels of clinical communication self-efficacy would relate to lower levels of caregiver burden. Self-efficacy is “the belief about what a person can do: it refers to subjective judgements of one’s capabilities to organize and execute courses of actions to obtain designated goals” (Capone & Petrillo, 2014, p. 340). The results from data analysis revealed a statistically significant association between clinical communication self-efficacy and caregiver burden.

This hypothesis was posed to address a gap in the existing literature that linked poor communication with physicians and caregiver/patient distress (Capone and Petrillo, 2014), as well as research that supports the need for patients and caregivers to engage and possess more agency in the clinical setting to achieve patient-centered care and collaborative decision making (Makoul & Roloff, 1998; Capone & Petrillo, 2014). What this study adds to the literature is the

revelation that a specific communication skill, clinical communication self-efficacy, can decrease caregiver burden. Clinical communication self-efficacy is constructed of several specific skills such as providing and collecting information during clinical encounters, expressing concerns and doubts, and verifying information with the physician (Capone & Petrillo, 2014). This finding has implications for caregivers, clinicians, and caregiver researchers and training programs alike – by highlighting the importance for more engagement and question asking on the part of the caregiver in order to achieve communication goals in the clinical setting and thus decreasing caregiver burden. Additional skills associated with clinical self-efficacy and high-quality communication with doctors within the literature include (1) information giving –or participating in conversations with doctors in order to reveal information and make shared decisions (Frederikson, 1995); (2) Listening to the doctor – and to ensure that the patient/caregiver truly understands the information that is being relayed about the condition and disease progression of the patient (Cegala, McClure, Marinelli, & Post, 2000; Street, Gorden, & Haidet, 2007; Lipkin, Putname, & Lazare, 1995); and (3) construction and maintenance of the relationship – in which the patient/ caregiver is responsible for building trust and ensuring honesty with the doctor in order to establish and maintain a positive working relationship (Leckie, Bull, & Vrij, 2006). It is clear that the caregiver’s ability to communicate with medical teams is necessary in order to provide higher quality care for the patient. Several of the qualitative responses spoke to this end as well, mentioning that increased knowledge about the disease process would help them to understand how to better care for their patient. Future studies in the caregiver and clinical communication realm could inform caregiver trainings and interventions that specifically teach clinical communication skills, in addition to the emotional and medical skills training that are oft provided in caregiver educational programs.

### *Family Communication*

This study predicted that communicative behaviors that occur within the processes of seeking and receiving social support would relate to caregiver burden. Specifically, we predicted that caregiver disclosure of patient's medical information would decrease caregiver burden, whereas increased ownership and privacy rules around that information would increase caregiver burden. We also predicted that increased negative interactions with family members would increase caregiver burden. As expected, all of our results supported the hypotheses. The finding that disclosure of patient's medical information would decrease caregiver burden falls in line with existing literature that links disclosure to increased social support, whereas social support is widely documented to decrease caregiver burden. The findings from this study add to the literature and offer a unique view on the role of medical disclosure in decreasing caregiver burden.

The implications of this finding could inform future research which focuses on interventions for caregivers. Given that disclosure builds trust and intimacy among relational partners (Holmes, 1991; Reis & Shaver, 1988), and that caregivers are likely experiencing loss as the health and/or cognitive ability of their patient is declining, disclosure of distressing information to a loved one or family member could be particularly beneficial to caregivers who are losing their primary confidant to disease. The findings from this study also support the notion that disclosure is a recommended strategy for improving quality of life and overall well-being (Cameron, Holmes, and Vorauer, 2009). It should be noted that over half of our survey responses were received in the middle of the night, between the hours of 12 a.m. and 4 a.m., after I had posted the survey link to an Alzheimer's caregiver support Facebook page that had over 11,000 followers. Prior to posting to that page, the qualitative responses were minimal and contained

only at most a sentence or two. However, after the link was posted to the Alzheimer's caregivers, the flood gates opened on the responses, and participants were submitting full and multiple paragraphs about their caregiving experiences, challenges, and woes. This response alone is a testament to how disclosure may provide relief or catharsis for caregivers. Disclosure is also a mechanism for soliciting or receiving social support from others during a difficult situation – by revealing information that may be emotionally distressing, individuals benefit from counsel, caring, and support from others in response to their disclosure (Laurenceau, Feldman, Barrett, and Pietromonaco, 1998; Laurenceau, Feldman, Barrett, and Rovine, 2005).

