PROBLEMATIC INTEGRATION AND INFORMATION MANAGEMENT: THE

COMMUNICATIVE BEHAVIORS OF ADULT SIBLINGS DURING ELDER CARE

by

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ABSTRACT OF THE DISSERTATION

Problematic integration and information management:

The communicative behaviors of adult siblings during elder care

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Scholars describe the sibling relationship as one of the most important interpersonal relationships; it is a lifelong affiliation that spans other well documented relationships such as those of parents, friends, and married couples (Cicirelli, 1995). Most research on siblings, however, has focused on their interactions during childhood or adolescence. Less is known about the communication exchanges of siblings in middle to late adulthood. This study considered how individuals form the expectations, perceptions, and meanings of their sibling relationships as they negotiate a common task associated with later life stages. This research utilized Problematic Integration (PI) theory (Babrow, 1992, 2001) as a framework for assessing how adult siblings identify and evaluate the challenges of caring for an aging parent. Two studies were undertaken. Study One conducted interviews with adults currently negotiating elder care with their sibling. The goal of Study One was not to test PI theory but to explicate its concepts within the elder care context. Consistent with other health communication studies, uncertainty played a prominent role during the caregiving situation. The broader concept of ambiguity was revealed when participants were asked about the future of their sibling(s) relationships.

Making the distinction between uncertainty and ambiguity is an important aspect of PI Theory and differentiates the results of Study One from the more common relational uncertainty research. Study Two built on data from Study One, investigating the expectations, perceptions, and meanings of the caregiving situation in association with the information management behaviors enacted by individuals attempting to integrate varied problematic integrations. A new scale was developed to operationalize PI, the Problematic Integration Measure (PIM). Results included: caregiving burden was positively related to PI, while relational quality was negatively related to PI; information sharing was inversely related to PI, but topic avoidance was positively related to PI; no significant relationship was reported between secret keeping and PI. Differences were shown among the various aspects and multiple forms of PI in association with the three information management behaviors. The creation of a PI measure (PIM) moves the theory forward and allows it to be compared with other communication and relationship constructs.

Keywords: Uncertainty, problematic integration, information management, disclosure, adult sibling relationships, caregiving, elder care

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DEDICATION

To my husband
Shawn
My love, my comfort, my inspiration

To my children
Gregory and Camille
My joys, my blessings, my everything

To my parents
Dennis and Barbara
My guides, my supporters, my foundation

To my advisor
Dr. Kathryn Greene
My coach, my advocate … the reason I finished

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CHAPTER ONE – INTRODUCTION

Family and psychology scholars describe the sibling relationship as critically important because it is a lifelong affiliation that extends beyond other relationships, such as those of parents, friends, and married couples (Cicirelli, 1995). Yet, adult sibling interactions are an understudied sphere of interpersonal communication, with most research focusing on the interactions of adolescent or younger siblings. The studies that have considered adult sibling relationships tend to consider their types of communication, such as affectionate (e.g., Rittenour, Myers, & Brann, 2007) or critical (e.g., Martin, Anderson, Burant, & Weber, 1997), or their motives for communication (e.g., Fowler, 2009). Only a small portion of communication studies examine the process of adult sibling interactions as they negotiate their relationships during later stage developments, such as coping with the challenges of aging.

Studying communication exchanges between siblings in the context of eldercare is necessary in today's aging society. In the United States, the number of adults age 65 and older is expected to more than double over the next three decades (U.S. Census Bureau, 2010). The "oldest old," those 85 years old and older, are projected to be the fastest growing part of the senior population into the next century (U.S. Census Bureau, 2010). As the population ages, so does the need for personal assistance with everyday activities. The first line of assistance for aging individuals is often their immediate family, particularly their adult children. However, this personal assistance, and ultimately medical care, is constrained when adult children cannot communicate effectively when attempting to coordinate care decisions.

When an elderly parent is ill and needs care, the interactions of adult children are critical to preserving the health and well-being of the family (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2009; Lee, Netzer, & Coward, 1995; Lieberman & Fisher, 1999). Communication becomes both a resource for responding to a stressful event, as well as a source of misunderstanding and conflict around the event (Babrow, 1992).

All families experience conflict, the occurrence of which is neither good nor bad; rather, the response to conflict is what determines the long-term vitality and resilience of relationships (Sillars, Canary, & Tafoya, 2004). However, life events may occur that overwhelm family members. Caring for an aging parent may be a life transition that is seen as a normal event that occurs with the passage of time or as a traumatic event that is unexpected or unwelcome and sends the family into crisis. Why some families manage this transition effectively and others do not has often been attributed to the characteristics, relationships, perceptions, and communication behaviors of its members (Boss, 2001; Hill, 1958; McCubbin & Patterson, 1983; Patterson, 1988). This research explores the association between these four factors.

Differences in the way families manage transitions may depend on the ways that family members construct uncertainty (Babrow, Kasch, & Ford, 1998; Brashers, 2001), which is endemic to illness and caregiving experiences. The meaning of uncertainty, however, is quite varied (Babrow et al., 1998; Brashers, 2001). There is uncertainty about self (a matter of personal confidence), uncertainty about others (a matter of source doubt and distrust) and uncertainty about a relationship (Derlega, Winstead, Wong, & Greenspan, 1993; Solomon & Knobloch, 2004; Theiss & Solomon, 2006). There is also

potential uncertainty about the event (such as the illness) or the process of responding to the situation (Babrow et al., 1998; Berger, 1997). Communication is thought to be essential to the construction, management, and resolution of uncertainty (Babrow et al., 1998) as individuals choose communication strategies to meet their different uncertainties.

This study will utilize Problematic Integration (PI) theory (Babrow, 1992) to investigate how adult siblings negotiate their relationship as they transition to being caregivers of aging parents. PI theory asserts that humans continually construct and reconstruct the meanings of their experiences (Babrow, 1992, 2001). These meanings, in turn, shape the probabilistic (will it occur) and evaluative (will the occurrence be good or bad) orientations around the likelihood or benefit of an event occurring. Each person, however, constructs different meanings based on different experiences, resulting in orientations that are not the same. This creates great difficulty when individuals attempt to make joint decisions based on these varied perspectives, such as different views on parental care.

An additional complication for decision making is that these problematic integrations (synthesizing of uncertainties) may occur at different levels. For example, while two siblings may have uncertainty about their relationship, one sibling may be uncertain as to what the sibling relationship may look like in the future but the other may be uncertain as to what role each will fulfill during caregiving. The goals of the present research were to explore how adult siblings construct the expectations, perceptions, and meanings associated with their sibling relationships and subsequently devise communication strategies to address their divergent uncertainties as they transition to

caregivers. How siblings make sense of their relationships during the caregiving situation and their forthcoming unpredictabilities allows for the preservation of the family as a critical "unit of care" (Kramer, Boelk, & Auer, 2006) of aging parents.

To accomplish the goals of this research, two studies were conducted. The first study used interviews to explore the illness and relational uncertainties present during elder care. In addition, participants were asked to describe the information management behaviors which they exhibited with their siblings. A new measure of Problematic Integration was developed from the data collected in Study One. This was done to test in Study Two whether there was an association between PI and caregiving burden, sibling relational quality, information management behaviors, and family communication patterns.

The following chapters provide more detail about the rationale, methods, and results of the research. Chapter Two reviews the literature relevant to the goals of each study. These components include the nature of uncertainty and how uncertainty is formulated according to Problematic Integration Theory (Babrow, 1992, 1998), information management behaviors (information sharing, topic avoidance, and secret keeping), family communication patterns, and sibling relational quality. Chapter Three presents the methods, analyses, and results of Study One, and Chapter Four presents the methods, analyses, and results of Study Two. Finally, Chapter Five discusses the implications and limitations of the two studies, as well as future research ideas.

CHAPTER TWO – REVIEW OF LITERATURE

This research draws from two theoretical areas, namely uncertainty and information management. This review examines these within the understudied context of family, specifically the relationship of adult siblings as they negotiate the transition to elder care. The sibling relationship has frequently been studied at early stages of development (i.e., childhood or adolescence). However, the present research focuses on later life stages and how this affiliation becomes more critical in later stages of family life.

This project begins with a discussion of the nature of uncertainty and how uncertainty is formulated at various levels according to Problematic Integration (PI) Theory (Babrow, 1992). Because this research explores the relationship between perceptions of uncertainty and certain communication behaviors, a review of the information management techniques of information sharing, topic avoidance, and secret keeping follows. An examination of family communication patterns and the family life cycle, particularly as they relate to caregiving of an aging parent, is then put forth. The chapter concludes with a review of the sibling relationship and its distinct characteristics including frequency of contact, level of closeness, and persistence of rivalry.

Uncertainty in Communication

A seeming contradiction exists between notions that communication between people is a) virtually automatic and effortless and carried out with only minimal forethought and planning, and b) the product of considerable conscious deliberation and effort (see Berger, 1997; Kellerman, 1992; Langer, 1978, 1992; Reddy, 1979). This contradiction exists because even routine social encounters involving individuals who are

well acquainted with each other can have the shared knowledge underlying their relationship disrupted (Berger, 1997). Individuals, their relationships, and the contexts in which they are interacting can all change. Dramatic events may be associated with even more striking changes, creating conditions of considerable uncertainty. The next section will review the nature of uncertainty, the forms of uncertainty described in PI Theory, and the relationship between PI and communication. I begin with the nature of uncertainty.

Nature of Uncertainty

Uncertainty exists when "details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general" (Brashers, 2001, p. 478). Uncertainty is primarily a perception about one's own knowledge and ability to derive meaning from that knowledge (Brashers, 2001). Therefore, lacking knowledge is different from one's perception about knowledge, and one individual's perception may be very different from another person's perception.

Perceptions about uncertainty can be so different because there are numerous sources of uncertainty (Babrow, 1999, 2001; Berger, 1997), such as questions about the abilities, goals, and emotions of the parties involved. *Precondition uncertainty* includes uncertainties that arise from judgments about the ability of the parties involved to meet the basic prerequisites for carrying out verbal interaction (Berger, 1997). In caregiving situations, for example, one sibling may be a nurse and capable of processing medical terminology and diagnoses, while another sibling may be a banker and knowledgeable about financial instruments to pay for care. Both siblings may be very competent

individuals yet struggle to understand concepts outside of their expertise, resulting in a difficult decision making process as they attempt to integrate their viewpoints.

Another contributor to uncertainty is personal *goals and plans.* The goals of interaction partners may not be clear and make it challenging for message producers to set their own goals (Berger, 1997). Even if one sibling feels certain about another sibling's goals, he or she may have considerable uncertainty about how the sibling plans to achieve them (Berger, 1997). For example, siblings may agree that an aging parent needs help with activities of daily living. Yet, while one sibling may be certain that moving out of the family home to an assisted living community is the way to accomplish this goal, the other sibling may have very different ideas of how to accomplish the goal, such as hiring home help. These goals and plans may change in unpredictable ways as the caregiving situation changes.

Changes in a parent's health or changes in an individual's life may prompt various emotional responses. These responses (referred to as one's *affective state)* may also contribute to uncertainty. Berger (1997) describes how uncertainty about the affective state of a partner may present significant problems to the person communicating with that individual. These problems affect the content and structure of the messages and may determine whether the interaction continues (Berger, 1997) or is avoided. Such communication strategies present an interesting opportunity for research. The communication exchanges between siblings associated with an aging parent's injury or illness are filled with emotion and turmoil. For example, if a sibling is uncertain as to how another sibling will respond to requests to assist with caregiving, those requests may be withheld or go unanswered. The complexities of caregiving and its numerous

possibilities and outcomes create highly uncertain scenarios. A lens for examining the various facets of uncertainty is the Problematic Integration Theory (Babrow 1992, 1998), which the next section will discuss.

Problematic Integration Theory

Whereas uncertainty reduction theory (Berger & Calabrese, 1975) proposes that humans strive to reduce uncertainty, Problematic Integration theory (Babrow, 1992, 2001) proposes alternative responses to uncertainty including avoiding information or altering probabilistic or evaluative assessments (Dennis, Kunkel, & Keyton, 2008). These alternative responses may be considered because reducing uncertainty is not always possible (Brashers, 2001) or desirable and, even if it is, reducing uncertainty on one issue may give rise to a cascading sequence of other uncertainties (Babrow & Kline, 2000). Alternatively, some individuals may even seek to sustain or create additional uncertainty (Babrow, 1995; Lazarus, 1983).

PI theory (Babrow, 1992) considers the relationship between expectations and desires (Dennis et al., 2008) and presumes that humans need both probabilistic (will it happen?) and evaluative (will it be good?) understandings of their world. Babrow (1992) notes how humans must ultimately integrate these two orientations, a process involving the shared effects and the linking of each "to broader complexes of knowledge, feelings, and behavioral intentions" (p. 96). As a result, this integration often becomes problematic as behavioral intentions may muddy an individual's understanding of a given event or situation. Siblings' orientations and intentions may become more difficult to understand within the complex context of caregiving.

Integrating the two orientations, according to Babrow (1992), is a routine matter when probabilities are clear, evaluations are consistent, and when probabilities and evaluations readily converge. Integration becomes more difficult as probability and evaluation diverge, as when prospects become less clear or when ambivalence arises (Babrow, 1992). Such difficult integration may occur when the illnesses of aging parents require the attention of multiple adult children because each may have his/her own understanding of how to best manage the situation. The distinction, however, between routine and problematic integration is continuous rather than discrete for each individual. One sibling may see assisting a parent with daily activities as routine, but another sibling may see it as very problematic. As integration of probability and evaluation becomes more problematic, forming and maintaining associated cognitive, affective, and behavioral orientations (Babrow, 1992, 2001) becomes increasingly difficult and may leave siblings to employ counterproductive communication behaviors.

Another difficulty is that uncertainty can be either epistemological or ontological in nature (Babrow, 2007). Epistemological uncertainty involves having too much or too little information or having concerns about the reliability, validity, or relevance of available information (Babrow, 2007; Matthias, 2009). In contrast, ontological uncertainty depends on one's conceptions of the nature of the world, such as its complexity or indeterminacy (Babrow, 2007; Matthias, 2009). Quite often epistemological uncertainty is the focus in health-related contexts, including childbirth (Matthias, 2009), breast cancer (Dennis et al., 2008), and Alzheimer's disease (Polk, 2005). The solution to epistemological uncertainty is thought to be giving the patient or

their family more information. However, this may not be possible, may not fit with one's views of the situation, and may even yield greater uncertainty about other issues.

Even when someone understands the nature of another's stress and uncertainty, a failure to understand the focus of their uncertainty may limit coping and decision making. For example, Hines (2001) has shown a disconnection between physician and patient uncertainties. A physician may assume that uncertainty is from a lack of information and provide even more information. However, a patient's uncertainty may stem from information that is too complex to process (Hines, 2001). Another issue may be that care providers are trying to manage different sets of uncertainties. Hines (2001) gives the example that while a male lung cancer patient may be struggling to know whether he will survive for another year, his spouse may wondering whether she will be able to cope with life after her spouse's death. Siblings may experience similar differences regarding the forms or types of uncertainty associated with parental caregiving. However, research has yet to explore uncertainty in this context.

Problematic Integration and Communication

Problematic Integration theory places communication at the center of both the experience of uncertainty and the coping with uncertainty (Gill & Morgan, 2011). Uncertainty, for example, is associated with a delay in personal decisions (Germeijs & DeBoeck, 2003), the use of alternate logic (Shafir & Tversky, 1992), or anxiety about decisions in uncertain environments (Jordan, 1960). Problematic integration involves decision making processes occurring within individuals, interpersonal interactions, and broader social practices (Babrow, 1992, 2001).

Any experience in which profound values are at stake, such as a parent's health, family finances, or personal responsibilities, has the potential to evoke PI (Babrow, 2007; Matthias, 2009). Cultural values regarding death may drive communication difficulties among hospice patients, their caregivers, and volunteers at the end of life (Planalp & Trost, 2008). Personal values about illness shape whether doctors and patients confront life threatening conditions and treatment decisions soon after diagnosis or avoid the discussion (Hines, Babrow, Badzek, & Moss, 2001). Even political values direct how individuals engage with and manage uncertainty concerning issues such as climate change (Norton, Sias, & Brown, 2011). PI can trigger wishful and defensive variations of probability or value judgments as well as individual action to cope with a problem (Babrow, 1992, 2001).

PI is also important to interpersonal communication because affective states influence social cognition, which, in turn, influences communication exchanges (Sypher & Sypher, 1988). These exchanges reflect an evaluation of possible outcomes, which are shaped by personal feelings and emotions (Babrow, 1992; Polk, 2005). For example, Cohen (2009) discovered that the fear associated with a breast cancer diagnosis changed how African American women approached and discussed the disease with loved ones. The emotional states associated with PI, along with historical patterns of interaction, may condition one sibling's response to communication from another sibling. The time when an aging parent becomes injured or gravely ill is highly emotional and may continue the communication patterns previously existing in the sibling relationship.

Destructive communication patterns may be the result of uncertainty misunderstandings. In addition to understanding the nature of uncertainty and the focal

issue in a situation, interactants also need to understand the form of uncertainty. For example, if a sibling is unable to determine the likelihood of an event, such as the future state of family relationships, ambiguity will emerge relative to the positive or negative value associated with what is at stake. In turn, ambivalence will result if an individual is unsure of how to feel about the event or must choose between mutually exclusive alternatives (Babrow, 2001; Gill & Morgan, 2011). Siblings may also experience PI as a result of divergence in expectations. One sibling may feel that something that is highly (positively) valued is unlikely to occur but should happen; another sibling may feel that the event will occur (Babrow, 2001; Gill & Morgan, 2011) but should not take place. Each family member involved in the process of making elder care decisions may experience a different form of PI or experience the same form in a different manner.

The misunderstandings regarding different orientations to and forms of uncertainty create interactional dilemmas filled with miscommunication between individuals (Babrow & Kline, 2000). For example, patients and health care providers have been shown to differ in their approach to reconciling incompatible probabilistic and evaluative judgments (Hines et al., 2001). Patients sought information that would enable them to cope with agonizing treatments rather than information the nurses believed would be necessary for them to make informed choices about whether to undergo such treatments (Hines et al., 2001). Siblings, as well, may differ in their approaches to judgments regarding parents' medical, residential, or personal care decisions and have even less preparation than professionals to deal with changes brought about by aging.