Inversely, caregivers may choose to hold tightly onto medical information and not share with others, or establish and communicate strict privacy rules with whom they share their patient's medical information. As predicted, higher levels of ownership and implicit and explicit privacy rules resulted in higher levels of caregiver burden. This finding is intuitive, given the inverse nature between privacy and disclosure: the more a caregiver perceives ownership over patient information, the less likely they are to disclose that information to others. The less disclosure to others results in less opportunities to discuss distressing information and receive social support from others. If social support decreases caregiver burden, then less opportunities for social support are likely to increase caregiver burden. Future studies on the implications of privacy ownership and rules surrounding this information could examine how stigma influences a caregiver's willingness to disclose information about a patient.

In this study, we also examined how negative interactions with family members influenced caregiver burden. Not only did we find that negative interactions increased caregiver burden, we also revealed that negative interactions served as the strongest predictor of caregiver burden among all three of the communication variables studied within the family communicative

environment. Our findings align with a large body of work that discusses the impact of negative social interactions and the willingness to seek social support, but our study is unique in that we specifically examine and link negative interactions directly to caregiver burden. Extant literature currently agrees that social support can become *a source* of stress, which prevents caregivers from interacting with family members (Rodakowski, Skidmore, Rogers, & Schulz, 2012). If primary caregivers avoid conversations and support from family members, then they are privy to less opportunities to receive social support. Future studies within this context could examine which aspects of negative social support emerge as the highest predictors of caregiver burden when caregivers are seeking, maintaining, and receiving social support, including aspects reported by Wittenberg-Lyles and colleagues, such as *perceived relational boundaries (2) being in control, (3) loss of patient social support* , and (4) *family dynamics*.

### **Limitations**

There are several limitations of this study to discuss. First, the sample population could have been more keenly targeted to a specific caregiving audience, such as Alzheimer's caregivers or other cognitive or dementia-related conditions. We did not ask for medically-identifying information in the survey other than whether the patient's condition was chronic or acute. This leaves very little insight into whether our caregiver respondents are answering within the context of a physical or a cognitive impairment. Future studies conducted by this researcher will specifically target certain caregivers or somehow distinguish among conditions during the data collection process.

Another benefit of specifically targeting a particular type of caregiver and not "opening a wide net" to collect responses is the quality of answers in the qualitative section of the survey. The survey was set up to require participants to fill in all of the answers in order to proceed to the



next page, but the first half of the participant responses in the qualitative category were relatively weak in content and length. It wasn't until the survey link was posted on the Alzheimer's support group Facebook page that the qualitative responses became substantial. The richness of the data received after this point was substantially greater than previous replies.

Another possible limitation was the wording of the qualitative questions. This study overall investigated the communicative ecology of caregiving, but the questions posed on the survey only asked about caregiving challenges in general. Content analysis of these responses did reveal that interpersonal communication with the patient, clinical communication with doctors and medical teams, and communication with family members were all included in challenges that caregivers face – but asking specifically about communication challenges would have perhaps allowed more poignant themes to emerge.

## CHAPTER VI

### CONCLUSION

This study offered a unique perspective on caregiver burden by examining the communicative ecology that caregivers must navigate as a part of their responsibilities, and also examined how emotional intelligence influences the relationship between communication behaviors and caregiver burden. Results revealed that higher levels of emotional intelligence, clinical communication self-efficacy, and disclosure of patient medical information decrease caregiver burden, while interpersonal communication competence, information ownership, privacy rules, and negative interactions with family members increase caregiver burden. These results add to the current body of literature by linking specific communication skills and the trait of emotional intelligence to caregiver burden, which may inform future communication studies that seek to assist caregivers, clinicians, and families.

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## APPENDIX A

### MEASURES

#### **Zarit Burden Interview – Shortened Version**

All questions are answered as “never” (1), “rarely” (2), “sometimes” (3), “quite frequently” (4), or “nearly always” (5).

1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?
3. Do you feel angry when you are around your relative?
4. Do you feel that your relative currently affects your relationship with family members or friends in a negative way?
5. Do you feel strained when you are around your relative?
6. Do you feel that your health has suffered because of your involvement with your relative?
7. Do you feel that you don't have as much privacy as you would like because of your relative?
8. Do you feel that your social life has suffered because you are caring for your relative?
9. Do you feel that you have lost control of your life since your relative's illness?
10. Do you feel uncertain about what to do about your relative?
11. Do you feel you should be doing more for your relative?
12. Do you feel you could do a better job in caring for your relative?

## Interpersonal Communication Competence Scale

Rubin and Martin (1994)

Instructions: Here are some statements about how people interact with other people. For each statement, circle the response that best reflects YOUR communication with others. Be honest in your responses and reflect on your communication behavior very carefully.

- If you ALMOST NEVER behave this way, select 1.
- If you act this way only SELDOM, select 2.
- If you behave in this way SOMETIMES, select 3.
- If you communicate this way OFTEN, select 4.
- If you ALMOST ALWAYS interact in this way, select 5.

### Empathy

1. I can put myself in my care recipient's shoes.
2. I don't know exactly what my care recipient feeling. [R]  
Assertiveness
3. When I've been wronged by my care recipient, I confront him/her.
4. I have trouble standing up for myself to my care recipient. [R]  
Interaction management
5. My conversations with my care recipient are characterized by smooth shifts from one topic to the next.
6. I take charge of conversations with my care recipient by negotiating what topics we talk about.  
Environmental Control
7. I accomplish my communication goals with my care recipient.
8. I have trouble convincing my care recipient to do what I want them to do. [R]

## **Patient's Communication Perceived Self-Efficacy Scale**

Capone and Petrillo (2014)

Answer the degree with which you agree with each of the statements on a scale from 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

[Provide and Collect information]

1. I can ask my CR's doctor to explain a new and complicated therapy in a simple way.
2. I can tell the doctor what kind of treatment my CR prefers (e.g. pills, syringes” even if he/she is most unwelcoming.
3. I can hold my CR's doctor's gaze while I'm telling him/her that CR didn't follow prescribed therapy.
4. I can tell my CR's doctor what CR likes/dislikes about the treatment.

[Express concerns and doubts]

5. I can claim doctor's attention if he/she looks distracted.
6. I can tell my CR's doctor I and/or my CR is not capable of handling the disease
7. I can express my disagreement to the doctor who behaves arrogantly.
8. I can express my doubts about the treatment if the doctor is hurrying me.

[Verify Information]

9. I can keep my mind on clinician's words, even if I had a dispute with a member of my family.
10. I can listen to the information about treatment even if I already know it because it is the same therapy of a friend of mine.
11. I can repeat in my own words to the doctor the information that he/she just gave to me.
12. I can express my perplexity when my doctor speaks to me about the course of my CR's disease with long words.

## Patterns of Disclosure About A Health Condition

Checton and Greene, 2012

Answer the degree with which you agree with each of the statements on a scale from 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

[Breadth]

1. I discuss a wide variety of issues related to my CR’s health condition.
2. There are some issues about my CR’s health condition that I do not talk about. [R]
3. There are some areas related to my CR’s health conditions that I avoid discussing. [R]
4. I am hesitant to share small health concerns I have about my CR. [R]

[Depth]

5. I have heart to heart talks with family members about my CR’s health condition.
6. My family members and I only talk about superficial issues related to my CR’s health condition. [R]
7. I hold back from sharing intimate issues about my CR’s health condition with my family members. [R]
8. I share my innermost fears about my CR’s health condition with my family members.