Problematic Integration and Relationships

Problematic integration may occur because of the relational uncertainty that exists between individuals. Relational uncertainty is defined as a person's level of confidence in his or her perceptions of involvement within a relationship (Knobloch & Solomon, 1999, 2002; Knobloch & Theiss, 2010) and stems from self, partner, and relationship sources of ambiguity (Berger & Bradac, 1982). Self uncertainty stems from individuals' doubts or questions about their own involvement in a relationship, while partner uncertainty encompasses doubts about a partner's commitment to the relationship (Theiss & Solomon, 2006). Relationship uncertainty involves ambiguity about the partner and self as a social unit (Theiss & Solomon, 2006) and whether they will continue in a relationship into the future.

Relational uncertainty has been shown to alter the communication behaviors of those in the relationship. Relationship uncertainty tends to yield more indirect communication as people are unsure what consequences their words and actions will produce (Knobloch & Solomon, 2002). Doubts about self and a partner's commitment to the relationship are associated with avoidance about the nature of their relationship (Baxter & Wilmot, 1985; Theiss & Solomon, 2006). In addition, romantic partners experiencing relational uncertainty have been found to engage in topic avoidance (Afifi & Burgoon, 1998; Knobloch & Carpenter-Theune, 2004) and refrain from discussing surprising relationship events (Knobloch & Solomon, 2002). Prior research has also shown that people often conceal private information to prevent harm to the relationship (e.g., Afifi & Guerrero, 2000; Rosenfeld, 1979) or to protect a relational partner from distress (e.g., Derlega, Winstead, Mathews, & Braitman, 2008; Vangelisti, Caughlin, &

Timmerman, 2001). The concept of relational uncertainty, which is most often applied to romantic partners, will be applied to siblings in the present research.

Summary of Uncertainty

Efforts to manage a particular uncertainty are likely to vary depending on the expected response of another (Hines, 2001; Magsamen-Conrad, 2012), and this response may have been established through years of personal interactions. Expectations that others will respond negatively to a particular strategy are likely to decrease the chance of that strategy being used (i.e., that strategy will be avoided) (Hines, 2001; Magsamen-Conrad, 2012). Conversely, siblings may exhibit certain communication behaviors if they expect those behaviors will support the goals of another while also meeting their own goals simultaneously. Siblings are most likely to attempt to actively manage those uncertainties that they consider most important (Hines, 2001). As a result, siblings may have very different ideas of which uncertainties to manage, creating turmoil and conflict that may affect parental care.

Communication is essential for clarifying or obscuring the message themes associated with developing probabilities and evaluations (Babrow, 1992, 2001). Both automatic and calculated responses, possibly the result of family communication patterns over the years, determine whether situations are seen as routine or problematic. Communication behaviors also determine which particular form of PI characterizes a given situation. At the individual level, these forms include ambiguity, ambivalence, divergence, impossibility (Babrow, 1999, 2001); each form may contribute to a sibling's broader sense of uncertainty about a situation. The present research will examine what forms of uncertainty (ambiguity about an event, ambivalence about alternatives, or

divergence in expectations) emerge during caregiving and whether these forms are associated with particular communication behaviors such as information sharing, topic avoidance, or secret keeping. Each form of information management will be further discussed in the next section.

Information Management Strategies

While caring for aging parents, some of the common communication behaviors that may be employed are the information management strategies of topic avoidance, secret keeping, or information sharing. An additional aspect to be investigated in this study is how siblings manage the information associated with caregiving decisions relative to perceptions of ambiguity, ambivalence, and divergence. When discussing an issue openly, such as the need for additional help with caregiving, siblings take the risk of displaying some weakness, revealing hidden information, or challenging their relationship. During the discussion, siblings may recognize that they are at risk of personal or financial loss (Roloff, 1976) or that their relationship is at risk (Greene, 2009). Siblings may decide to use the potentially antisocial communication strategy of keeping information about themselves or their position hidden in order to manage the situation. Information sharing, topic avoidance, and secret keeping provide ways by which individuals can manage privacy in relationships (Guerrero & Afifi, 1995a).

Altman (1975) describes privacy as an interpersonal boundary process by which a person regulates interaction with others. This boundary setting process is regulated through the verbal transmission or avoidance of information about oneself (Derlega & Chaikin, 1977) and also discussed as disclosure/non-disclosure. During elder care, a sibling may choose to share a parent's new medical prognosis and the resulting changes

in caregiving needs with other siblings. This information serves the dual function of

advising the siblings about the parent, as well as informing the siblings about how the

caregiver is responding to the changes. At the same time, the caregiver may avoid talk

that reveals information about his or her own personal health or finances. By avoiding

such topics, the caregiver is setting a boundary that keeps personal information private.

Secrecy, however, goes a step beyond privacy. Whereas privacy is voluntarily

choosing what and how much to share with others, secrecy is actively hiding private

information from others (Kelly, 1999, 2002). In the elder care context, secrecy may

involve actively hiding the true cost of service providers from a parent or sibling, while

privacy may involve not sharing the news of a job promotion or emotional state. The

decision of whether to disclose information or to keep information secret, however, is a

delicate balancing act between the risks inherent in the disclosure and the benefits that

may be gained for individuals, others, and their relationships (Greene, 2009).

The decision to share information is often seen as either an attempt at catharsis or

relational development (Derlega et al., 2008), and the decision to keep information secret

is often viewed as an attempt to avoid shame and embarrassment or relational damage

(Derlega et al., 2008). Others have determined that there are physical and psychological

health benefits to revealing secret information (Kelly, 1999; Pennebaker, 1990) because

cognitive and emotional resources are no longer expended and new insights may be

gained into complex situations. However, revealing undesirable personal information

may have negative implications for one's self-image and reputation (Kelly, 1999, 2002).

People may become vulnerable to influence and possible exploitation and hence lose their

independence when others know their private information (Derlega & Chaikin, 1977).

The ability to maintain independence and control over decision-making about information management may be important to those siblings that are primarily responsible for the care of their parents. The ability to adjust the level and type of information revealed may be critical to maintaining their sense of self-worth (Altman, 1975; Derlega & Chaikin, 1977) or relational quality. As a result, siblings involved in elder care may employ various information management strategies, such as information sharing, topic avoidance, or secret keeping, in order to manage different personal and relational aspects during a particularly challenging time. The next section will begin with a review of the strategy of information sharing followed by the literature on topic avoidance and secret keeping.

Information Sharing

Information sharing may involve self-disclosure, relational disclosure, or informational disclosure. Greene, Derlega, and Mathews (2006) define self-disclosure as "an interaction between at least two individuals where one intends to deliberately divulge something personal to another" (p. 411). Even though self-disclosure is usually studied in terms of verbal messages, non-verbal messages may also be examples of self-disclosure if the goal is to reveal something personal (Greene et al., 2006). An abundance of communication research has focused on high-stress, potentially stigmatizing disclosures, most notably HIV infection (e.g., Derlega et al., 1993; Greene, Carpenter, Catona, & Magsamen-Conrad, 2013), but also heart conditions (e.g., Checton & Greene, 2012), cancer (e.g., Venetis et al., 2012), and infertility (Steuber & Solomon, 2011). This research has concentrated on how significant life events, such as medical diagnoses or

family-planning information, affected patients' revealing or concealing private

information about such events (Durham, 2008).

Greene et al. (2006) distinguish between personal self-disclosure (disclosure

about oneself) and relational self-disclosure (disclosure about a relationship with another

person). Both forms of disclosure have consequences for the development and

maintenance of personal relationships (Derlega et al., 1987; Greene et al., 2006; Petronio,

2002). Personal disclosures give relationship partners up-to-date information about what

each other is thinking and feeling and relational disclosures give partners information on

the state of their relationship (Greene et al., 2006). Both personal and relational

disclosures may simultaneously be occurring in sibling relationships. During caregiving,

one sibling may disclose to another sibling "I am worried about Mom being home alone"

or may share "I am behind at work from taking Dad to so many doctor appointments."

These are examples of personal disclosures. At the same time, one sibling may reveal to

another during caregiving, "You never help me. You only think of yourself." Or "We

have to find a way to pay for more care for dad." These relational disclosures are a

negative relational statement and filled with considerable risk to their future affiliation.

Due to the high level of risk to the relationship, such a disclosure may require

considerably more deliberation than one about a parent's health.

The decision to disclose. Individuals disclose information of varying degrees of

sensitivity, extending from less personal to highly guarded information (Petronio, 2002).

Individuals may differ in their patterns of disclosure based on their assessment of the

information (e.g., Afifi & Steuber, 2009; Afifi & Steuber, 2010; Greene, 2009; Petronio,

2002; Venetis et al., 2012). Greene (2009) proposed five dimensions of information

assessment for health disclosure: stigma around the information, preparation for receipt of the information, health prognosis, visible symptoms, and relevance to others. Other methods of information assessment used in prior research include information valence (e.g., Afifi & Steuber, 2009; Caughlin, Afifi, Carpenter-Theune, & Miller, 2005) and information importance (e.g., Derlega et al., 1987; Petronio, 2002). Assessment of the information rests on whether the information is of high importance and whether the information is at risk of being revealed. The present research will explore whether siblings assess information regarding elder care in a manner similar to these other contexts.

Decisions about whether to disclose also depend, in part, on an individual's assessment of the relative benefits and costs to the discloser, the target (the sibling) and their relationship (Dindia, 1998; Greene et al., 2006; Vangelisti & Caughlin, 1997). According to Petronio (2002), motivational criteria for disclosure consist of evaluative judgments about how compelled a person is to reveal private information at a given point in time (Durham, 2008; Petronio, 2002). Reasons compelling a person to self-disclosure include needing to seek help, feeling a duty to inform, wanting to educate the recipient, and desiring increased intimacy (Derlega et al., 1987, 2008). Much of the disclosure literature (e.g., Harber & Pennebaker, 1992; Jourard, 1971; Pennebaker, 1990; Stiles, 1987) initially focused on the assumption that people desire "catharsis" and so purge themselves of the information that they hold (Afifi & Steuber, 2009), unless the risk is considered too high.

In considering disclosures, people also assess the potential receiver according to their relational quality and anticipated response (Derlega, Winstead, Greene, Serovich, &

Elwood, 2004; Greene, 2009; Omarzu, 2000). Better relational quality is related to increased intentions to disclose and may even overcome the suppressive effects of perceived stigma (Greene, 2009). A sibling acting as the primary caregiver may reveal difficulties in managing all the activities associated with caregiving to a sibling with whom there is a close relationship. However, people do not disclose information if they anticipate that others will give unhelpful responses to their revelations, such as unwanted advice or comments (Lehman, Wortman, & Williams, 1987; Magsamen-Conrad, 2012; Pennebaker, 1993). For example, voluntarily child-free couples consider the potential negative reactions of pity and disappointment from recipients (Durham, 2008; Durham & Braithwaite, 2009; Steuber & Solomon, 2011) before disclosing their reasons for remaining child-free. Siblings may consider similar reactions from other siblings about their caregiving choices and involvement levels when deciding what information to share.

Greene's (2009) Disclosure Decision-Making Model proposes that persons also assess disclosure efficacy (see also Risk Revelation Model, Afifi & Steuber, 2009), a person's ability to share the message to produce the desired results (Bandura, 1977), before revealing information. Individuals may fear being rejected because they are not able to articulate their feelings and motivations accurately when revealing their private concerns or problems (see Nisbett & Wilson, 1977). Potential communication difficulties (Derlega et al., 2008) present a great challenge to caregivers, particularly those needing additional assistance. People who express their struggles actually elicit more rejection from others than do people who act as if they are coping quite well (Coates, Wortman, & Abbey, 1979). Thus, caregivers that confide their elder care struggles with their sibling may get less help than those that keep such information hidden.

Finally, pressures to reveal information may come from other people, as well as the target person. Other family members who know a piece of information might persuade people to reveal their information to the target family member (Afifi & Steuber, 2009). Patterns of interacting in the family have an important socializing affect on people's valuation of communication (Avtgis, 1999). Families that encouraged open communication when children were young may still expect the siblings to be open with one another as adults. This openness may become more difficult as the topics addressed become more sensitive or complicated. Another strategy, therefore, may be to avoid, rather than hide, difficult information.

Topic Avoidance

One means of limiting damage to relationships is to restrict the expression of dissimilarity or, rather, avoid communicating about issues of disagreement. Roloff and Ifert (1998) argue that romantic partners should not be assumed to have identical interests, and siblings also do not necessarily share identical interests. Adult siblings may have different interests, priorities, and viewpoints due to different life experiences. To manage differences, topics can be avoided by never being placed on the floor for discussion or banned by temporarily suspending discussion of issues that have already been mentioned (Roloff & Ifert, 1998). The former is a unilateral decision to restrict a topic, while banned topics that become "taboo" (unacceptable to discuss) imply that some dialogue has taken place (Roloff & Ifert, 1998). For example, a taboo topic with a sibling during caregiving may be the parent's end-of-life wishes or personal finances.

Guerrero and Afifi (1995b) found four reasons for topic avoidance in parent/child relationships: 1) self-protection, wanting to avoid judgment, criticism, and

embarrassment; 2) relationship protection, wanting to avoid feeling vulnerable; 3) partner

unresponsiveness, avoiding topics because one feels the partner will not respond; and 4)

social inappropriateness, tendency to avoid topics that are not socially acceptable. Futility

of discussion tied to an expected response is an additional motivation for avoidance later

identified by Afifi and Guerrero (2000). Individuals may avoid communicating because

they feel that they cannot change anything or consider it useless to talk about a particular

issue. Motivations to avoid topics may change, however, over the life span and in

different situational contexts. For example, why a teen keeps the details about prom night

from a parent is different from why an adult keeps the details about personal finances

from a parent.

Guerrrero and Afifi (1995b) confirmed the effects of age on the level of topic

avoidance. Teenagers, as compared to pre-teenagers, increase avoidance with parents, but

that avoidance decreases when the teenagers become young adults. During the teen years,

siblings avoid more topics with their parents, particularly negative life experiences, than

with one another (Caughlin et al., 2000). There are no studies, however, that have

examined the later stages of development in the family life cycle and whether topics

avoided change in the transition to parental caregiving.

In middle to late adulthood, siblings develop ways of interaction that avoid

conflict and overt rivalry (Cicirelli, 1991). Individuals may choose to avoid conflict by

withholding their complaints about another, by suppressing arguments or preventing

elaborate discussions, and/or by negotiating an agreement to stop talking about the source

of conflict (Roloff & Ifert, 2000). However, a family crisis may require communication

about these once avoided topics, such as a sibling's lack of responsibility or a spouse's

interference in family affairs. Early rivalries and aggression between siblings may be reactivated in later adulthood at times of crisis or stress, leading to conflicts and aggressive actions with siblings (Cicirelli, 1991).

When a major life event occurs, individuals must decide whether to reintroduce an avoided topic, how to reintroduce it, and what the consequences might be for the relationship. These are decisions filled with considerable uncertainty. One reason to reintroduce an avoided topic is when urgent action is required, such as when a parent suffers an injury or becomes critically ill and requires care. Planned conversations that reintroduce topics in romantic relationships most often occur when the topics deal with relational norms (Roloff & Ifert, 2001). However, unanticipated events, such as a job loss, force romantic partners to deal with issues in an immediate and unplanned fashion, which, in turn, inhibits positive interactions (Roloff & Ifert, 2001). Siblings may experience the same rush to confront issues during elder care, but their topics are more likely to address matters of specific personal behaviors (not calling or visiting a parent) or attitudes (not feeling respected by a sibling).

Individuals in various professional and personal roles may also avoid topics to manage conflict about an issue or decision. A physician who is unsure how a patient or family members will cope when informed of an illness may avoid disclosing this information as long as possible (Hines, 2001; Hines, Badzek, & Moss, 1997; Katz, 1984; Koddish & Post, 1995). A patient who is not certain that family members will understand or support a decision to forgo a life-sustaining intervention may never express a preference to the family (Hines et al., 1997; Miles, Koepp, & Weber, 1996; Singer, Martin, & Kelner, 1999). Additionally, family members that are uncertain about how

seriously a disagreement about treatment will damage family relationships will avoid the discussion (Hines, 2001) and may even avoid family members themselves. The question remains as to what other interpersonal (such as relational quality) or situational (such as the type of illness or level of caregiving) dynamics may be related to feelings of uncertainty and uncertainty management.

Avoiding topics with family members is different from knowingly keeping information from family members. During caregiving, certain adult children may develop alliances with their parents, withholding information from their siblings, or siblings may form coalitions with one another, keeping information from their parents or even other siblings. Family secrets require greater levels of negotiation than "taboo topics" over who owns the information, who gets to share that information, and what level of information they get to share. The next section will review more of the complexities of family secrets and their association with sibling relational quality.

Secret Keeping

Secrets are distinct from more general private or non-disclosed information. Secrets are composed of information that is purposefully hidden, typically viewed as negative (Vangelisti, 1994), and usually involve the secret keeper (Kelly & McKillop, 1996). In addition, secrets are held within a social context, and secret keepers may believe that other people may have some claim to the hidden information (Kelly, 2002). For example, people's daily bathing rituals are considered to be private but not secret because people agree that these practices are not for public display. However, hiding a dangerous contagious disease from a sexual partner is considered a "secret" because the partner may perceive a right to know this information in such case (Derlega & Chaikin,

1977; Kelly, 2002). But what may be private information in one aspect of society or in one relationship may be secret information in another (Kelly, 2002). The difficulty in a family setting may lie in knowing how different family members categorize information, for example as private, secret, or "open." Privacy and secrecy cannot always be so neatly distinguished because it is not always clear who has the right to know or control the information (Caughlin & Vangelisti, 2009).

Types of family secrets have been categorized as taboo topics, rule violations, or conventional topics (Kelly, 2002; Vangelisti & Caughlin, 1997). Examples of taboo topics that may arise in an elder care context include a pending divorce, substance abuse, financial status, and mental or physical health. Rule violations may relate to sibling expectations about the share of caregiving tasks, such as house maintenance, financial management, personal care, or meal preparation. Conventional secrets involve information that is not necessarily wrong but is considered inappropriate to discuss (Kelly, 2002; Vangelisti & Caughlin, 1997). During caregiving, conventional secrets may be the changing status of a parent's health or personality conflicts among family members (Kelly, 2002). Keeping information secret may help a primary caregiver better manage the stress of aiding an aging parent but also presents risks.