[Frequency]

9. My family members and I often talk about my CR’s health condition.
10. I rarely talk about my CR’s health condition. [R]
11. My family members and I have frequent conversations about my CR’s health condition.
12. How often do you talk with your family members about your CR’s health condition?



## Privacy Rules

Venetis et al. (2012)

Answer the degree with which you agree with each of the statements on a scale from 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

### [Perception of Ownership]

1. I feel that I “own” my CR’s health information
2. Family members do not have the right to share my CR’s health information

### [Explicit Privacy Rules]

3. I ask family members not to share the CR’s health information with anyone else.
4. I am clear about to whom family members can tell/ not tell about my CR’s health information.
5. Before I share my CR’s health information with family members, I ask them not to share the information with anyone.
6. After I share CR’s health information with family members, I ask them not to share the information with anyone.

### [Implicit Privacy Rules]

7. Although I do not ask family members not to, they know not to tell others [about CR’s health information).
8. I know that family members won’t share CR’s health information even if I don’t ask them to keep to themselves.

## **Negative Interactions**

(Adapted from Social Support Behavior Code, Cutrona & Suhr, 1992)

Answer the degree with which you agree with each of the statements on a scale from 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

1. When I am seeking support from my family members, they are often sarcastic with me when we are discussing my care recipient.
2. When I am seeking support from my family members they often criticize me when we are discussing my care recipient.
3. When I am seeking support from my family members, we often disagree about what to do about my care recipient.
4. When I am seeking support from my family members, I always feel like I am getting interrupted by my family members during our conversations.
5. When I am seeking support from my family members, my family members complain to me about issues concerning my care recipient.
6. Whenever I ask for help with caregiving, my family members often refuse.

## Trait Emotional Intelligence Questionnaire – Short Form

Petrides and Furnham (2006)

Answer the degree with which you agree with each of the statements on a scale from 1 to 5, with 1 being “strongly disagree” and 5 being “strongly agree”.

1. Expressing my emotions with words is not a problem for me.
2. I often find it difficult to see things from another person’s viewpoint.
3. On the whole, I’m a highly motivated person.
4. I usually find it difficult to regulate my emotions.
5. I generally don’t find life enjoyable.
6. I can deal effectively with people.
7. I tend to change my mind frequently.
8. Generally, I find it difficult to know exactly what emotion I’m feeling.
9. On the whole I’m comfortable with the way I look.
10. I often find it difficult to stand up for my rights.
11. I’m usually able to influence the way other people feel.
12. On the whole, I have a gloomy perspective on most things.
13. Those close to me often complain that I don’t treat them right.
14. I often find it difficult to adjust my life according to the circumstances.
15. On the whole, I’m able to deal with stress.
16. I often find it difficult to show my affection to those close to me.
17. I’m normally able to “get into someone’s shoes” and experience their emotions.
18. I normally find it difficult to keep myself motivated.
19. I’m usually able to find ways to control my emotions when I want to.
20. On the whole, I’m pleased with my life.
21. I would describe myself as a good negotiator.
22. I tend to get involved in things I later wish I could get out of.
23. I’m generally aware of my emotions as I experience them.
24. Given my circumstances, I feel good about myself.
25. I tend to “back down” even if I know I’m right.
26. I don’t seem to have any power at all over other people’s feelings.
27. I generally believe that things will work out fine in my life.
28. I find it difficult to bond well even with those close to me.
29. Generally, I’m able to adapt to new environments.
30. Others admire me for being relaxed.

APPENDIX B

TABLES

Table B1

*Demographic Characteristics of Sample*

	Frequency	Percent
<u>Gender</u>		
Male	100	33.1
Female	202	66.9
<u>Ethnicity</u>		
White	167	55.3
Hispanic	76	25.2
African Amer.	29	9.6
Other	30	9.9
<u>Employment</u>		
Full Time	158	52.3
Part Time	79	26.2
Unemployed	50	16.6
Student	6	2.0
Other	9	3.0
<u>Income</u>		
Less than \$30,000	13	4.3
\$30,001-\$49,999	42	13.9
\$50,000 - \$74,999	80	26.5
\$75,000 - \$99,999	99	32.8
\$100,000- \$149,999	56	18.5
More than \$150,000	12	4.0

Table B2

*Caregiving Characteristics of Sample*

	Frequency	Percent
<u>Relationship of Patient</u>		
Parent [Step, In-Law]	218	72.2
Partner/ Spouse	38	12.6
Sibling, Other	46	15.2
<u>Sharing Care with Others</u>		
Sole Caregiver	188	62.3
Share with one other	80	26.5
Share with 2+	34	11.3
<u>Caregiving Time per Week</u>		
20-30 hours	132	43.7
30-40 hours	144	47.7
40+ hours	26	8.6
<u>Patient Condition</u>		
Acute	194	64.2
Chronic	108	35.8
<u>Length of Care (Months)</u>		
Less than 3 months	24	7.9
3-6 months	59	19.5
6-9 months	52	17.2
9-12 months	88	29.1
12-24 months	53	17.5
More than 24 months	26	8.6

Table B3  
*Means and Standard Deviations of Communication Variables*

	N	Minimum	Maximum	Mean	Std. Deviation
CGB	302	1.00	4.67	3.0817	.87155
ICC	302	1.38	4.75	3.2144	.62627
PCC	302	2.42	5.00	3.7930	.51202
DSC	302	1.08	4.92	3.0833	.48028
PRV	302	1.00	5.00	3.6022	.58564
NEG	302	1.00	5.00	3.2748	.92342
TEQ	302	2.40	4.63	3.2587	.39642
Valid N (listwise)	302				

Table B4

*Correlations among Continuous Variables*

	1	2	3	4	5
1. CareTime	-				
2. CareLength	.234**	-			
3. Education	-.014**	-.112	-		
4. Employment	.331**	.158*	-.259**	-	
5. Income	-.330**	.046	.224**	-.340**	-

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\* . Correlation is significant at the 0.05 level (2-tailed).

Table B5

*Correlations associated with Nominal Variables*

	1	2	3	4	5	6
1. Ethnicity	-					
2. Education	.008	-				
3. Employment	-.010	-.259**	-			
4. Income	-.005	.224**	-.340**	-		
5. Gender	-.120*	-.039	-.063	.175**	-	
6. CGB	.028	.070	.215**	-.117*	-.072	-

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\* . Correlation is significant at the 0.05 level (2-tailed).

Table B6

*Correlations of Communicator Characteristics with Caregiver Burden*

	1	2	3	4	5	6	7
1. Emot. Intell.	-						
2. Interp. Comp.	-.207**	-					
3. Clin. Comm.	.360**	-.037	-				
4. Disclosure	.343**	-.271**	.365**	-			
5. Privacy	.04	.290**	.268**	-.128*	-		
6. Neg. Inter.	-.506**	.224**	-.274**	-.319**	.172**	-	
7. Care Burden	-.440**	.656**	-.313**	-.400**	.103	.465**	-

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\* . Correlation is significant at the 0.05 level (2-tailed).