Benefits of secret keeping. Secrets likely serve more than a single function, as well as different functions for different members of the family. Parents may keep a secret from the children to prevent the children from worrying. However, an entire family may keep a secret from non-family members because the information is "none of their business." Additionally, family members may keep secrets to protect family relationships. The reasons to keep secrets include creating and maintaining intimacy,

building and maintaining group cohesiveness, protecting the family structure from falling

apart, or shielding family members from social disapproval (Vangelisti, 1994). Each of

these reasons necessitates the evaluation of uncertainty around family relationships and

external events.

Keeping information secret can serve beneficial and even necessary functions for

interpersonal relationships (e.g., Petronio, 1991). For example, keeping a secret can

protect the other person emotionally, maintain the other person's respect, and preserve a

level of relational satisfaction that may not exist once the information is revealed

(Derlega et al., 1987, 2008). Family secrets can maintain illusions about family

relationships by managing from whom a secret is withheld (e.g., some family members,

all family members), what secret is withheld (e.g., relationship status, health diagnosis),

or why a secret is withheld (Vangelisti, 1994).

Risks of revealing secrets. Unlike information that is merely private or avoided,

these intra-family secrets are consciously guarded by the people who hold them (Bok,

1983; Caughlin et al., 2000; Vangelisti, 1994). This means that intra-family secrets are

typically known by fewer people and are less likely to be disclosed than other types of

private information (Caughlin et al., 2000; Derlega et al., 1993). Among family members,

secrets may only be shared with another family member if the boundary between the

secret holder and another family member is relaxed (Caughlin et al., 2000), meaning

there is less risk associated with disclosing the information.

The risk to revealing a secret is associated with perceptions about the functions of

the secret and the relationship between the secret keeper and the people to whom the

secret pertains (Kelly, 2002; Vangelisti & Caughlin, 1997). Revealing secrets can help a

person gain new insights into the problem before them, and yet not revealing secrets may help a person maintain a particular image or identity to an audience (Kelly, 1999). If one sibling reveals undesirable information to another (such as a lack of financial resources or a lack of interest in providing care), the sibling may come to develop an undesirable image (Kelly, 1999). Another problem associated with revealing secrets to a sibling is that the sibling may not be able to be trusted to keep one's secrets or to protect one's identity (Kelly, 1999; Venetis et al., 2012). A sibling acting as primary caregiver may reveal feelings of stress and burden and ask the other siblings to help hire a home health aide for the parent. The other siblings may then tell the parent that "a stranger" will be coming to the house because caregiving was overwhelming the original caregiver.

Summary of secret keeping. Secrets have most often been explored in the family context either in terms of parent-child dyads or the whole family unit. This research is difficult to extend to siblings because siblings may be keeping secrets within a dyad (one sibling keeping information from another) at the same time that they are keeping secrets as a unit (all siblings keeping information from a parent) or as a whole (the family not telling those outside the family). For example, one sibling may be keeping a secret from another about a parent's medical diagnosis. Yet, all siblings may be keeping from their parent the siblings' (or one sibling's) wish to move the parent into an assisted living facility. In addition, a sibling may also be keeping a personal secret from the whole family, such as a job loss or a child's struggle in school.

Past histories with disclosure recipients form the basis for positive or negative responses (Greene, 2009). If the secret keeper has known the sibling well and for a considerable period of time, the secret keeper has a high level of experience on which to

base a prediction regarding whether the sibling's response will be helpful (Kelly &

McKillop, 1996; Magsamen-Conrad, 2012). Siblings typically have such relationship

history and will use that knowledge of prior behavior to gauge their uncertainties about

relational expectations during caregiving. These expectations may pertain to how a

sibling might respond to a previously avoided topic or a personal secret. Based on those

expectations and subsequent risks, a sibling will decide whether or not to disclose

previously withheld or unknown information. The following section will further discuss

aspects of family communication and an individual's decision to share information with

siblings.

Summary of Information Management

For sibling communication to be better understood, researchers need to study

information management in relation to the "problems" that siblings are seeking to

integrate, such as constructing meaning and managing the uncertainty of their

relationships in various contexts. The level and type of uncertainty can shape the nature

of the encounters that take place, the topics selected for conversation, and the intimacy

with which topics are discussed (Fowler, 2009). Although studies have examined the self-

disclosure between siblings (e.g., Floyd, 1996), for example, few have examined topic

avoidance or addressed the dialectical contradictions (such as openness-closedness)

experienced by siblings (Fowler, 2009). Yet, these questions could add to an

understanding of how adult siblings manage conversations and confront uncertainty

during times of transition from one family development stage to another. The next section

will discuss family communication patterns and the influence of stress and uncertainty on

those patterns.

Family Communication

Individuals learn to communicate and acquire behaviors initially through observation of their family environments (Bandura, 1977, 1986; Kunkel, Hummert, & Dennis, 2006). A situated knowledge perspective views families as a culture, a collection of beliefs and assumptions related to personhood, relationships, and common resources (Fitch, 1994). Children grow up learning ideas of what is appropriate behavior. These include when to speak or when to stay silent and when to challenge an idea or when to follow ideas presented. Issues of when to pursue a task independently versus when to look to others for help also get incorporated into the family culture. These ideas of family priorities and appropriate behavior are referred to throughout life.

When siblings are faced with the transition to parental caregiving, how they respond to the transition may be a reflection of how their parents responded to changes over the years. For example, children might learn by watching their parents that the daughter is to care for the older generation rather than hiring external caregivers. Children may also learn that when a parent loses a job, every member of a family is expected to make choices to reduce spending for the overall well-being of the family. Throughout these events, family members may openly discuss options and expect everyone to contribute to a solution or avoid conversations and handle matters independently or even employ a mix of approach and avoidance. The question remains whether certain communication behaviors change how individuals manage uncertainty with siblings as they struggle to blend their ideas regarding their relationship and their caregiving activities. The dimension of openness within the framework of the Family

Communication Patterns (Fitzpatrick & Ritchie, 1994) will be the first concept reviewed in this section.

Open Family Communication

McLeod and Chaffee (1973) suggested that families tend to develop fairly stable and predictable ways of communicating with one another. Fitzpatrick and Ritchie (1994) discovered that sharing a social reality is an ongoing process in families and identified two contrasting communication orientations. The conversational orientation is one in which all family members are encouraged to participate in open exchange about a wide array of topics (Fitzpatrick & Ritchie, 1994). In contrast, the conformity orientation is one in which family communication stresses a climate of homogeneity of attitudes, values, and beliefs (Fitzpatrick & Ritchie, 1994).

The family with a high conversational orientation is one that spends a lot of time interacting with each other and family members freely share their individual activities, thoughts, and feelings with each other (Koerner & Fitzpatrick, 2006). They hold the belief that open and frequent conversation is essential to an enjoyable and rewarding family life and the primary method of educating and socializing children (Koerner & Fitzpatrick, 2002). As such, siblings develop a competence for communicating that may lead to a later decrease in their uncertainty about what others are thinking about caregiving.

Associated with a high conformity orientation is a belief in a traditional family structure, one is which families are hierarchical and parents make all decisions (Koerner & Fitzpatrick, 2006). Family members come to expect that resources such as space and money will be shared (Koerner & Fitzpatrick, 2006). Siblings with a conformity

orientation develop a conflict approach, along with a communication skills deficit, that may later increase aspects of uncertainty and lead to the use of greater destructive communication behaviors.

The conversation and conformity dimensions are individual perceptions of family communication and reflect whether one feels communication was open and inclusive or closed and directive. Different members of the same family may have very different perceptions depending of their own family experiences. For example, parents may have been strict with older children but more lenient with younger children. This might create a situation where the older children were not allowed to question their parents' authority while the younger ones were. In another example, children living at home may witness parents caring for an aging family member. This experience may create expectations for the provision of elder care that those living away from home would not have. Those siblings from families with more open orientations may experience less or different kinds of uncertainty regarding their relationships and their responsibilities at times of change. Now that family communication patterns have been reviewed, the next section will discuss how those patterns may be affected by stress and uncertainty.

Stress and Uncertainty

An aging parent's need for assistance with daily activities raises many uncertainties and challenges family relationships. For some siblings, this type of change is expected with the passage of time (Cowan, 1991) and may not prompt the same level of stress as an unexpected event, such as a fall requiring surgery and intense medical care. This type of event is more difficult to foresee because it seems to be somewhat random and does not occur in all families. Without any preparation, some siblings may be

shocked by the sudden changes and experience heightened uncertainty about the event. Family stressors can also be classified along the dimensions of temporary versus permanent or voluntary versus involuntary (Adams, 1975). The care needed after a fall may be only for a short period of time, however, the care needed for a parent developing Alzheimer's is for a much longer duration. The resulting uncertainty can produce varied individual reactions and alter the communication behaviors of family members (Segrin & Flora, 2005), including that between siblings.

In addition, family members sometimes willingly enter into situations that can be stressful. A son or daughter may feel an obligation to care for an aging parent and volunteer for the task. Segrin and Flora (2005) note that many individuals conclude that voluntary stressors are easier to cope with than those that are involuntary. However, voluntary stressors carry with them more personal responsibility but more uncertainty about the role of others. This can create considerable emotional distress within the family (Segrin & Flora, 2005). For example, one adult child might volunteer to care for a parent, expecting that siblings will help. If those expectations are not met, the caregiver is left with more uncertainty about the caregiving situation and their sibling relationships than might have otherwise have occurred (i.e., why are my siblings not helping, how will our relationship adapt to this situation?).

What determines the level of stress is not just the event itself, but also family member perceptions of and subsequent reactions to the event. According to Hill's ABC-X Model (1949), a stressful event (A) was seen as the event or situation that brought about some type of change in the family, and family resources (B) were the buffers enacted against the potentially destructive changes of such events. Family members'

perceptions (C) were their appraisal or assessment of the situation and (X) was the resulting stress or crisis (Hill, 1949, 1958). The present study argues that the perceptions of the event and siblings' relationships contribute to stress and, therefore uncertainty as outlined by PI Theory, among siblings facing elder care.

Family members experience stress when they do not have the means to handle the challenges or changes that come with certain stressors. Some family members internally create stressors through their own problematic interactions, such as those between a parent and a teenage son or daughter (Pearlin & Skaff, 1998). Other family members are subjected to stressors that are externally placed on them, such as when a spouse is laid off from work (Pearlin & Skaff, 1998). In either case, each family member must decide how to respond to a life event (*the stressor*); their choices will determine the tensions (*the stress*) family members experience as a result.

Summary of Family Communication

Communication can play a key role in shaping the factors in Hill's ABC-X (1949, 1958) model. Traits, abilities, and qualities of individual family members, the larger family network, and the greater community are the resources that could be used to address demands imposed by an event (McCubbin & Patterson, 1985), such as injury or illness. Families that possess communication resources are considered less vulnerable to stressful events (Segrin & Flora, 2005), but their attitudes about the situation could make these resources inaccessible. How family members discuss and characterize life events and situations is strongly tied to how stressed they are in response to those situations (Lazarus & Launier, 1978). Siblings in a family with an orientation toward open

communication may not see an event as stressful, and, therefore, may experience less uncertainty about the event, care alternatives, and relationship expectations.

Siblings are the greatest source of interpersonal stress around elder care and, therefore, readily contribute to caregiver strain (Brody, 1990; Suitor & Pillemar, 1993). Bedford (1996) has cautioned that due to a lack of long-term longitudinal data, it is not known whether these feelings are typical of a particular relationship, whether they are a temporary response to the life event, or whether they are the start of a shift in feelings towards the sibling. How family members frame and respond to the stress of elder care could alter the existing and future sibling relationship. The next section will discuss how caregiving may be seen as an expected or unexpected part of family development.

Family Development

Although particular developmental events (e.g., getting married or having children) are known to change the dynamics of adult sibling relationships, how communication patterns and strategies change due to those events is not known (Mikkleson, 2006). This is a critical piece for understanding sibling relation dynamics during times of parent injury or illness. Normative life changes (those expected or traditionally occurring) are often welcome and accompanied by less stress than unexpected changes. Some siblings may not be ready to step into the caregiving role, preferring to hold on to their ideal of the parent-child relationship or to maintain a steady state of personal activities and responsibilities.

Siblings experience uncertainty in light of their understanding of context and frame of reference (Babrow et al., 1998). Their understandings could be quite different, even for those siblings raised in the same household. After years away from their family

of origin, adult siblings may differ dramatically in terms of demographics (such as marital status, educational attainment or income level) or life stage. These differences may lead to contrasting views that increase the levels of uncertainty between siblings and have substantial implications for their relationships (Babrow, 2001) and their ability to provide care to aging parents. The next portion of the literature review will discuss the family life cycle and its relation to uncertainty at various life stages, followed by a discussion of family caregiving.

Family Life Cycle

Adult sibling relationships exist within the context of overall family development. Family development models, such as that proposed by Duvall and Hill (1948), commonly divide the family life cycle into eight stages of family development: establishment (no children), first parenthood (infants and toddlers), family with preschool children, family with school children, family with adolescent children, family as launching center, family in middle years, and family in retirement. Stages are defined as periods of relative structural stability which are distinct from adjacent stages (Mederer & Hill, 1983). Family members are forced to change the patterns of interrelating each time one or more members are added to or depart from the family. Although researchers have argued that the patterns must also vary each time the oldest child changes a development stage (e.g., Mederer & Hill, 1983), no studies have investigated those times when the oldest member of the family changes developmental stages. The present study will examine the stage when parents move from being the caregivers to the care recipients.

Family development models view the family as a system made up of various social positions, each with a corresponding set of rules. The family system typically

maintains predictable patterns of role relationships involving the division of labor, communication, affection, and decision making (Mederer & Hill, 1983) as the family ages. However, some phases result in dramatic role disruptions, such as when children are leaving home and transitioning to adulthood. This launching phase has traditionally been the time of the greatest deficit in expressive communication (Mattessich & Hill, 1987). Whether the caregiving phase will also see the same communication shortfall, as siblings struggle over what to say or do about aging parents, has not been explored.

One reason that family development models may not have focused on mature families is that the focus has too often been on descriptions of family life within stages and given little attention to the processes of transforming between stages, which is where parental caregiving usually occurs. In addition, the assumption is often made that structural change is consistent and that each role structure is different (Mederer & Hill, 1983). However, transition between stages does not necessarily change all roles, rules, and patterns of interaction. Sibling uncertainty about roles and rules may manifest itself in feelings of ambiguity around caregiving or ambivalence regarding care alternatives.

Traditional presumed roles (the provider, the nurturer, the controller) may be in conflict with actual roles being fulfilled and contribute to uncertainty regarding family. A family that has typically turned to the oldest child in the family for leadership and decision making may be forced into turmoil if the oldest becomes unwilling to participate in caregiving. Conversely, the oldest child may continue to make decisions, but the other children may be left to carry out the decisions with little input as to how such choices will affect their lives. Each scenario may create uncertainty about the various aspects of caregiving. Destructive communication behaviors may result as adult siblings attempt to

integrate their multiple perceptions of uncertainty. The next section will discuss how this complex transition to caregiving is something that will be experienced by most adult siblings.

Family Caregiving

More than three in ten U.S. households (or almost 40 million households) have at least one person serving as an unpaid family caregiver (National Caregiving Alliance, 2009). Caregivers are predominantly female and primarily care for a relative, with over one-third caring for a parent and over one-eighth caring for their own child (National Caregiving Alliance, 2009). On average, caregivers spend more than 20 hours per week providing care. Caregiving is even more time intensive for those who live with the care recipient (almost 40 hours/week) and for those caring for a child under the age of 18 (almost 30 hours/week) (National Caregiving Alliance, 2009). Most of this time is spent assisting the relative with at least one Activity of Daily Living (ADL), including getting out of bed, getting dressed, assisting with bathing, assisting with toileting, and feeding (National Caregiving Alliance, 2009). All of the activities provided by caregivers lead to a high levels of caregiving burden, with a strain on physical and emotional health and tensions with work (including a decrease in wages or even a loss of employment) and family responsibilities (including less time with spouse/children or even increased instances of divorce), particularly since over half of all caregivers claim to provide all or most of the unpaid care (National Caregiving Alliance, 2009). This increase in burden may then be associated with lower level quality of care for the aging parent.

Caregiving burden is associated with the type and length of caregiving tasks being performed. The more personal the activity or the longer length of time providing the

activity, the higher level of caregiving burden (National Caregiving Alliance, 2009). This is a reason why family caregivers of people with dementia are more likely to experience caregiving burden. About one-third of caregivers of a person with dementia provide help to their care recipients with getting to and from the toilet, bathing, managing incontinence and feeding (Alzheimer's Association, 2014). Fewer caregivers of other older people report providing help with each of these types of care (Alzheimer's Association, 2014). Caring for a person with dementia also means managing symptoms that family caregivers of people with other diseases may not face, such as neuropsychiatric symptoms and severe behavioral problems (Alzheimer's Association, 2014). The heightened degree of dependency experienced by some people with Alzheimer's and other dementias results in some caregivers spending an average of nine hours per day providing care for well over 5 years. The question remains as to what connection the type and/or degree of a parent's illness has with problematic integration and caregiver relationships, including siblings.

Parental caregiving and adult siblings. The most commonly cited tasks of siblingship during middle adulthood relate to cooperation in the care of elderly parents and later in the dismantling of the parental home (Goetting, 1986). Caring for an aging parent typically involves completing activities of daily living, providing direct physical and emotional support, and assisting with health care and financial decisions on the parent's behalf (Khodyakov & Carr, 2009). Researchers have argued that the entire family of an aging parent, rather than individual family members (as is the case in spousal caregiving) or parent-child dyads (in parent-child caregiving), is the proper unit of caregiving analysis (Matthews & Rosner, 1988). According to Checkovich and Stern (2001), caregiving decisions are not independent across family members.

The number of activities involved in caregiving increasingly makes it a team effort with multiple family members needing to trade off and coordinate care efforts (Silverstein & Giarusso, 2010). Family caregiving represents a broad range of activities that can include providing personal care, doing household chores, preparing meals, shopping, taking care of finances, arranging and supervising activities and outside services, and coordinating medical care (Roberto & Jarrott, 2008). In addition, a family that emphasizes the emotional needs of its members provides companionship, a sense of continuity, belongingness, and family identity. In this type of family, kinship ties and familial responsibility take precedence over personal roles and obligations (Pyke & Bengston, 1996). This does not mean that everyone participates equally, rather each family member does a different part of the caregiving process (Matthews & Rosner, 1988).