Table B7

*Summary of Regression Analysis for Emotional Intelligence predicting Caregiver Burden**(N = 302)*

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Relationship	-.118	.057	-.101*	-.034	.046	-.029
CareShare	-.341	.068	-.270**	-.223	.055	-.177**
CareTime	.146	.075	.106	.162	.060	.118**
Condition	-.438	.093	-.241**	-.196	.077	-.108*
CareLength	.063	.035	.101	.036	.028	.058
Employment	.100	.045	.114*	.095	.036	.108**
Income	.028	.039	.037	.004	.031	.006
TEQ	-.447	.088	-.254**	-.358	.071	-.203**
ICC				.720	.056	.518**

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



Table B8

*Summary of Hierarchical Regression Analysis for ICC predicting Caregiver Burden (N = 302)*

Variable	Model 1		Model 2			Model 3			
	<i>B</i>	<i>SE B</i>	<i>B</i>	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
CareShare	-.37	.07	-.29**	-0.25	0.06	-.19**	-.20	0.05	-.16**
Condition	-.50	.09	-.28**	-.24	.08	-.13**	-.12	.07	-.07**
CareLength	.11	.04	.18**	.08	.03	.12**	.003	.025	.01
Employ	.116	.047	.13*	.11	.04	.12**	.108	.032	.12**
ICC				.75	.06	.54**	.75	.051	.54**
Emo Intel							-.75	.09	-.34**
ICCXEmo							-.98	.132	-.27**
<i>Adj R</i> <sup>2</sup>			.31			.55			.66
<i>F</i> for $\Delta R^2$			20.05**			163.67**			50.96**

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

Table B9

*Summary of Hierarchical Regression Analysis for PCC predicting Caregiver Burden (N = 302)*

Variable	Model 1		Model 2			Model 3			
	<i>B</i>	<i>SE B</i>	<i>B</i>	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
CareShare	-.37	.07	-.29**	-.33	.07	-.26**	-.26	.07	-.21**
Condition	-.50	.09	-.28**	-.45	.10	-.25**	-.43	.09	-.24**
CareLength	.11	.04	.18**	.10	.04	.17**	.08	.03	.12*
Employ	.12	.05	.13*	.11	.05	.13*	.13	.04	.15**
PCC				-.24	.09	-.14**	-.09	.09	-.05
Emo Intel							-.62	.11	-.28**
PCCXEmo							-.46	.18	-.12*
<i>Adj R</i> <sup>2</sup>			.31			.32			.40
			20.06**			7.23**			21.11**

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

Table B10

*Summary of Hierarchical Regression Analysis for DSC predicting Caregiver Burden (N = 302)*

Variable	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
CareShare	-.37	.07	-.29**	-.27	.07	-.21**	-.23	.07	-.18**
Condition	-.50	.09	-.28**	-.48	.09	-.26**	-.41	.09	-.23**
CareLength	.11	.04	.18**	.09	.03	.15**	.06	.03	.10
Employ	.116	.047	.13*	.12	.05	.13*	.11	.04	.13*
DSC				-.41	.10	-.22**	-.27	.10	-.15**
Emo Intel							-.62	.11	-.28**
DSCXEmo							-.03	.15	-.01
<i>Adj R</i> <sup>2</sup>			.31			.35			.41
<i>F</i> for $\Delta R^2$			20.06**			18.03**			15.84**

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

Table B11

Summary of Hierarchical Regression Analysis for PRV predicting Caregiver Burden ( $N = 302$ )

Variable	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
CareShare	-.37	.07	-.29**	-.35	.07	-.28**	-.29	.07	-.23**
Condition	-.50	.09	-.28**	-.51	.10	-.28**	-.42	.09	-.23**
CareLength	.11	.04	.18**	.12	.04	.19**	.07	.03	.11
Employ	.116	.047	.13*	.13	.05	.15**	.13	.04	.15**
PRV				.16	.07	.10*	.17	.07	.12*
Emo Intel							-.72	.11	-.33**
PRVXEmo							-.16	.15	-.05
<i>Adj R</i> <sup>2</sup>			.31			.32			.40
<i>F</i> for $\Delta R^2$			20.06**			4.40*			22.12**

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

Table B12

*Summary of Hierarchical Regression Analysis for NEG predicting Caregiver Burden (N = 302)*