The type of caregiving tasks to be performed and the feelings of kinship and emotional closeness (Ganong, Coleman, & Rothrauff, 2009) may also change caregiving expectations. Although closeness among family members creates a greater sense of kinship and responsibility, the type of caregiving task (such as one more personal in nature) decreases expectations of assistance. However, adult siblings' normative responsibilities to assist older parents are generally greater when exchanges are reciprocal rather than one-sided or nonexistent (Ganong et al., 2009). Adult children are often expected to assist their parents in exchange for resources previously received (Ganong et al., 2009). This differs from spousal or parent-child caregiving situations, in which spouses do not have such expectations, or, in the case of small children, are unable to give a comparable level of resources.

The provision of help is largely shared when there is a family culture of using effective methods for resolving conflicts among family members (Lieberman & Fisher, 1999).Family members align with the philosophy of the group because they will feel guilty if they do not, they will be shamed if they do not, or they will be punished if they do not (LePoire, 2006). In other words, the mechanism of self-regulation within the family operates according to socialization, the induction of social sanctions, and formal penalties (Broderick, 1993). However, family goals also grow out of the evolving development needs of individual members and new challenges imposed by changing family structures and situations (LePoire, 2006). The developmental stage of the family affects the multiple goals that are operating at any given time, and goals may shift according to the life event before the family.

Demographic differences affect the willingness and ability of an adult child's provision of care to aging parents. Kivett and Atkinson (1984) found that parents of only children were less likely than others to receive assistance. Parents were also less likely to receive direct care from their children if they or their children had higher incomes, if they were geographically distant from their children, if their children were married (Stoller, 1983), or if their children were employed (Brody & Schoonover, 1986). Rather than providing care themselves, some families hired home care assistance for their parents (Mancini & Blieszner, 1989). Although the first portion of the current research collected demographic information, it did not explore the information further. Future research will need to consider whether demographic differences among adult siblings contribute to the divergence of expectations, ambivalence regarding caregiving alternatives, and overall uncertainty about the caregiving situation.

Communication about caregiving. The roles and parts of the caregiving process are typically coordinated by a main care provider who directs the efforts of all subordinate caregivers. When one adult child has primary responsibility for caregiving, other siblings take secondary roles or completely remove themselves from caregiving (Merrill, 1996). Primary caregivers must then devise a number of strategies for involving siblings in care (Merrill, 1996). These included asking for respite care and occasional help, hinting that they could use help, demanding that their siblings help, attempting care for period of time, or forgoing any further involvement. Caregivers stated that their challenge to involve others was greatest when the parent lived with the caregiver or when the caregiver volunteered for the role (Merrill, 1996). Although research has highlighted the actions of primary caregivers, little is known about the siblings' response to and interpretations of the requests from the primary caregiver.

When siblings attempt to negotiate among themselves about who will provide care for an aging parent and in what manner, conflict often arises (Connidis & Kemp, 2008). If the primary caregiver feels that there are inequalities in the division of labor among adult siblings, the caregiver may confront other siblings and ask them to contribute more (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003) or avoid their siblings and change their perceptions of the situation. Children asked by their parents to be caregivers will have very different perceptions than those who volunteered or just "fell into" the position because no one else would provide care. Even if siblings find a way to equitably deal with their caregiving responsibilities, advance directives for health care that appoint one child as power of attorney, for example, may undermine sibling relationships (Khodyakov & Carr, 2009). For example, early patterns of cooperation may

account for sharing responsibilities for parent care (Tonti, 1988), while the reactivation of early conflicts may account for conflicts that arise over parent care (Bedford, 1996). How siblings communicate with one another during adolescence is associated with the development and perception of relationships later in life (Rocca & Martin, 1998).

Families rarely have explicit discussions about end-of-life decisions, and little congruence exists between the caregiver's, the care recipient's, and other family members' perceptions of these issues (Pecchioni, 2001). Explicit discussions involve active problem solving through direct, conscious and verbal agreements that require expressivity, self-disclosure, and proactive planning from participants. However, families tend to avoid open conflict and rely on silent arrangements in which decisions evolve without conscious, verbal discussions about the topic (Pecchioni, 2001). Problems arise when family members make caregiving decisions based on false assumptions that are not consistent with the care recipient's desires. With siblings, the matter is complicated because one sibling may have strong opinions about what should be done and others may have very different ideas, leading to difficulty as they attempt to integrate their ideas and make decisions.

Summary of Family Development

The time when the head of the family suddenly needs assistance marks a change for all members. Mederer and Hill (1983) categorize such a change as a structural event that forces families into major reorganization and marks a new stage of development. Typical events include a change in the number of family members (through birth, death or marriage), major status changes (i.e., those related to marriage or employment), and age composition changes. Age related changes have usually been associated with the

individual development of children and not the changes involved when parents age and their needs change. Just like other family transitions, uncertainty surrounds the caregiving events as siblings may no longer understand or agree upon changing family roles or structures. For example, if a parent was always the family decision maker, siblings may be uncertain as to who will step into that role. The uncertainty may prove too much if there are a large number of care alternatives to choose among at the same time that there is a wide divergence in sibling expectations, overwhelming the family system. The next section will discuss how sibling expectations are established early in life (Levitt, 1991), and these past experiences persist in influencing the sibling relationship during the second half of adulthood.

The Sibling Relationship

With recurring shared interests and life courses, sibling relations are often considered more similar to peer relations than other family relationships. However, there are some notable differences between sibling and friendship ties. The first unique characteristic of the sibling relationship is its pervasive nature. Sibling ties exist across the lifespan. As such, they are often the longest lasting relationship in people's lives (Bedford, 1993). In addition, few relationships affect as many people's lives as the sibling relationship, with close to 90% of adults reporting at least one sibling in their lives (Smith, Marsden, Hout, & Kim, 2011).

Another unique aspect of sibling relationships is that they are involuntary and permanent. Because they are not chosen like friendships, there are often fewer desired characteristics in our siblings compared with friends. Those differences may lead to conflict or even suspension of any relational contact, but even without contact the sibling

status remains (Cicirelli, 1995). This presents a situation where siblings always have an opportunity to revitalize their relationship, particularly when personal needs or family events arise. For example, siblings who have severed relations may reconnect when a parent suffers a serious injury or develops a critical illness.

A final noted characteristic is that sibling relationships are influenced by long, shared family histories, and this shared history with siblings is different from that with friends (Mikkleson, 2006). The sibling relationship includes such things as the historical perception of parent's treatment of the siblings, the specific parent-child relationships, and the management of sibling conflict during childhood (Brody, 1998; Stocker & McHale, 1992). These perceptions could dramatically affect the sibling relationship into adulthood and enhance or lessen the ability to communicate effectively during life transitions. For example, if one sibling was perceived to be favored by the mother during childhood, other sibling(s) may not feel a need to participate in decisions about or provisions of caregiving, adding uncertainty and negativity to the situation.

The sibling relationship is one that is never static but rather evolves over time as individual roles in the family change (Cicirelli, 1991). Most of the research on sibling relationships has centered on aspects of closeness, frequency of contact, types of support and persistence of rivalry while examining how different interaction strategies have influenced the adult sibling relationship. Although these studies are related to communication, little is known about the actual communication behaviors within adult sibling relationships (Mikkleson, 2006). Questions remain about how siblings initiate a connection, produce or avoid talk around family issues, and manage personal perceptions and uncertainties to yield a care decision.

Care decisions may be easier for siblings that have more frequent contact. Those that see or talk to one another more often may have greater opportunities to discuss life events, such as elder care. Increased discussions about family issues may yield lower levels of uncertainty about an event and leave fewer questions about the sibling relationship. The next section will review patterns of sibling contact and how those patterns changes over time.

Sibling Contact

The pattern and frequency of sibling contact may be a cursory index of general socio-emotional support (Goetting, 1986). A sibling's decision to assist with caregiving tasks may be viewed as a provision of social support, an interaction that provides individuals with assistance (Hobfoll, 1988). Sibling frequency of contact, however, can vary greatly (daily to once a year or less), as can the medium used to communicate (face-to-face, phone, email, or social media, etc.). Lee, Mancini, and Maxwell (1990) found that emotional closeness, sense of responsibility, similar expectations, and geographic proximity were the most important variables in explaining existing patterns of sibling contact. Emotional closeness was also shown to be positively related to the desire for additional interactions (Ross & Milgram, 1982). No previous research details the connection between the frequency of sibling contact and the persistence of uncertainty in family matters.

The lack of research about contact and uncertainty is unfortunate, particularly since family ties are known to change over time. Sibling contact tends to decrease temporarily during the first half of adulthood, as siblings move out of the family home and into their own spaces and perhaps begin their own nuclear family (Bedford, 1996).

During the middle portion of their life span, siblings become preoccupied with their own lives. Raising children and building careers results in sibling separation (Bedford, 1996), as these activities take added time and attention. The relationship is largely constrained by different values and interests during this period. Once this stage is over, sibling contact and interaction generally increases (Gold, 1989).

Little is known, however, about the communicative processes that occur during this ebb and flow of the sibling relationship (Bedford, 1996) in later life stages. This leaves a critical gap in the research because it is during the separation associated with middle adulthood that siblings often need to make decisions about care for aging parents. Feelings of closeness or responsibility may affect which sibling reactivates the relationship, and communication behaviors may change from that of emotional support to that of informational exchange (life updates). Questions remain about how adult siblings juggle the new and uncertain elements associated with later life activities and how these are translated into provisions of assistance. Assistance may come more naturally to those siblings that feel a greater sense of closeness. The next section elaborates on the concept of sibling closeness and its association to elder care.

Sibling Closeness

The closeness felt in the sibling relationship may be more important than the frequency of interaction between siblings. Closeness in adult sibling relationships has been defined as common experiences, mutual values, shared religious beliefs, family tradition, and common interests (Floyd, 1994, 1996). Closeness may be influenced by whether the siblings felt close when they were children (Scott, 1983), the number of similarities (interests, opinions, beliefs, and attitudes) shared by siblings (Folwell, Chung,

Nussbaum, Bethea, & Grant, 1997), and whether the siblings are near in age. The current age or life stage of adult siblings also affects feelings of closeness. Older adults tend to rate relationships with their siblings as very positive (Cicirelli, 1995). Just as marital couples experience increasing commitment with increasing age (Booth, Johnson, White & Edwards, 1986; Vaillant & Vaillant, 1993), sibling relationships are more highly valued in senior years due in part to greater similarities in life experiences and a greater need for emotional support (Atchley, 1991).

Siblings who are supportive both emotionally and affectionately remain committed to one another despite barriers such as geographic distance, parenthood, and differing lifestyles (Rittenour et al., 2007). Compared to siblingships, friendships exhibit more reciprocity, positive affect, mutual activities, and shared topics of conversation (Floyd, 1994). Siblings, however, report closeness in instrumental ways such as doing favors for one another, providing help in an emergency, and "just knowing we are close" (Floyd, 1994). This is similar to parent-child closeness, which is a matter of affection, comfort, and time spent together (Buchanan, Maccoby, & Dornbusch, 1991) and more general psychological closeness, which is a reflection of mutual respect and understanding and time spent together (Checton, 2010; Greene, 2009; Vangelisti & Caughlin, 1997). In the sibling relationship, closeness may emerge as a function of dependability ("my siblings are there for me when I need them") and translate into a team approach to parental care. Feelings of constancy, however, could quickly become overshadowed by feelings of uncertainty in times of transition and stress.

Closeness may play a role in how siblings manage the uncertainty associated with the tasks and decisions of caregiving. Siblings' shared experiences, mutual values, shared

religious beliefs, and common interests could contribute to relationships where siblings experience a greater level of knowledge and comfort around the decisions to be made and the associated roles and responsibilities each will undertake. However, siblings who are not close or who experience high levels of rivalry could have little idea of what could result from such a life change. Their levels of uncertainty around elder care and its impact on siblings' relationships could dramatically increase. The next section will further discuss issues of sibling rivalry.

Sibling Rivalry

There is conflicting research as to whether sibling rivalry decreases with age or remains relatively stable (Cicirelli, 1995). Some research has found that sibling rivalry declines over time, as siblings move out of the family home and into their own lives (Cicirelli, 1985). However, results using clinical interview techniques suggest that sibling rivalry may be greater than indicated on self-reports (Bedford, 1989; Ross & Milgram, 1982) and persists into old age. One difficulty in adult sibling studies is that participants might not be willing to admit certain negative feelings toward their siblings on self-report surveys.

Most adults will admit that they feel that their family environment is differential, meaning they believe that they or their siblings are the recipients of preferential treatment by their parents (Daniels & Plomin, 1985). Aune and Comstock (2002) found that 48% of adults with siblings recalling recent family jealousy indicated that a sibling was the jealous target. The more siblings perceive parental favoritism, the more negative the relationship between siblings (Boer, Goedhart, & Treffers, 1992). This negative relationship may result in more destructive communication in the sibling relationship and

less companionship, intimacy, affect, and interaction between siblings (Martin et al.,

1997). This destructive communication, in turn, may result in increased uncertainty about

family caregiving tasks because siblings may be less aware of the feelings and intentions

of other siblings.

The uncertainty about feelings and intentions of siblings may be greater

depending on the gender make-up of the sibling relationship. Ross and Milgram (1982)

found that brothers reported more competiveness, ambivalence, and jealousy in their

relationships than did any other sibling gender combination. Furthermore, they found that

sibling rivalry is most often initiated by a brother rather than a sister. These findings

complement research about sibling support, which finds females are more supportive of

their siblings than males (Cicirelli, 1995). Sisters are more likely to share information for

the purpose of seeking emotional support than brothers (Dolgin & Lindsay, 1999), and

sisters are also more likely to give and receive help (Gold, 1989). This suggests that the

gender composition of sibling pairs could influence the amount and intensity of

conversations about parental care.

Summary of Sibling Relationship

In sibling relationships, Myers and Weber (2004) demonstrated that sibling

closeness and commitment is positively related to sibling relational maintenance

behaviors. Relationship maintenance behaviors are those actions, including assurances

and disclosures, employed to sustain a desired level of relational quality (Canary &

Stafford, 1992; Stafford & Canary, 1991). Rocca and Martin (1998) discovered that

among siblings, a relationship exists between interpersonal solidarity and frequency,

breadth, and depth of communication. People use family communication standards as

benchmarks for assessing their family relationships (Caughlin, 2003). Siblings with better perceptions of their relationships are more likely to engage in pro-social communication behaviors (e.g., Martin, Anderson, & Rocca, 1997).

The sibling relationship can involve encouraging sentiments, building morale, counseling in times of crisis, serving as confidant and supplying information (Cicirelli, 1977). In addition, the sibling relationship can function as a helping relationship in times of poor health, bad finances, or emotional stress (Troll, 1980). Previous studies, however, have focused on how siblings responded to the needs of their siblings. The present research will assess how siblings come together to meet the needs of others in the family, specifically aging parents. What is not known is whether the communicative process of siblings assisting siblings with their own needs is different from siblings assisting siblings with parental needs.

While patterns of mutual assistance between generations often lead adult children to feelings of filial responsibility (Lee et al., 1995), siblings may not feel an obligation to one another, particularly if the destructive communication associated with rivalry has created more uncertainty about their sibling relationships. While individuals may have doubt about their own perceptions of the relationship, they may also have doubt about their sibling's perceptions. In addition to doubts about their relationship, siblings may also be uncertain about their parents' illness and the alternative care paths. Based on research reviewed on uncertainty, information management, family communication, family development, and sibling relationships the next chapter proposes the research questions for and discusses the methods, analyses, and results of Study One.

CHAPTER THREE – STUDY ONE

Study One – Rationale

There are no known published studies using PI to frame how or if siblings might attempt to structure difficult conversations with one another about parental elder care. The present research extended Gill and Morgan's (2011) work which illuminated the ways older adults make sense of the challenges of aging within the context of moving to a care-related facility to how siblings confront uncertainty within the context of becoming a caregiver for an aging parent. As such, participants described their uncertainties and communication behaviors related to their sibling relationship during elder care in two studies. All procedures were approved the Institutional Review Board of a large northeastern university.

Study One used interviews to explore the uncertainties present during a transition to caregiving (Dennis et al., 2008; Gill & Morgan, 2011; Hines et al., 2001). Drawing on Problematic Integration Theory (Babrow, 1996, 2002), participants responded to questions regarding their perceptions of uncertainty (including whether epistemological or ontological) and the other forms of problematic integration (including divergence of expectations and ambivalence about alternatives) related to their sibling relationships during elder care. The paragraphs below review why the state of the sibling relationship is expected to play a role in the formation of PI. Participants were also asked to describe the information management behaviors, specifically those involving topic avoidance or secret keeping, which they exhibited with their siblings during this elder care transition.

Sibling Relationships

Closeness along with maintenance behaviors shape perceptions of the sibling relationship. Closeness in adult sibling relationships has been defined as shared experiences, mutual values, shared religious beliefs, geographic proximity, family tradition, and shared interests (Floyd, 1994). Closeness may be influenced by whether the siblings felt close when they were children (Scott, 1983), the number of similarities (interests, opinions, beliefs, and attitudes) shared by siblings (Folwell et al., 1997), and whether the siblings are close in age. Therefore, the question is whether those siblings that have more frequent communication with their sibling and more shared interests and experiences with their sibling will have lower perceptions of uncertainty regarding elder care.

RQ1: What relational characteristics do siblings bring to bear when coping with caregiving challenges?

Perceptions of Uncertainty

Babrow et al. (1998) describe uncertainty as a broad and complex construct that is frequently present during life transitions or after health diagnoses. Uncertainty can reflect simple inadequacies in available information. Uncertainty can entail intrinsic features of information, such as the ambiguity of signs and symbols. Uncertainty may also involve complexities arising from both the nature of experiences and events (e.g., knowing what might happen to an elder parent, when it might happen, where it might occur, how long it will last, and what might be the effects) (Babrow et al., 1998) and the reciprocal relations among dimensions of experience and events. In other words, perceptions of the when,

where, and duration of caregiving determine how people experience uncertainty. This study will consider how the various dimensions of elder care shape sibling perceptions.

RQ2: How do siblings perceive the challenges and uncertainties associated with their parent's needs during elder care?

According to Babrow et al. (1998), variations in the meanings of uncertainty mandate different courses of action. For example, uncertainty due to personal ignorance or lack of knowledge may require a search for additional information. Uncertainty due to protective avoidance may need a greater understanding of personal motivations (Babrow et al., 1998). Even if a sibling understands another's uncertainties, that person may fail to understand the form or the source of the uncertainty and compromise well-intentioned efforts (Babrow et al., 1998). Communication about serious illness or approaching death may necessitate the need to talk with others who may misjudge the uncertainties that another finds of most concern (Babrow et al., 1998).

Problems arise among individuals when there is a discrepancy between what we believe to be so and what we want to be so (Babrow, 1992). When caring for aging parents, siblings may have to come to terms with the knowledge of both the high likelihood and the exceedingly negative evaluation of their sibling or their sibling relationship during this time. Siblings have options for how to make this situation less problematic. They may downgrade the likelihood of an event or a behavior and possibly reduce the temptation to avoid the topic, or they may upgrade the evaluation of the event or behavior by reframing it in more positive ways (Planalp & Trost, 2008).

Babrow and Matthias (2009) argued that perhaps the main goal of communication should be relational rather than informational. Therefore, the present study will narrow

the focus, asking participants to report their perceived uncertainties about a sibling relationship within the context of elder care.

RQ3: How do participants perceive the challenges and uncertainties associated with a sibling relationship during elder care?

At the same time, this study will open the possibility that other forms of PI are present when individuals are processing the personal, parental and familial aspects of caregiving.

RQ4: In addition to Uncertainty, are other forms of Problematic Integration are present during elder care?

Problematic Integration Theory has most often been applied to how people process uncertainty with regard to a number of health issues, including mammography screening (Babrow & Kline, 2000), kidney dialysis (Hines et al., 2001), coping with breast cancer (Ford, Babrow, & Stohl, 1996), and moving to assisted living facilities (Gill & Morgan, 2011). These studies surveyed patients and practitioners to describe the different forms of uncertainty they experienced. Examining PI from a caregiver's perspective was a new context for the theory.

Definition of the stressor. The need for assistance to older parents results in complex role transitions that are challenging for family members to navigate (Gill & Morgan, 2011). These transitions may be further complicated if the assistance required is highly personal or time intensive. In this study, participants were asked to describe their parent's current health status and the caregiving tasks being completed by them and their sibling(s). The purpose of these questions was to gauge the participant's perceptions (including whether the caregiving situation was possible to manage successfully or

overwhelming to the individual or family unit). Individuals exhibit different communication behaviors depending on whether caring for an aging parent is seen as a challenge or a threat (Babrow et al., 1998). Therefore, the definition of the stressor as manageable or burdensome may influence sibling interactions and perceptions of PI.

RQ5: Does the type or level of care needed by a parent influence what

forms of Problematic Integration are perceived during caregiving?

Information Management Behaviors

The integration of uncertainty becomes more difficult when there is decreasing clarity about the probability of an event occurring or increasing conflict regarding expectations (Bradac, 2001). These difficulties may manifest themselves as the information management behaviors of information sharing, topic avoidance, and secret keeping. When discussing an issue openly, siblings take the risk of displaying some weakness, revealing a secret, or challenging their relationship. Avoiding topics and keeping information secret provide ways by which individuals can maintain privacy in relationships (Guerrero & Afifi, 1995a) and protect against personal risk. Therefore, this study investigates whether an individual will avoid or keep secret information when that individual does not know how a sibling will respond to information or feels that the sibling will respond negatively.

RQ6: Do siblings enact the information management behaviors of topic

avoidance or secret keeping when interacting with their siblings during the

caregiving process?

Summary

Recent efforts to differentiate and categorize the forms and foci of uncertainty (e.g., Babrow, Hines, & Kasch, 2000; Babrow et al., 1998; Hines, 2001) demonstrate the need to avoid treating uncertainty as a "linguistic wastebasket" (Atkinson, 1995). Hines (2001) has argued that identifying multiple uncertainties would contribute to a better understanding of their relationship to communication challenges in the family. The multi-faceted nature of an uncertainty may prompt different information management behaviors.

Uncertainty is central to the illness experience (Babrow & Kline, 2000; Mishel, 1981), and it may serve the same central role in the caregiving experience. Different kinds of uncertainty about caregiving may be shaped by different frames of experience, including family communication. Any interventions to resolve the integration of siblings' uncertainties are unlikely to succeed without more completely understanding the inadequacies in prevailing communication within a family (Hines et al., 2001). Better understanding how historical communication patterns and sibling relationship perceptions, in particular, influence conflict and negotiation behaviors may help develop or refine methods for ensuring quality care to the ailing parent and greater well-being to the family caregivers.

Study One – Method

The first step in preparing Study One was to determine how to constrain the study. Caregivers of Aging Parents (CAPS) represent all demographics and family structures. Having a healthy spouse available to provide the bulk of care to an aging parent takes some of the burden off of the adult children. Therefore, for this study, the

aging parent needed to be receiving assistance solely from their adult children (and not a spouse, niece, nephew, sibling or other extended family member). In addition, the number of siblings a participant may have was limited to three in this first study in order to limit variation in family size for this initial exploration. The specific procedures used in Study One (including participant recruitment, procedure, and measurement) are discussed in more detail next.

Participants

A purposive sample of adults who had recently negotiated care for an aging parent with their sibling(s) was solicited from the national and local chapters of various professional and networking organizations. Additional participants were recruited via the researcher's personal and professional contacts (including senior housing executives, social work professionals, and home health care organizations in New Jersey), as well as through social media accounts and email listservs (see Appendix A). An IRB approved recruitment flyer was distributed electronically to these contacts or physically posted at an organization's location (see Appendix B).

There were multiple criteria for inclusion in Study One. Consistent with Merrill (1996) and Checkovich and Stern (2001), participants included adults over the age of 35 with one, two, or three living siblings and an unmarried parent (i.e., divorced, widowed, or never married) or two parents to whom the participant or a sibling had provided direct assistance (versus advice or information). Provision of direct assistance was identified as Activities of Daily Living (Fillenbaum, 1987), health care decisions, financial matters, or living arrangements within the past twelve months. At least one sibling had to provide

assistance (virtually or face-to-face) with the aging parent no less than once per month during the previous year.

Participants included 22 adults (21 females and one male) from across the United States, but primarily the Northeast region. Ages ranged from 38 to 72 years, with a mean of 56.7 years ($SD = 9.19$). Nearly all participants were caring for one unmarried parent; however, one participant was involved in the care of two aging parents, another participant was caring for a parent with an unmarried spouse, and a third was caring for a parent but not involved in the care of the parent's spouse. The ages of the parents receiving care ranged from 77 to 97 ($M = 88.5$, $SD = 5.92$). Five participants lived with the parent (either in their or their parent's home), eight participants were within an hour drive of the parent, and nine participants were at a distance from the parent. Those participants living with or geographically close to the parent tended to be the primary caregiver.

One participant was African American; all other participants were Caucasian ($n = 21$). Over half of the participants indentified as Christian ($n = 12$), while the others identified as Jewish ($n = 5$), Unitarian ($n = 2$), or no specific affiliation ($n = 3$). Over half of the participants reported being married ($n = 13$), others were single ($n = 5$), divorced ($n = 3$), or widowed ($n = 1$). Participants reported between 0 and 3 children ($M = 1.41$, $SD = 1.05$). The mean age of those children was 27.7 with a range from 5 to 41 years old ($SD = 14.2$). All participants were college educated, and 15 reported earning graduate degrees. The mean participant income was over $75,000 with a range from $20,000 to $150,000 (three participants declined to report income).

Procedure

Data collection occurred either face-to-face ($n = 3$) or via phone ($n = 19$). The face-to-face meetings took place at a public location and time convenient to the participant (e.g., their office or a restaurant). At the outset of the meeting, participants were given a consent form with an audiotape addendum to review and sign (see Appendix C & Appendix D). If a potential participant lived at a distance, interviews took place via phone and the consent forms were emailed in advance of the call. All interviews were conducted by the same interviewer (a Caucasian female age 40-45) and were audio-recorded. No patterns of difference were noted between the face-to-face and the phone interviews, and thus they were combined for analyses.

Individuals were first asked to provide answers to general demographic questions (see Appendix E). Following completion of the demographic section, each participant was then asked about caring for the aging parent. Following Matthews and Rosner's (1988) loosely structured format, participants were asked to respond to a series of questions describing the current health or living situation of their parent, caregiving roles and tasks being completed by them and their sibling(s), and the resources available to cope with this transition (see Appendix F). In addition, participants were asked to describe any uncertainties they had about: the parent's illness or injury, possible care alternatives for the parent, or their expectations for relating with their sibling(s). Finally, participants were asked to describe the information management tactics displayed by them or their sibling(s), for example, did they share information, avoid certain topics, or keep pieces of information secret.

At the end of the interview, participants were given a Debriefing Form (see Appendix G) and, if they chose, were entered into a drawing for one of three $50 American Express gift cards (see Appendix H). If the interview brought up issues that created psychological distress of any sort, the participant could request a list of referrals for counseling (Appendix I). No participants terminated the interview or requested the list of referrals.

Analyses

The interview data were initially transcribed by an undergraduate Communication major who was blind to study hypotheses and research questions. A second undergraduate student read the interview transcript to verify that all aspects of the interview had been captured completely and accurately. A total of four trained and IRB certified undergraduate students were randomly assigned the initial transcriptions and the second reads of the interviews. The researcher conducted final reads of the transcripts, formatted the transcripts, and removed references to any names or places in order to de-identify the transcripts. A total of 847 minutes of audio-recordings were transcribed ($M =$ 40.34 minutes, $SD = 13.85$ per interview, ranging from 14.34-63.03 minutes), resulting in 256 pages of interview text ($M = 12$ pages, $SD = 2.77$ per interview, ranging from 7-19 pages).

Each transcript was imported into NVivo and coded using an abductive technique (Miles & Huberman, 1994). This approach calls for starting with concepts from existing literature and then adding any ideas that emerge from the data in an effort to extend a conceptual framework. Abductive coding was used because Problematic Integration Theory has been previously explored in other health contexts (i.e., Babrow & Kline,

2000; Hines, 2001; Matthias, 2009) but not within the framework of elder care. Similarly, the information management behaviors of topic avoidance, secret keeping, and information sharing have been well documented in social relationships (i.e., Afifi & Guerrero, 1998; Caughlin & Vangelisti, 2009; Greene et al., 2012; Petronio, 2002) and family relationships (i.e., Checton & Greene, 2012; Guerrero & Afifi, 1995a, 1995b; Vangelisti, 1994). However, researchers have yet to explore the narrower context of adult sibling communication behaviors.

The researcher analyzed the transcripts to look for statements suggesting forms and foci of PI and strategies of information management. The forms of PI include Ambiguity (which includes the frequently explored concept of Uncertainty), Ambivalence, Divergence, or Impossibility (Babrow, 1992), and the foci of PI in this context include the participant, the parent, the parent's illness or injury, care for the parent, a sibling, the sibling relationship, or caregiving in general. Analyses yielded a distinction between Ambiguity as it relates to the sibling relationship and Uncertainty as it relates to the parent's illness. Additionally, the concept of Transcendence emerged as an alternative to Divergence and was identified as a new form of PI. These results are described in further detail in the subsequent section.

Study One – Results

The next sections discuss the Problematic Integration categories and the information behavior categories that emerged from the Study One interviews. Quotes from participants illustrate each concept. The numbers following each quote indicate the study (S1 = Study One) and the participant identification number. The first forms of PI discussed are Perceptions of Ambiguity and Perceptions of Uncertainty. Then, the PI

form of Divergence is reviewed, as well as Transcendence, a new category of PI that reveals how some participants "find peace" with their diverging expectations (an emotional resource). The final sections discuss the communication resources of Information Sharing, Topic Avoidance, and Secret Keeping that participants employed with their siblings.

Conceptualizing Ambiguity

Einhorn and Hogarth's (1987) claimed that there are crucial distinctions among uncertain, ambiguous, unknown, and unknowable probabilities during decision making. As such, Babrow (1992), in his initial discussion of PI, uses "ambiguity" as a broader, more encompassing term than "uncertainty" to describe one form of Problematic Integration. Babrow (1992) describes ambiguity as risk among a set of probabilities where neither the outcome nor the probability of the outcome is known, and uncertainty as risk for a situation where probability of a particular outcome is between zero and 100%. This distinction became apparent in the results of Study One. Participants had a sense that their parent's needs would be different in the future but were uncertain as to what those changing needs would require and what impact those needs would have on their own or their parent's life. Participants were less clear about the relationship with their sibling(s) in the future. The results highlighting situations of uncertainty and ambiguity will be presented below. A review of participant responses about the parent's health and well-being will come first, followed by responses about participant's own health and well-being. A discussion of perceptions of ambiguity will come later. Responses regarding Uncertainty and Ambiguity are summarized in Table 1 with definitions and sample quotes.

Perceptions of uncertainty. Participant uncertainty centered on two key areas: uncertainty about the parent and uncertainty about the self. Each of these areas included specific concerns related to mental and physical health, housing, and finances. Uncertainty about self included an additional concern about levels of personal knowledge and information, the one result reflecting the traditional literature on uncertainty reduction (Berger & Calabrese, 1975). Concerns of uncertainty related to the parent will be discussed first, followed by concerns that participants expressed about themselves.

Parent's mental health. The first type of uncertainty was regarding the parent's mental health. When expressing uncertainty about their parent's mental health, participants most often talked of cognitive declines due to various forms dementia. A 66 year old female whose mother had lived with her said, "I was mostly worried about the early stages of dementia and my mom not remembering . . . how to do simple things like how to turn the heat up or work the toaster oven" (S1-15). The concern here was whether the mother would be able to manage around the house while the participant was away. A 63 year old female whose mother also lived with her said, "During the last six months my mom was going downhill really quickly. It has been difficult watching her not be able to remember how to do everything she wants to do and she gets frustrated and she starts to cry" (S1-09). This participant was describing her struggle with watching her "best friend" slip away. As parents' cognitive abilities diminished, participants had more questions and greater uncertainty about what life would be like for themselves and the parent.

The concern about cognitive declines was particularly salient to those participants whose parent had been living independently. A 53 year old woman was concerned because her parent lived at a distance. "She is beginning to lose her memory and so I

needed to have her where I could keep track of her because she was on the east coast and I'm on the west coast" (S1-01). Her mother had become quite "childlike" and needed someone to "take care of her," but the participant was uncertain as to what that care should involve. Participants would notice things when they visited parents, which made them wonder what was happening when the parent was alone and whether more monitoring was necessary:

> She doesn't want to cook for herself, so she doesn't eat. She may open up a can of soup for herself, and that's it . . . but in a ways it's kind of good. When I've been there and she's cooking for us, I'll go in the kitchen and notice there's no pot on top of the flame. "Ma, did you notice that you left the fire on?" (S1-12)

The uncertainty about mental health translated for this participant as a concern for her mother's safety "with the fire and other things like that." Those respondents who lived with their parent, but the parent was home alone during the day while the respondent worked, had similar concerns to those participants that were at a distance:

> Then there were times where I came home and I found a pot in the sink that was badly burned. I didn't make a big deal out of it. I washed it the first time, but then it happened again. Then I found out through her friend that my mother has set a towel on fire. She got rid of that real quick, but then I kept seeing other things. (S1-03)

These "other things" left this participant wondering about safety and also feeling uncertain whether these were signs of something other than general aging.

Even if a parent had not yet shown any signs of cognitive decline, many participants still worried: "My biggest concern is if she starts to get dementia or

Alzheimer's. We don't have anything like that in our family, but who knows" (S1-13).

This participant was expressing general uncertainty about a disease for which there

remains much mystery. So while the occurrence of dementia and its associated diseases

are increasing rapidly in the United States, many families were unprepared for the type

and level of care involved with such a diagnosis (Alzheimer's Association [ALZ], 2014).

A 45 year old female participant summed up the heart break that often comes with

Alzheimer's:

> My mom's just really been having some rough times. She's crying a lot, crying
>
> and crying and not sleeping; she's up in the middle of the night and pacing and
>
> crying. She's gone through quite a lot of bouts like that and we've been trying to
>
> get medication that'll help her without any results, so that just breaks my heart.
>
> (S1-14)

The heartbreak for this participant came from not knowing what to do to help a loved one

through such difficult moments. The uncertainty about her mother's mental health led to

uncertainty about caregiving, a common course of events in PI referred to as "chaining"

(Babrow, 1992) in which perceptions about one event changes perceptions about another

event. The next quotes show other examples of chaining as well.

Besides the concerns about the forgetfulness of dementia, participants also

worried more generally about their parent's mental health. A 49 year old woman whose

brothers had struggled with addiction commented, "[My mom] is always worrying about

her two sons. I wanted her retirement years to be more fun and relaxing, not filled with

stress" (S1-13). In this instance, the siblings' behavior contributed to the parent's anxiety,

which in turn amplified the participant's uncertainty. In another example, the fact that her

86 year old mother was driving on a regular basis contributed to the participant's worry: "My mother has some mental problems. She is not the picture of mental health. How is that going to affect her driving? I mean she is having hallucinations" (S1-22). Just as earlier quotes described a melding of mental health and safety concerns, this quote did as well. As the participant became uncertain of her mother's mental health, she became less certain about her mother's capabilities with daily activities.

In other situations, the parent's personality was a reason for the concern. A 54 year woman was at a distance from her 84 year old mother and worried how her mother "was never very social, and as time went on she became less social" (S1-17) leaving her mother feeling isolated. This participant was uncertain as to how her mother's unsocial disposition would contribute to her mother's overall health and wellness. Another participant, a 49 year old woman on the east coast, had a similar concern about her 80 year old mother and said, "My mother is her own worst enemy. She'll be like 'I'm so bored' and I'm like 'Mom please. I've tried to get you involved. It's your own fault you're sitting here'" (S1-13). This participant was uncertain whether her mother's unwillingness to meet new people led her mother to be unhappy or even depressed.

Even if the parent lived with or near the participant, there was still a concern about social interaction. A 64 year old female participant who visited her 95 year old mother daily said, "I'm most worried about her being lonely and not having companionship" (S1-07). This participant recognized the danger of her parent being socially disconnected from others but was uncertain how to increase the connection to others even within her own family.

The uncertainty about a parent's mental health was not only a question of what was happening to the parent's mental capacities, but what should be done if they are on the decline. A parent's desire to live independently was often in contradiction with the participant's desire to keep the parent safe and mentally and socially stimulated. This often resulted in participants taking calculated risks about the warning signs being shown by the parent. Participants wondered how long before the small danger became a huge risk to the parent or others and how long before the participant had to intervene. For many participants in Study One, this uncertainty regarding mental health evolved as one of the biggest concerns around caregiving. The next section will show how similar uncertainties were experiences about the parent's physical health.