Variable	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
CareShare	-.37	.07	-.29**	-.25	.07	-.20**	-.25	.07	-.20**
Condition	-.50	.09	-.28**	-.44	.07	-.24**	-.38	.09	-.20**
CareLength	.11	.04	.18**	.08	.03	.14*	.06	.03	.09
Employ	.116	.047	.13*	.16	.04	.18**	.13	.04	.15**
NEG				.34	.05	.36**	.28	.05	.30**
Emo Intel							-.48	.12	-.22**
NEGXEmo							-.18	.11	-.10
<i>Adj R</i> <sup>2</sup>			.31			.42			.44
<i>F</i> for $\Delta R^2$			20.06**			56.22*			7.57**

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

Table B13

*Summary of Hierarchical Regression Analysis for DSC, PRV, and NEG predicting Caregiver Burden (N = 302)*

Variable	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
CareShare	-.37	.07	-.30**	-.18	.07	-.14*
Condition	-.50	.10	-.28**	-.43	.09	-.24**
CareLength	.11	.04	.18**	.08	.03	.12*
Employment	.12	.05	.13*	.16	.04	.19**
NEG				.30	.05	.32**
DSC				-.28	.09	-.15
PRV				.07	.07	.05**

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

Table B14  
*Summary of Qualitative Results and Thematic Analysis*

<b>Interpersonal with Patient</b>	<b>Clinical with Med Teams</b>	<b>Family Communication</b>
Cognitive Decline: “Mental degradation is increasingly more difficult as reality slips further and further away”	Postponement of or failure to make medical appointments or themselves.	“A general lack of support from other family members”  “Siblings are the worst, and are selfish”
It is very important to treat the patient like an adult. She is 85 and often acts like a child. I try to remember to allow her to make her own decisions, just manage the outcomes.	Learn the family member’s diagnosis. This will help you understand the illness and plan ahead.	Getting my mother and stepfather to realize I am no longer 13. Getting and family members to admit he is in early stage Alzheimer’s  No one in the family, except me, will face the fact that my step-father is suffering from Alzheimer’s.
Challenge of dealing with the altered perceptions of my mom experiences and her interactions with other people that result (thinking people stole from her, violent outbursts, etc)	I was not prepared to be expected to do things for which I have no training.  Performing dialysis at home.	My child will learn from me- we need to love each other and take care of each other. It is my duty to take care of my family. I need to take care of my parent because they took care of me when I was younger.
The Patient’s incomprehension –The Patient is too demanding and difficult to cope with – The patient always has a bad temper  Patient very reluctant to accept any help because he saw it as an infringement on his independence.  My mother in law cries if I go out without her and when I return she refuses to speak with me.	Not prepared: Caregivers are often left performing professional duties without the requisite skills.	I wish I knew the keys to sibling harmony when caring for parents