Parent's physical health. The same struggle between independence and safety was apparent when participants discussed their uncertainty about a parent's physical health. A male participant who, along with his siblings, was living at a distance from his mother, said "I am worried about my mom's physical health. We worry that she's gonna trip and fall, break her hip, the classic thing that would happen to an older person" (S1-16). The family was particularly worried because the mother was living by herself in a large, historic home in a remote, coastal area. Even though a home health care agency was employed to regularly visit the mother, the family was concerned about the time between visits. The family was uncertain about what might happen to the mother when she was alone.

Similarly, a female participant whose mother was living alone in a multi-family dwelling in a large city commented that she was most worried about "her mobility, just being able to get around and the possibility of her falling down and breaking a hip . . .

How would she call anyone?" (S1-12) The parent did not have a close relationship with the other tenants in the building, and her children all lived over an hour away. Typically, urban living, with its options to walk or ride public transit to services, allows aging adults a greater opportunity to maintain independent living. However, this independence often leads family members to worry more about physical safety. The daughter of an 88 year old man said, "What I am most worried about is that he doesn't fall before he gets into assisted living" (S1-20). The participant was uncertain whether her father had the physical strength to manage the stairs in his building or the sidewalks in his neighborhood. This parent had gone through a lot of physical changes in the previous months and the daughter was uncertain whether they could get to the next phase without one more stressful event occurring.

In another situation, a parent's medication exacerbated the concern about safety: "I've been worried about medication management. Her medication [levels were] causing her confusion and balance problems" (S1-21). The participant felt this was a dangerous situation for a 94 year old woman living at a distance from her family and highlights a common occurrence in caregiving. Often one family member recognized that life has changed for the parent, but others did not realize what was happening. This created uncertainty between this participant and her brothers about family roles and left her to wonder whether "it's my place" to step in and intervene.

The challenges to the parent's physical safety in these examples were primarily the structure of the house and its location, particularly if the location leads to the parent being socially isolated. Concerns about safety raised uncertainties about the parent's

current and future living arrangements. The next section will detail uncertainties that participants reported about their parents' housing and financial needs.

  Parent's housing and finances. Uncertainty surrounding a parent's cooking, heating, personal care, social interaction, physical mobility and medication management drove participants to wonder where a parent was going to live in the future. The struggle for participants was balancing the parent's wishes to remain in their home with the parent's changing care needs. In one instance, "Irish guilt" made a participant question her role in the decision. A 49 year old female respondent with a fiercely proud, independent mother said:

> I wanna abide by her wishes, and I want her to be happy. But if it gets to the point
>
> where I can't physically care for her and know that she's safe when I'm not there,
>
> I would probably consider a nursing home, and that would devastate her. (S1-13)

The uncertainty for this participant was not just about where the parent would live, but whether the participant would still be "a good daughter" if she moved her mother.

  In other instances, the participant was uncertain about a third party's role in the moving decision and the subsequent outcomes. For one participant, the assisted living facility where her parent was residing was dictating a move: "We kind of thought that would be our decision. It never occurred to us that that may be the facility's decision" (S1-18). This family wanted to keep the mother near her friends and social group, while the facility wanted the mother in a more secure location for those with dementia. The uncertainty for this participant was around what would be best for the mother and who gets to make that call. Another participant worried whether the home health care agency hired to visit his mother might hinder a move:

At some point there could be a conflict between our desire to get [our mother]

into a place we feel might be more helpful and [the home health care agency's]

desire to keep her in the home for a longer period of time. (S1-16)

This participant and his siblings were many states away from the parent and had

been relying on the agency for information on the mother's health. He was

uncertain whether the agency may remain more positive about the mother's

condition in order to remain employed longer.

Regardless of who was driving the decision to move, the decision about what

comes next was filled with great uncertainty for participants. A 43 year old female

participant said, "What are we going to do? Where is she going to live? She won't be able

to stay [in her home] forever. [We] will have to get her into some kinds of assisted living.

We don't really know what that entails" (S1-11). Each of these questions highlighted the

participant's various uncertainties associated with the parent's housing. The question of

what comes next was heightened when the parent's mental abilities were in question. One

participant felt that the current situation with her mother was stable but things were

quickly going to change: "Her mental abilities are slipping so fast that I think she's

probably going to need to move to another level of care and we really don't know what

we are going to do about that" (S1-18). Adding to the complexity in this instance, the

participant was uncertain whether her parent was cognizant enough to participate in the

decision of when and where to move.

The uncertainty about housing was often compounded by financial concerns.

Numerous participants described such fear: "For financial reasons, we moved her out of

one assisted living facility and into another" (S1-06); "The only concern I had was

whether mom's money would last to the end of her life" (S1-15); and "As she started to degenerate, I started to be concerned about financial matters as I began researching a move to a place with a continuum of care" (S1-06). All these statements were made by participants who were the primary caregivers for their mothers, and, either formally or informally, were mainly responsible for making the health and living decisions related to the parent. Each possible decision, however, was met with uncertainty around "How are we going to pay for it?"

For one female participant, the concern about money even outweighed any issues that she faced with her two brothers: "All along it's been the finances. It's never been anything that has to do with my brothers. All along it's been keeping track of, monitoring, all of her finances that was my biggest concern" (S1-06). This worry became particularly salient after the family had to move their mother out of their preferred assisted living residence. The uncertainty of what was occurring with the parent's health and financing subsequent care needs produced considerable stress for participants.

Summary of parent-centered uncertainty. Throughout this section, participants described being "uncertain" about what comes next for their parents. Eighteen of the 22 participants expressed worry or uncertainty regarding their parent's mental health. Many of the parents were displaying signs of cognitive decline or had received a formal dementia diagnosis. Participants with these kinds of parents knew that cognitive abilities would further decrease but did not know what that would mean in terms of care. This uncertainty about how the disease would change prompted uncertainties about where the parent was going to live. Thirteen of the 22 participants made references to concerns about their parent's housing. Eventually, the illnesses or physical ailments of the parents

would mean that the parent could no longer even live independently, thus requiring a move to an assisted living or a nursing facility. This move would mean further uncertainty, particularly how the parent or family was going to pay for the level of care needed.

The stress of caregiving was so overwhelming for some participants that it negatively affected the participant's mental and physical health. The energy required for caring for a parent also left some participants wondering if they would have anything left for their jobs or their own families. As a result, participants expressed uncertainty during the interviews about their own mental or physical health, as well as their own financial or living arrangements. In addition, participants reported uncertainties about their level of knowledge related to caregiving. The next section will discuss and present examples of each of these uncertainties: a participant's mental and physical health, a participant's housing and finance, a participant's general knowledge. These uncertainties are distinct from the previous concerns about the parent's mental health, parent's physical health, and parent's housing and finances.

Participant's mental and personal health. When participants described worries related to themselves, they typically told stories of being tense and overwhelmed because of a constant need to know about the parent's well-being. A 54 year old woman said, "I was calling her [my mother] every day. I was starting to get a little over the edge and stressed out" (S1-21). This woman worked full-time and, although she lived less than an hour from her mother, was not able to visit as often as she wanted. When she was unable to see her mother, she experienced great uncertainty about her mother's wellbeing. She

"needed to have this check in with her" to know that her mother "was all right" in an effort to reduce some of her worry.

Those trying to manage their parent's care, as well as managing their own personal and family activities, described very difficult and uncertain situations. This was highlighted by two comments. One participant said, "I have to take care of a 13 year old and hope to have a social life, but I rarely get things done" (S1-04). This woman was a single parent who worked full-time and received little support from her brother when she asked for help assisting their mother. Another women said, "The hardest part sometimes was just being tired . . . I would run a lot for my mom but I was still working, managing my business and trying to fit everything in" (S1-15). This participant knew what needed to be done in her own life, but with the addition of parental care was quite uncertain about how to manage everything else.

Some participants who were also the primary caregivers wondered when (and not if) the stress would debilitate them. For example, a 63 year old single woman whose mother was living with her and showing signs of worsening dementia said, "I'm always afraid I won't be able to handle whatever comes next. I mean physically I just won't be able to handle it" (S1-09). This participant was managing every aspect of caregiving on her own. She was single, had no children, and felt ignored by her brother. As her mother needed more and more assistance with personal care activities, such as feeding and bathing, the participant felt more uncertain about her ability to manage.

The previous example was similar to other participants who had a parent with a form of dementia. These individuals described greater feelings of stress and needed additional support from their siblings. The later stages of dementia and related cognitive

diseases such as Alzheimer's not only result in a lost ability to complete personal care activities, but also result in major personality and behavior changes (ALZ, 2014). A 63 year old female participant noted, "Her [mother's] personality and everything else the dementia has just compounded. That's a lot of stress for me" (S1-11). For this participant, her mother was now like a child whose behaviors created much uncertainty as to how best to respond. Often those changes in the parent and the stress associated with them are not understood by the sibling(s) who are not actively involved in care. If the non-primary caregiver is "not living the situation, they are not gonna fully appreciate why you need a break" said a woman desperately hoping to "recharge her batteries" (S1-11). The participant was trying to arrange a vacation per her doctor's orders, but she received high levels of resistance from her brother. She was uncertain how she might accomplish both respite and still find someone who could stay with her mother.

Not feeling that sibling(s) understood the demands of caregiving contributed to feelings of uncertainty about whether a participant could manage the activities of caregiving. Six participants, believing that they would "have to go it alone," reported uncertainties about their own mental and physical health. Just as uncertainty about how the parent's health contributed to uncertainties about where the parent was going to live and how the family was going to pay for it, a similar type of chaining occurred for participants. However, whereas uncertainties about parents tended to extend in one direction (parent's health to parent's housing to parent's finances), uncertainties about participants chained in multiple directions (participant's housing to parent's housing or participant's finances to participant's health). The next section will discuss the wide array

of uncertainties that were described by participants related to their own living situation and personal finances.

Participant's housing and finances. Uncertainties about a participant's housing and finances may be solely related to the parent's care needs or may be related to the participant's decisions around those care needs. As such, siblings may contribute to the care of their aging parent in various ways. Some siblings offer the parent a place to stay, others pay for groceries, transportation or medicine, others contribute to the rent at a senior community, and others support the parent in non-monetary ways. What each sibling does may be a reflection of the willingness to help the parent, but each sibling may contribute quite differently. For example, one 53 year old female participant placed a high priority on the type of community where her parent lived. This, however, resulted in her paying a large portion of the bill and made her very anxious: "What it's meant is that I've had to take a second job. There's always stress about whether or not I'll . . . be able to cover her expenses in this type of independent living situation" (S1-01). Two of her siblings were estranged from her mother and one only called sporadically, so the participant felt responsible for providing her mother with a high level of care but yet she remained uncertain as to how she was going to manage the expense, even with the income from two jobs.

What each sibling contributes may also be a reflection of his or her ability (i.e., financial means) to assist the parent. A female participant who was unemployed at the time of the interview said she felt she was "coming from a position of feeling less than [my brother] just because of my financial situation" (S1-17). This difference in finances influenced their caregiving roles (i.e., the one with the money makes the decisions) and

created stress and uncertainty around the participant's living arrangements. This participant was living in the family vacation home. She had previously contributed a large sum of money towards the home but was not on the title. As a result, she was uncertain as to how long she might be able to live there if she could not contribute to the upkeep of the home. Another female participant who was in a position of greater financial means than her siblings confirmed how this allowed her to be the decision maker:

> Financially, we were able to cover the cost of that caretaker for quite a while. Now we've decided to have my father's finances cover it until he runs out of money. If that happens, we'll pick up [the cost] again. So, I was in a position to make that call. My family is in a position to cover some [expenses] that my sister and brother are not. (S1-08)

Participants' experienced different uncertainty depending on their financial means relative to their sibling(s)'. Those with greater financial means tended to be uncertain about their sibling's financial role. Those with fewer financial resources tended to be uncertain about their own decision-making role.

What a parent needs and how a sibling may respond contributed to other housing uncertainties as well. A young primary caregiver (38 years old) said, "At some point, I would like to be able to move, but I would only live [with my mother] if there's gonna be [further] decline." This participant was uncertain of the level or type of care that her mother would receive from her brother if the participant moved away. Another participant was uncertain of her own housing choices due to the lack of input from her parent, as well as her siblings:

When we [participant and spouse] were looking at houses, I just kind of stopped

and said 'I don't see the point.' If we sell [my mother's] house, it makes sense for

her to move in with us. But nobody wants to have that discussion. (S1-12)

The above is another example of how uncertainties can "chain" (Babrow, 1992). In this

situation, the uncertainty about the parent's health contributed to uncertainty about the

parent's living situation. The parent's living situation, in turn, contributed to uncertainty

about the participant's living situation, and even further uncertainty about the

participant's daughter's school enrollment. This chaining shows how complicated the

caregiving situation is for some and relates to how participants started to question their

own level of knowledge about how to handle the many facets of caregiving. Examples of

knowledge uncertainty will be discussed next.

Participant's knowledge. A final area of uncertainty identified during the

interviews in Study One centered on the participant's level of knowledge about the

parent's illnesses and care needs. As noted earlier, this type of uncertainty mirrors that

traditionally discussed in the early uncertainty literature (Berger & Calabrese, 1975),

which describes uncertainty as the result of insufficient information. The section below

will discuss how participants in Study One felt that they did not have sufficient

information about a wide range of issues including parent care needs, doctor protocol,

and medical prognoses.

Feelings regarding one's level of personal knowledge about a parent's situation

influenced a participant's level of uncertainty. For example, one participant questioned

her own caregiving abilities: "I don't know how far I can take it before I'm not able to

give her the proper care" (S1-09). As her mother's health rapidly declined, this

participant needed to carry out more personal tasks for her mother. The increase in the number and type of tasks left the participant uncertain about whether she had the physical strength and skill to perform the tasks. Another participant questioned whether her mother's team of doctors was fully able to understand and explain what was happening: "The hardest part has been trying to communicate with the doctors. They do seem to really communicate with each other, but . . . they're not seeing the whole picture" (S1-18). This participant wanted more information from the doctors in an effort to coordinate the uncertainties associated with each of her mother's illnesses. Not all participants, however, wanted more information.

Other participants initially attempted to gain more information to reduce their uncertainty but then decided against it. For example, a 59 year old, female described how she "tried to understand what's going on medically and sort of know a lot of Google sites. But there's really no way to know, and there's not even any reason to know. I've kind of given up on being wise" (S1-18). This participant decided, instead, to focus on the immediate, day-to-day needs of her mother and worry about other matters when they occurred. This type of "I need to focus on my parent's care" attitude was expressed by many of those participants that were primary caregivers (further examples will be discussed in the later section on Transcendence). These participants decided to manage their uncertainty by not concentrating on it.

The examples presented above mirror previous research about uncertainty management that suggests some individuals will want to reduce uncertainty but others will choose to maintain their level of uncertainty:

Although people quite often want to reduce complexity and ambiguity in their

lives, perhaps as a prerequisite to decision making, planning, or predicting the

behavior of others, there are other times when uncertainty allows people to

maintain hope and optimism or when tasks can be performed despite, or because

of, uncertainty. (Brashers, 2001, p. 478)

One challenge during caregiving is that members of the same family may have differing

levels of comfort with the uncertainty of the situation. This variation in comfort prompts

an array of responses, including the questioning of one's own knowledge as was seen in

the examples above. Yet, even if participants had the same response to uncertainty, their

solutions may be quite different. Some participants in Study One chose to expend

considerable effort to enhance their knowledge and reduce uncertainty, others made the

decision to focus their energies elsewhere.

   Summary of participant-centered uncertainty. Each area of uncertainty about the

participant's own mental and personal health (12 participants), the participant's housing

and finances (5 participants), and the participant's knowledge (4 participants) tied back to

uncertainty about the parent's mental health, physical health, or housing and finances.

For some participants, these uncertainties were compounded by a feeling of "if I could

just know more, then I could do more or manage better." Others did not feel that knowing

more information would alleviate any uncertainties and just braced themselves for the

parent health declines to come. However, when predicting the course of their sibling

relationships, participants were less clear about the paths before them. This suggested

perceptions of Ambiguity, which will be further discussed in the following section.

Perceptions of ambiguity. Babrow (1992) reports that ambiguity exists when an individual is uncertain about a set of possibilities in a given situation. The results of Study One showed that in caregiving situations the sibling relationship is full of possibilities, leaving many to wonder just what their sibling relationships would look like once caregiving was over. Some participants worried if there would be a positive ending. For example, "I think of my mother moving to hospice or passing away and I think that our [sibling] relationship is just going to deteriorate" (S1-11). This participant was saddened by the ambiguous prospect of not knowing whether she would have any association with her brother. Another female participant cautioned that the future relationship will likely be a reflection of what it has always been:

> One of the realities is if you have a very negotiable, supportive relationship with your siblings, you will go into the care of your mother or your father with that same type of pattern. [Otherwise], don't expect things to change. (S1-07)

This participant said that she and her sister were very competitive when they were children and that non-cooperative spirit had carried over into multiple aspects of their adult lives including caregiving. This participant kept longing for their relationship to change but felt ambiguous about if it would. She did not know what direction, if any, their relationship would go.

Others participants held out cautious hope that the relationship with their siblings might rekindle but had difficulty thinking about the future with everything currently happening with their parent. One woman said, "I could see things changing in some ways, but it's hard for me to imagine right now" (S1-19). This participant and her siblings had experienced mixed feelings about their father's remarriage after their

mother's death, and those feelings were now compounded by mixed feelings about caregiving. Another woman who lived at a distance from her brother echoed this sentiment of being currently engulfed in caregiving and not knowing what would happen with her siblings when the caregiving was over:

> I have not even thought about what I would do with the rest of my life because it's so involved with [my mother] right now. I know it will be an enormous vacuum, but I haven't thought about what I'm gonna do. Maybe I'll move closer to my brother, but I have no idea. (S1-06)

The "I have no idea" sentiment is a sign of ambiguity. There are a host of possibilities about the future of their sibling relationship, but participants did not know the likelihood or the valence (positive or negative) of any of those options.

A 53 year old female participant wondered, "Maybe there will be time to enrich our relationship again. I mean, we have a lot of shared . . . experiences" (S1-11). This participant expressed a longing to have a close relationship with her sibling like they once did but was not certain it would happen. Another 46 year old woman hoped her siblings might change and that, in turn, would change her view of them. She said, "It's just the little things I see in terms of my brothers. Maybe they'll just step up to the plate" (S1-12). This sentiment was more of a wondering than a certainty. This participant lacked any definitive notion about what her siblings' future caregiving actions would be and, therefore, what her relationship with them would be. A 59 year old female participant felt that as their life stages changed and family events occurred the siblings could be drawn back together:

>We won't have my mother to talk about anymore, so I don't know. I would
>
>assume there will eventually be some weddings and some grandchildren. We
>
>might get together for those things. I'm really not sure. (S1-18)

This participant was still hoping for a future relationship with her siblings, but she did not

know if that was possible or, if it was possible what that relationship might look like.

This is what distinguishes ambiguity from uncertainty: for ambiguity neither the outcome

nor the probability of the outcome is known (Babrow, 1992).

Participants were more ambiguous and less optimistic about their future sibling

relationships if those relationships were influenced by other family members. A 64 year

old female participant said, "What complicates things a bit is that my other sister's

husband is really on the lookout [for money]" (S1-22). This woman was referring to her

brother-in-law's attempt to gain financially from her mother's demise, leaving the

participant seeking to distance herself from current and future family relationships. While

this participant wanted a relationship with her sibling she felt ambiguous as to whether

that was possible. Another female participant in her 60s wondered about her relationship

with her brother because she could not even "spend five minutes" with his wife. This

participant described her brother's wife as "this person who is nasty and makes all these

crass comments about other people," (S1-20) but she could not say anything to her

brother out of fear that "he would just say good-bye". Instead, this participant stayed

quiet and distanced herself from her sister-in-law in hopes of maintaining some type of

relationship with her brother, yet the possibility of a relationship with her brother

remained ambiguous.

Summary of ambiguity. Not being sure about the future is an overarching theme in the form of PI labeled Ambiguity. As noted earlier, this form can present itself in numerous ways including ambiguity, uncertainty, and unknowing (Babrow, 1992). Participants in Study One primarily reported ambiguity and uncertainty. Ambiguity was experienced by 16 participants as they described their sibling and the sibling relationship. Uncertainty was mentioned by almost all participants (18 participants mentioned at least one area of uncertainty) and tended to be present when participants were thinking of parental and personal "decision items," what to do regarding mental and physical health, housing, and financial concerns. Although uncertainty dominated participant responses (as it does in much of the health communication literature), another large area of discussion was about mismatched expectations. Babrow (1992) calls this form of PI Divergence, which is discussed in the section that follows.

Conceptualizing Divergence

In participant responses in Study One, divergence related more to the interpersonal relationships present in the caregiving situation than the caregiving itself. Divergence can be described as a discrepancy between what participants believe will happen and what participants want to happen (Babrow, 1992). Past and current communication patterns shape the structures individuals use to interpret messages related to these expectations and desires (Babrow, 1992). During the caregiving process, siblings may call on years of communication and behavioral interactions and their current emotional states to interpret one another's responses to requests for assistance. These actions often left individuals feeling disappointed or frustrated with one another and the

caregiving situation. Fourteen participants made references to feelings of divergence (see Table 2 for definitions and examples of Divergence).

One female caregiver expressed disappointment about her sister, "You cannot realistically expect a sibling that you were not able to negotiate, or compromise, or talk to before to all of a sudden be supportive and helpful in such a situation" (S1-07). When experiencing her own health problems, this participant expected her sister to come and assist with the caregiving of their mother. Instead, her sister went on vacation leaving the participant scrambling for care and feeling incredibly distraught. Divergence occurred because of her expectation that her sibling would help her at such a challenging time and, instead, her sister went on vacation. Another female caregiver expressed frustration about her brother: "[I'm trying to] get him to understand that his mother isn't going to last forever and he should show up occasionally" (S1-09). As the one living with and caring for the parent, this participant could see her mother's decline but struggled to understand why her brother could not. This participant's ideas about being a "good child" were different from her brother's, and these differences were causing divergence.

Some participants hoped the caregiving situation would generally be different. For example, a 46 year old female participant said, "My friends joke about how 'it's always the daughter, it's always the daughter.' For some reason the daughter is the one expected to be the caregiver" (S1-11). Although this participant agreed with her friends, she did not want her caregiving experience to be that way and was quite frustrated by the diverging expectations of her and her brothers. Others hoped that their siblings' actions would be different: "If [my sister] was more understanding and if she didn't jump to judgment right away, it would make things easier" (S1-03). This participant wanted

someone to talk to, someone to vent to so that she did not feel so overburdened and she had hoped that someone would be her sister. However, these hopes were not being met and divergence occurred.

A 63 year old female participant commented, "Well it would be nice to have a real brother that kept some interest in what was going on here" (S1-09). The divergence she expressed was about her ideas of what it means to be a sibling versus her brother's level of involvement in caregiving. This participant's sentiment and that of another female participant highlighted the frustration that women who were primary caregivers often felt with their brothers:

> I had hoped that he would participate more, maybe pick her up for a visit with the kids, get her out of the house for a little bit and give me a little time to myself. But that doesn't happen enough. (S1-11)

This participant's comment not only showed divergence about the type of caregiving activities being performed by her brother but also about the frequency of those activities.

The 14 participants with diverging expectations and desires were typically contrasting their current caregiving situation with a perceived ideal and were frustrated that the ideal was not being achieved. Divergence was the third most frequently mentioned form of PI following Uncertainty and Ambiguity. New to Problematic Integration Theory, however, the results of Study One showed that while some individuals were not having their ideal being met, they were no longer experiencing Divergence. This new form of PI has been labeled "Transcendence" and is discussed in the following section.

Transcendence: An alternative to divergence. Babrow (1992) describes

divergence as the predicament that arises when there is a discrepancy between what we

believe to be so and what we want to be so. This predicament typically evokes negatively

valenced responses. However, some participants in Study One that experienced

incongruity in their expectations experienced more neutral or even positive perceptions.

This alternative response is being called Transcendence and is a new form of PI.

Transcendence can be defined as an unprotesting acceptance of the caregiving

situation (see Table 3 for definitions and examples). The situation may not be exactly

what participants wished, but they were accepting and not going to try and change it. Ten

participants demonstrated Transcendence and spoke of "being at peace" with the

situation. For example, a 49 year old woman said, "This is my life. I'm in charge of mom,

and I'm okay with it" (S1-13). After years of her brothers making "empty promises," this

participant decided not to waste personal energy on them. Some participants called on a

higher power to find this peace around caregiving: "I've had to lean on my personal

theology that we're on this earth to do what we can in the best way that we can . . . and to

leave the result of everybody else's choices with God" (S1-01). This participant did not

feel it was her role to judge the actions of her siblings and focused on herself and her

parent's care needs. Other participants left it to a higher power in order to find peace with

their parent: "At the end of the day, I've turned this whole thing over 'cause I have to live

my life. My attitude is it's [my mother's] house, her money, it's her life; she can do

whatever she wants with it" (S1-22). There had been questions in the participant's family

as to how assets might be divided following the mother's death. However, regardless of

her expectations on the matter, this participant chose to "let it go" and became resigned on the matter.

Some participants in Study One realized that changing a sibling was neither their responsibility nor worth their energy. One participant commented, "I'm dismayed at [my siblings'] response, but it's not my responsibility to make that all right" (S1-01). Although this participant and her siblings had very different relationships with the mother, there was still an expectation of what being a "good son" or "good daughter" meant. However, the participant's response, indicating a deflection of a desire to change, is what made this an example of Transcendence rather than Divergence. Later in the interview, the same participant said "I could continue [sending him emails] and feeling hurt every time or I could just say, 'That's your decision, and I'll respect that.'" The quotes from this participant are examples of Transcendence as a caregiver decided to focus on herself and her parent rather than her sibling(s).

Summary of divergence and transcendence. While ambiguity and uncertainty played a dominant role in the results of Study One, other aspects of PI were also apparent to a lesser extent. Divergence about relational aspects contributed greatly to the frustration in the caregiving situation between siblings. About one-half of participants had reached a point of Transcendence, where diverging expectations no longer troubled them. The next question to answer was how such ambiguity and divergence are related to how siblings communicate with one another. The next section discusses the communication behaviors of topic avoidance and secret keeping that were utilized by participants and their sibling(s) in Study One.

Communicative Behaviors with Siblings

The results of Study One described how siblings employed various communication strategies to manage the flow of information about the caregiving situation and about their relationship with sibling(s) and others in the family. Most participants chose to avoid conflict with the sibling in an attempt not to "make things worse" for themselves or their parent. This avoidance either occurred directly, by limiting contact and/or communication with a sibling, or indirectly, by avoiding conversation about particular issues or holding back personal feelings. A smaller number of participants chose to keep secrets from their sibling(s) or others within the family. These communicative behaviors will be further discussed in the following sections.

Avoidance. Participants described topic avoidance as a strategy to prevent conflict with siblings. The results of this study revealed a tendency by participants to avoid what one participant labeled "poking the bear" (S1-11). Years of previous interactions with their siblings provided participants a sense of certainty about how their siblings would react to particular topics or behave in specific situations. Seventeen participants in Study One primarily reported using one of three strategies to avoid conflict with their sibling(s): curtailing interaction, restricting topics, and suppressing thoughts (see Table 4 for definition and examples of each strategy). How participants went about evoking those strategies will be discussed in the sections below, beginning with curtailing interaction as an Avoidance strategy.

Curtail interaction. Curtailing interaction was the first form of avoidance that participants identified (see Table 4). A sense of certainty regarding sibling behavior prompted some participants to *curtail interaction* with their siblings. Participants chose to

limit face-to-face contact and other means of communication (including phone calls, emails, or text messages) with their siblings. A 43 year old female participant commented, "I don't really interact with him a lot to be honest with you, because he's very combative; I just don't need to deal with it, so honestly I try to interact with him as little as possible" (S1-11). This participant was making a calculated choice about when and how to talk to her brother. Later in the interview, this same participant said, "I just look at [my brother] as someone I don't get along with, who I don't agree with most of the time, and that's someone I don't wanna have any kind of a relationship with." In this situation, the participant had a long history of difficult interactions with her sibling and, thus, was now choosing to focus on the needs of the parent versus the response of the sibling. The participant felt that less interaction was a better choice.

Concern about an in-law's behavior was another reason that participants curtailed interaction with family. A 64 year old woman said, "My sister is married to a man who hates, who is very disagreeable to all of us, and is not very nice to my husband and not very nice to my child, so I sort of stay away from them" (S1-22). This participant admitted that the relationship with her family was "really bad" and that her brother-in-law's attitude contributed to the decline. As a result, this participant chose to avoid interactions with her siblings and their spouses. Another way that participants set out to control conversations with the sibling and to focus on the parent was by restricting topics open for discussion. This strategy is discussed below.

*Restrict topics***.** The previous section reported that curtailing interactions was one strategy used by participants to manage their sibling relationship. This strategy was employed when participants had a strong sense of how their siblings would react.

Expectations regarding sibling behavior also prompted 17 participants to *restrict topics* when engaging in conversation with their siblings (see Table 4). A female participant, whose mother suffered from mental illness and created a difficult childhood for her and her siblings, chose to avoid talking about personal matters or "anything that's happening in our house," because she knew "it would not be received well" (S1-22). In the past, any personal news that this participant shared about her immediate family "was thrown back at [her]," thus she restricted this information in conversations with her mother and siblings.

Other participants chose to "keep the conversation light, really nothing too deep" (S1-11) or to avoid anything that "might potentially be divisive" (S1-19). One woman specifically chose to avoid talking about politics or religion "because we have very different views on that" (S1-05). Long ago, this participant had moved from her hometown to a very disparate location and now felt that she viewed the world differently from her siblings. As a result, this participant chose not to share these changed opinions on certain topics in order to avoid conflict. A 63 year old female participant avoided a wide range of topics, including "anything about abortion, religion, her kids, my degree" (S1-03) because they would all get her sister angry. Therefore, this participant chose to restrict talking about any of these topics with her sister. These participants were confident that any topic of a sensitive nature would result in an argument with their siblings, so the participants restricted talking about them.

Participants believed that talking about certain people in the family was off limits as well. Some participants avoided talking to their parent(s) about a certain sibling. In a family where one child was estranged from the parent, the participant said, "We have . . .

a quiet agreement that I'm not going to talk about my mother to her and . . . I'm not gonna talk to my mother about her either" (S1-01). The participant had a good relationship with both her mother and her sibling and felt that she was in a "weird neutral position" and wanted to avoid conflict by restricting the conversation on this topic.

In one family, a sibling was estranged from the other siblings but not the parent. The participant said, "[I avoid talking about] my brother. [My mother] will always stand up for him and, I didn't think very highly of him because he left six kids and a wife" (S1-03). The mother chose to see the son in a very different light than her other children viewed their brother. As a result, the participant and her siblings choose to restrict any mention of their brother. This happened in another family as well. A female participant said, "[my brothers'] alcoholism is always the elephant in the room" (S1-13). While the participant saw the alcoholism as the reason for her brothers' lack of response to her mother, the mother still held them in high regard. The participant found her mother's opinion very frustrating and so restricted talk about her brother.

The examples above represent instances where 17 participants had discussed a topic and received a particularly unnerving response. In an effort to avoid this type of reaction again, the participants chose to avoid or restrict certain topics. When "a quiet agreement" to avoid topics did not exist, participants often chose to hold back their personal thoughts and feelings. The next section will discuss the avoidance strategy of suppressing thoughts and feelings.

***Suppress thoughts*.** After *curtailing interaction* and *restricting topics*, the third type of avoidance strategy enacted in Study One was to *suppress thoughts* (see Table 4 for definitions and examples). Participants most often concealed thoughts and feelings

about siblings' caregiving efforts following a process of calculating the risks in a situation. A 43 year old female caregiver chose to suppress her thoughts in order to protect herself: "He's just going to throw it back in my face later" (S1-11). This participant had a lot to say to her brother, but she chose not to share anything with him unless she felt the information was critical to her mother's care. A 53 year old female caregiver choose not to say anything in an effort to limit damaging the sibling relationship, describing: "When you have moments of frustration, that's not necessarily productive to express those" (S1-10). This participant and her brother had a relatively good relationship, and she did not want to say anything to alter that and so chose to suppress her thoughts and keep them to herself. A 45 year old female participant said, "I don't wanna make her [my sibling] feel bad either, like feel like she's not doing her part or doing the right thing. You know like, so, I won't say to her I'm disappointed that you're not seeing mom more" (S1-14). Even though this participant wished her sibling was doing more, the participant recognized that the sibling was doing the best she could. Raising the issue might not only damage the relationship but might also lead to the sibling to contribute even less to care. Therefore, the participant suppressed her thoughts on the matter. A similar calculation of risk was undertaken when participants decided to suppress thoughts about others in the family, particularly their sibling's spouses.

Suppressing personal thoughts to others in the family about a sibling's spouse was common in the descriptions. A 46 year old female participant said, "He knows I don't like his spouse, he knows that I feel [disappointed] when he doesn't come to my kid's, you know, events" (S1-12). This participant was frustrated that her sister-in-law limited the time her brother spent visiting her and her family, but she chose to suppress her

thoughts and not say anything. Another participant said, "I never criticized [my brother-in-law] to my sister. So we didn't talk about him, we talked about her" (S1-05). Her brother-in-law had "flown off the handle a couple of times" while the mother was living with him and her sister. The participant was upset that he had treated her mother this way, but she kept her feelings to herself. Another participant clearly articulated why she suppressed these thoughts about her brother's spouse:

> My brother's first wife, who is this person who says all this nasty, makes all these nasty crass, you know, comments about other people, um how can you spend five minutes, I mean that's not going . . . to be useful [to say something] that's going to be seen as an attack. (S1-20)

This participant was worried that if she were to say anything about her brother's wife, her brother "would have just said goodbye" (S1-20). The participant suppressed her thoughts about the spouse in hopes of maintaining a relationship with her brother.

Some participants were so fearful of the needs of their aging parent and what tasks that would require that they had yet to discuss the situation with their siblings. A 46 year old female participant said,

> We've never had that discussion, so maybe the whole tension that we had was that I saw them as being male and older that they should step in and maybe they saw it as me being the female of the family, that I should be stepping into a certain role. (S1-12)

For this participant, the tension with her brothers had been building since the passing of their father, and yet she and her brothers chose to suppress a conversation about what

needed to be done for their mother. A 54 year old female participant had similar tensions

stemming from perceived gender roles:

> I think my brother is concerned he's going to get stuck . . . paying for my mother.
>
> And there's also a component where just because I'm a single woman does not
>
> mean I'm gonna go down to [SE state] and go live and take care with, of my
>
> mother. (S1-17)

This participant questioned her expected versus actual caregiving roles. However, she

suppressed her thoughts on the matter because she was not ready to have those questions

answered.

Other participants suppressed thoughts about their siblings when communicating

with their parents. A female participant limited how she responded to her mother, saying

"Oh, I keep my mouth shut when my mother starts talking about how wonderful her other

daughter is, how perfect and how hardworking, I just sit there and you know don't say a

word" (S1-07). This participant had a very different opinion of her sister but chose to

suppress talk with her mother about a topic that had generated negative emotions over the

years.

Most of the suppressed topics centered on participants' feelings about their

siblings' caregiving efforts. Few participants described money or property as potential

sources of conflict. Therefore, if participants did suppress thoughts on these topics, their

comments revealed a broader emotional component. For one participant, the challenge

involved the family vacation home: "The cottage. This place is an elephant in the room

for sure and a lot of it also has to do with my mother creating a lot of emotional upset

around, around it" (S1-17). The participant's mother owned the cottage and her brother

paid for maintenance, but the participant lived there. The participant felt she needed to suppress her thoughts on the property because others were paying it. For another participant, it was a question of her family's home. "You know, this should really be a discussion as a whole family, because if we sell the house in [city in MA] it's, it's all of us involved and nobody wants to, for whatever reason, have that discussion" (S1-12). Once again, this was an example of a participant having questions about caregiving activities but suppressing thoughts because they are not ready to hear the answers.

Whether participants chose to curtail interaction with a sibling, restrict certain topics during a conversation with their sibling, or suppress thoughts about their sibling or another family member, they did so to avoid a particular response from their sibling or parent. Avoidance tends to involve topics and people with which all parties are familiar. Secrets, however, tend to involve issues that purportedly only the secret keeper knows (Derlega et al., 1993; Kelly, 1999, 2002). This difference in "who knows what" typically shifts the communication exchange from one of relationship maintenance to information maintenance. The next section will discuss the use of secret keeping as an information management strategy during caregiving. Examples of what information participants chose to keep from their siblings and other family members are presented below.