APPENDIX C

FIGURES

Figure C1

*Communicative Ecology of Caregiver Burden Model*

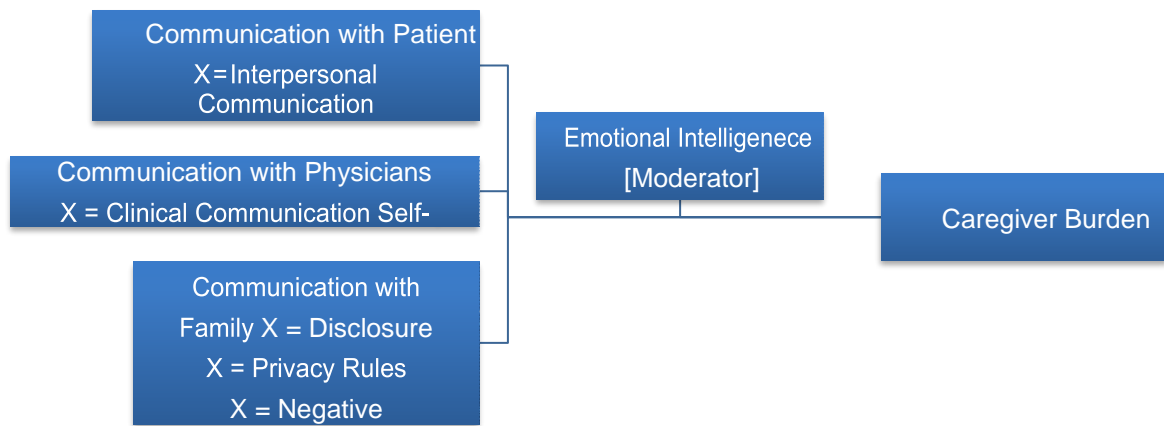




Figure C2

*Moderating Effect of Emotional Intelligence on ICC and Caregiver Burden*

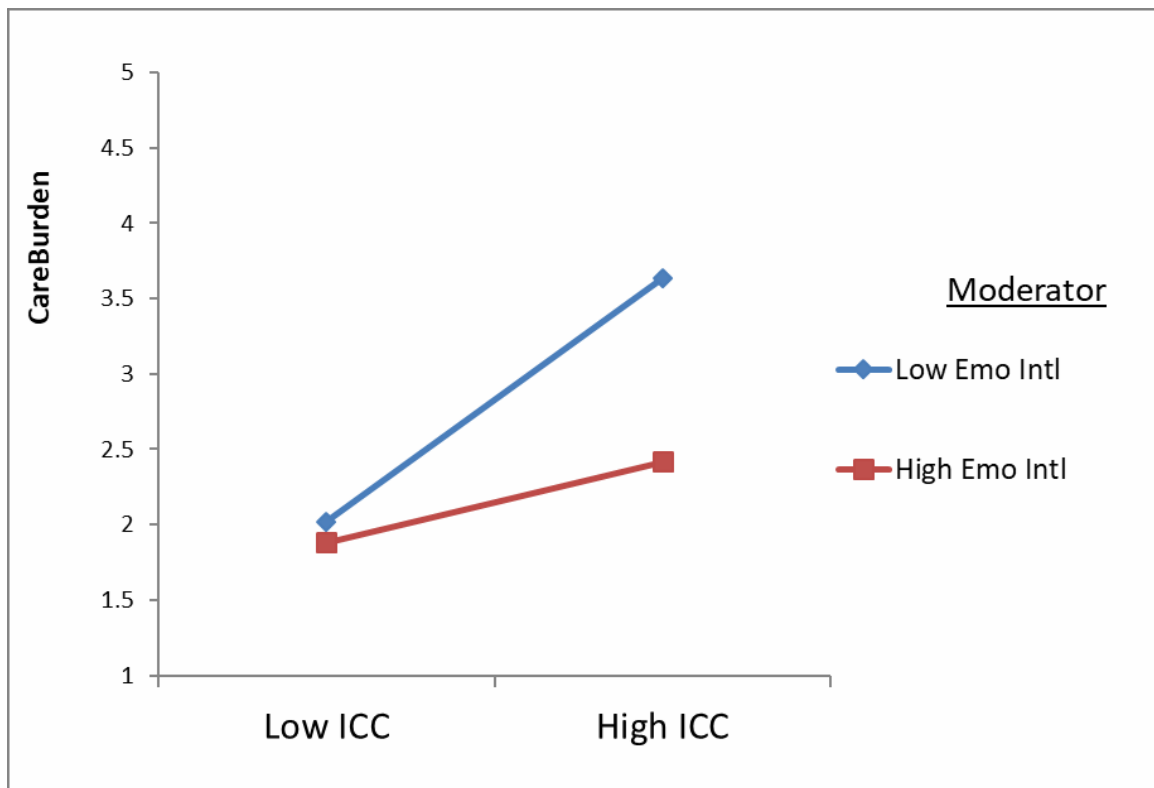


Figure C3

*Moderating Effect of Emotional Intelligence on PCC and Caregiver Burden*