Secret keeping. Secret keeping involves actively hiding private information from others (Kelly, 1999, 2002). Secrecy has also been related to self-concealment (a personality trait) and active inhibition of disclosure (Kelly, 1999, 2002). In Study One, some family members chose to hide particular pieces of information from one another. Results showed that participants kept secrets from their parent(s), their sibling(s), and their extended family, but parents and siblings often jointly kept secrets from the larger

family as well. Examples of information that participants kept from their parents and siblings, as well as information that parents and siblings kept from other family members, are presented in the following paragraphs. Table 5 provides definitions and examples of each type of secret keeping in Study One.

Participant secret keeping. Some participants chose to keep information from their parent. In an effort to make her caregiving situation more bearable, one participant admitted to knowingly keeping financial expenses from her mother:

I have to tell lies, my mother . . . is really nervous about money, I mean really nervous about money. I decided that I'm hiring someone to come in that my mother knows already on Thursday, and lie to my mother and tell her that the county is paying for it. (S1-07)

Upon keeping these secret from her mother, this same participant then found herself having to keep secrets from her sister: "I'm careful not to tell my sister that I'm telling my mother a lie. My sister might feel it's very important not to lie to our mother" (S1-07). This participant had been shouldering the care needs of their 96 year old mother in addition to her husband's and her own care needs. She felt that as a caregiver taking care of herself sometimes needed to take precedence over honesty.

Other participants admitted to being so caught up in the day to day activities of caregiving that they often kept details from their sibling. A 63 year old female participant said, "I don't tell [my brother] she has these episodes that all of a sudden people are saying they are mild seizures" (S1-09). This participant admitted to "just trying to survive" caregiving and felt the biggest struggle with her brother was "just getting him to show up" (S1-09). She did not want to struggle with her brother over the small details

and so kept these from him. Another female participant chose to keep information from the family in an effort not to worry them: "There is nothing I really didn't wanna tell them, or chose not to tell them, other than, we're probably gonna move in about a year and a half, two years . . . I don't wanna worry anybody" (S1-03). This participant was nearing retirement and making plans for life after her current job but kept those plans secret.

In each of the examples above, participants were choosing to keep secret some information that they thought might complicate the caregiving situation. Nine of 22 participants discussed keeping secrets from one or more of their siblings. They were the primary caregivers of the parent and wanted to control the level of conflict that they might experience with their parent or their sibling. They were the principal owners of the information and were choosing what to do with it. The next section presents examples where parents and siblings, rather than the participant, kept information from family members. In these instances, the parents or the siblings were the owners of the information and did not share it for quite some time.

Parents and siblings. When parents or siblings keep information secret from the family, their actions were sometimes an attempt to diffuse family members' possible disapproval. A 62 year old female participant told the following story:

[My stepmother] wanted to move [into an assisted living community]. She got frightened by thinking that my father had died when he'd gone to sleep one afternoon. We didn't actually know the whole back-story at first. They started planning it [the move] without even including us. (S1-19)

This participant and her siblings questioned whether this move was something that their

father really wanted and wondered if that was why the information was kept from them.

In another instance, a brother's secret keeping was an attempt to keep family members

from worrying: "[My brother] had a malignant melanoma that he chose not to share with

any of us until the surgery was all over" (S1-10). The brother was in the medical field and

chose to keep the details of his diagnosis secret from much of the family. Another

participant only recently learned "[my sister] has not had heat in her house" (S1-15). Her

sister often "made poor choices" and hid the news from the participant in hopes of

averting the participant's disapproval.

There was only one reported instance in the interviews in which information that

was kept secret involved family assets. A 72 year old female participant told the

following story:

> My older brother was farming the family farm, which was a dairy farm, and he
>
> had such bad knees that he really couldn't do the milking. So he gave it back to
>
> my dad. . . He eventually went into beef farming and crop farming. Then my
>
> younger brother got the farm and . . . evidently my younger brother got it for a
>
> steal and my older brother never knew. When it came up in conversation one day,
>
> my older brother was blown away by that. It . . . was something that we didn't
>
> ever know. (S1-05)

This story was an example of how those directly involved in a situation did not see the

need to tell those who were not directly involved. Seven of 22 participants reported

family members keeping information secret. This differed from the previous examples of

secret keeping in which participants kept information secret in an attempt to evade

conflict or disapproval. Keeping secrets to limit conflict with siblings was consistent with participants' rationales about using the communicative behaviors of curtailing interaction, restricting topics, and suppressing thoughts. Participants found caring for an aging parent to be a mentally and physically exhausting pursuit and participants limited their involvement in any activity or conversation with their siblings that might tax their energies further.

Summary of Study One Results

Research Question 1 asked what personal and relational characteristics siblings bring to bear when coping with caregiving challenges. The rationale for Study One suggested that an examination of sibling relationships should consider closeness along with relational maintenance behaviors. Closeness in adult sibling relationships may be influenced by whether the siblings felt close when they were children (Scott, 1983), the number of similarities (interests, opinions, beliefs, and attitudes) shared by siblings (Folwell, Chung, Nussbaum, Bethea, & Grant, 1997), as well as whether the siblings are close in age. Participants in Study One described the current relationship with their sibling as a reflection of their childhood relationship. Those participants that felt they had a supportive or cooperative relationship with their siblings when they were younger tended to report the same type of relationship during caregiving. Those participants that perceived a competitive or emotionally distant childhood relationship reported a similar relationship while caring for a parent. Therefore, the relational quality that participants reported in Study One was the feeling of sibling closeness present since childhood.

Research Question 2 asked how siblings perceive the challenges and uncertainties associated with their parent's needs during elder care. Consistent with other health

communication studies, Uncertainty played a prominent role during the caregiving situation (e.g., Babrow, 2007; Checton & Greene, 2012; Dennis et al., 2008; Matthias, 2009). As mentioned earlier, the uncertainty generally surrounded questions about the parent's mental or physical health (i.e., will the symptoms worsen, how will we continue to provide care), the parent's housing and finances (i.e., where will our parent have to move, when will they have to move, will they have enough money for the care they need). However, participants also experienced uncertainty about their own mental and physical health and their own housing and financial matters.

Research Question 3 asked how siblings perceive the challenges and uncertainties associated with their sibling relationship(s) during elder care. The broader concept of Ambiguity came into play here, particularly participants referred to the future of their sibling(s) relationships. Participants had less clarity about what direction or form their relationship would take once caregiving had ended. Although Ambiguity was reported less frequently than Uncertainty, Ambiguity was still a predominant form of PI present in Study One. Making the distinction between Uncertainty and Ambiguity is an important aspect of PI Theory and differentiates the results of Study One from the more common relational uncertainty research.

Research Question 4 asked, in addition to Uncertainty, what other forms of Problematic Integration are present during caregiving. The manifestation of Divergence in the results of Study One supports PI theory and extends the understanding about where Problematic Integration may reside with family members during caregiving. The additional reporting of Transcendence extends PI theory and shows how individuals at times move past the frustration of diverging expectations to a place of acquiescence.

Finally, Research Question 6 asked what communicative behaviors siblings report when interacting with their siblings during the caregiving process. In Study One, numerous communication strategies were employed by participants to manage the interpersonal exchanges with siblings about caregiving. These included avoidance strategies (particularly curtailing interaction, restricting topics, and suppressing thoughts) and secret keeping strategies. Whether individuals use certain communication strategies or rely on particular personal dynamics to decrease the potential level of Problematic Integration or to come to a place of Transcendence is still to be examined. Understanding the connection between the forms of PI experienced during caregiving and the resulting communication behaviors exhibited by siblings could yield positive care outcomes for the parent and lower the caregiving burden for the siblings.

For this study, the concepts regarding forms of PI and forms of Uncertainty were used to provide initial guidelines that were built upon as data analysis continued. Just as Gill and Morgan (2011) suggested, the goal was not to test PI theory in this portion of the study but to use its concepts to clarify the texts while at the same time using the texts to refine the understanding of the PI concepts in an elder care context. The concepts that emerged from the data in Study One were used to construct the survey instruments employed in Study Two. The following paragraphs present a brief discussion of the results from Study One.

Discussion

The results of Study One suggested that the relational characteristic of emotional closeness was a critical part of coping with the challenges of elder care (RQ1). Those participants who were more positive about their sibling and their sibling's caregiving

actions spoke of feeling supported and respected by their sibling. Those participants who were more negative about their sibling and their sibling's caregiving actions spoke of feeling abandoned or dismissed by their sibling. Descriptions of sibling affection, comfort, and time spent together contributed to less negative descriptions of the current and future relationship with the sibling.

The results of Study One also supported Babrow's (1992) contention that Ambiguity is a broad construct comprised of the multiple, distinct concepts. Each concept poses different levels of information needs and different responses from individuals. The results of RQ2 and RQ3 in Study One highlighted how participants conceptualize Ambiguity differently depending on whether they are thinking about their parent's care needs or their relationship with their sibling(s) during caregiving. Participants in Study One tended to be uncertain (not knowing the risk in a situation) about "what's next" for the parent, including will their symptoms worsen, will they need more care, or will they have to move. Participants were also uncertain about "what's next" for themselves as caregivers, including will their own health worsen, is their job in jeopardy, or will they have to move. Although parents' health drove both living and financial uncertainties, the participants' living and financial circumstances often drove their own health uncertainties.

Uncertainties about a parent's mental health were highlighted in participant discussions. For some participants, the concern was more general as they wondered how to help their parent remain socially engaged and connected. For other participants, the concern was more specific and centered on the parent's possible cognitive decline. In the aging literature, these physical and mental concerns are connected. Cornwell and Waite

(2009) note how social isolation poses significant health risks including higher rates of morbidity and mortality (Brummett et al., 2001; Seeman, 2000; Uchino, Cacioppo, & Kiecolt-Glaser, 1996), infection (Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997; Pressman et al., 2005), and cognitive decline (Barnes et al., 2004; Wilson et al., 2007). The results of Study One demonstrate how families understand these risks but are struggling as they shoulder the burden of managing their parent's physical and mental needs.

Participants, however, were Ambiguous (not knowing the outcome of a situation) as to what the future will hold for the relationship with their sibling. Some participants could not even imagine what the relationship with their sibling would be like once caregiving was over. In contrast, participants had very strong feelings about what they hoped their sibling would do versus what they expected their sibling would do during caregiving. Participants held certain ideals of what it meant to be a good son or daughter or to be a good sibling. Yet, when these ideals were not met, this divergence in expectations was often associated with increased strain on the sibling relationship, thereby continuing a cycle of discontent.

According to the results of Research Question 4, the concept of Divergence was not new to caregiving. For some participants, these sibling relationship ideals had not been met since childhood, but the participants were still hoping that their sibling would change and rise to meet their personally held expectations. This mismatch of expectations was the source of conflict with their sibling(s) and greatly contributed to the stress of caregiving. Individuals experiencing Divergence were struggling with their sibling relationship as well as the uncertainties traditionally associated with the caregiving

experience. Healthcare and senior care professionals (Doremus, 2014) are aware of this "double struggle," yet previous research has focused solely on the Uncertainty aspect of illness and caregiving.

There were other participants who were resigned to the fact that their sibling was never going to meet their ideals for a relationship or a caregiving participant. These participants had no expectation that their sibling was going to change and so were resigned to their sibling's behaviors. These individuals found peace with the caregiving experience, but this was rare in the present data. The idea of Transcendence shifts the response to PI, a major change for the theory and significant to the healthcare context. The assumption of PI theory is that a mismatch between expectations (what is believed to be so) and values (what we want to be so) results in "problems." However, the results of Study One showed that this is not always the case and the characteristic PI mismatch can be reconciled for some people.

In situations of Transcendence, there is still a disparity between expectations and value, but the integration of these dimensions is not problematic. An individual is able to let go or see past the mismatch in order to refocus on other areas of concern. For example, in Study One, those participants feeling a sense of transcendence about their sibling's behaviors channeled energies into caring for their parent instead. The parent benefitted from the participant rising above the challenges of the situation.

In Study One, participants reported using a number of information management strategies to manage the interpersonal exchanges with their siblings during caregiving (RQ6). The avoidance strategies of curtailing interaction, restricting topics, and suppressing thoughts were most often used, but the strategy of secret keeping was also

employed to a lesser extent. Although avoidance strategies were used to prevent conflict-inducing topics from being reintroduced within the family, the secret keeping strategy was more often used to protect the participant from criticism about their caregiving methods. A second study was conducted to assess the relationship between the various forms of PI (including transcendence) and the communicative behaviors of information sharing, topic avoidance, and secret keeping.

CHAPTER FOUR – STUDY TWO

Study Two – Rationale

Study One provided an in-depth exploration of caregivers' perceptions of

problematic integration with a sibling during the transition to parent(s) care. One of the

strengths of Study One was obtaining participants' descriptions of their experiences of

sibling interactions and how they sought to make sense of the situation and

relationship(s) through this difficult transition. The concepts of caregiving burden and

relational quality were associated with different levels of information needs and different

PI responses in Study One. Participants who were more negative about their sibling

relationship and their sibling's caregiving actions often described feeling abandoned or

dismissed by their sibling. For some participants, the mismatch in expectations between

what was likely versus what was desired was the source of conflict with their sibling(s)

and greatly contributed to the stress of caregiving. In Study One, participants reported

using a number of information management strategies to manage the interpersonal

exchanges with their siblings during caregiving.

To explore the association between caregiving burden, relational quality,

information management, and PI, Study Two operationalized PI. A new scale, the

Problematic Integration Measure (PIM), was developed from the data collected in Study

One. This survey-based measure was the first of its kind, moving PI from a theory that

has primarily been examined qualitatively to one that could be explored quantitatively as

well. This is an essential development in PI theory. Previous studies utilizing the theory

have explored the forms of PI experienced in numerous health and interpersonal contexts.

However, by operationalizing the measure as a quantitative scale representing the various

forms and orientations of PI, researchers can gain a new understanding of how those forms are associated with various communication and relational maintenance behaviors.

Specifically, the present study explored the relationship of family communication and relational quality to the divergence in perceptions and expectations surrounding the sibling relationship during elder care. Study Two, then, considers whether these diverging expectations are associated with the information management behaviors exhibited with siblings. Because communication is central to both the construction of and response to PI, understanding information sharing and/or avoiding patterns is critical to understanding how individuals manage complex, problematic situations (such as elder care) and personal relationships (such as sibling relationships). The newly developed PIM presented in Study Two can assist both researchers and practitioners as they study and respond to the interpersonal exchanges occurring in families during times of later stage development.

The initial hypotheses investigated associations between problematic integration with caregiving burden, relational quality, and family communication. Caregiving burden is a representation of the physical and emotional well-being of a primary caregiver. Although various scales have been developed over the years to measure caregiving burden (e.g., Zarit et al, 1980; Miyashita et al., 2006), little is known as to how feelings of burden relate to responses to the care situation. This study postulates that the stress and negative emotion associated with feelings of burden may overwhelm the caregiver leaving little room to integrate the possibilities and expectations around caring for an aging parent. The experience of PI and burden is likely reciprocal, making it difficult to ascertain (in a cross-sectional study) if PI leads to greater burden or greater burden leads

to more challenges with problematic integration. Therefore, the first hypothesis is as follows:

H1: The greater the perceived level of caregiving burden, the greater the overall perceived level of problematic integration during elder care.

Zarit et al.'s (1980) original investigation of caregiving burden described how the ability of caregivers to cope with the caregiving situation might depend on the quality of their social relationships. As reported in Study One, descriptions of sibling affection, comfort, and time spent together were related to less negative descriptions of the perceived current and potential future relationship with the sibling. Greater relational quality may make the complexities of the caregiving situation more manageable and, therefore, may be related to more productive expressions of problematic integration. This leads to the second hypothesis.

H2: The greater the perceived level of sibling relational quality, the lower the overall perceived level of problematic integration during elder care.

Beyond caregiver burden and relational quality, researchers have focused on patterns of family interaction including family communication. More open communication has been associated with higher levels of problem solving and lower levels of conflict in past research (e.g., Koerner & Fitzpatrick, 2002). A greater openness in communication, therefore, may also make the complexities of care giving more manageable. As noted in the rationale, siblings that develop a competence for communicating may have a decrease in their uncertainty about caregiving and what others are thinking about caregiving. If siblings are more aware of the events surrounding

a situation including constraints of their siblings, they may have lower occurrences of PI. Thus, the third hypothesis is as follows:

H3: The greater the perceived openness of family communication, the lower the overall perceived level of problematic integration during elder care.

The initial hypotheses for Study Two focused on the relationship between PI with perceptions of burden and relational components (relationship with sibling and family communication patterns), but other issues raised in Study One included communication behaviors related to information management enacted during this family transition. The next set of hypotheses investigated the relationship between problematic integration and the information management behaviors of information sharing, topic avoidance, and secret keeping. Greater levels of information sharing (through less topic avoidance and less secret keeping) were expected to allow caregivers greater opportunity to make sense of the caregiving situation. Caregivers who shared more would have an increased understanding of the elder care situation and, therefore, an increased understanding of the probabilities of events associated with caring for their parent and their siblings' possible behaviors relative to their expectations. To manage PI most productively, then, the expectation is that caregivers would share more with siblings, avoid less, and keep fewer secrets. Avoidance, however, could possibly be seen as a strategic choice in managing problematic integration with a sibling. Overall, however, the rationale would lead to expecting greater sharing (and less avoidance and secrets) to be related to better problematic integration. Therefore, the next three hypotheses were as follows:

H4a: The lower the overall perceived level of problematic integration, the greater the information management behavior of information sharing.

H4b: The lower the overall perceived level of problematic integration, the fewer

the information management behavior of topic avoidance.

H4c: The lower the overall perceived level of problematic integration, the fewer

the information management behavior of secret keeping.

Multiple studies have explored how providers, patients, and caregivers

respond to challenges within a health context (e.g., Babrow & Kline, 2000; Gill &

Morgan, 2011; Hines et al., 2001). Using PI, these studies confirmed that people

respond to similar situations differently and assign different values and estimate

varied probabilities to the particular situation. These differences in responses were

also seen in Study One. Therefore, Study Two seeks to understand how those

varied PI estimations relate to how people perceive caregiving and their

relationships, as well as how they communicate with siblings during caregiving.

What has not been explored extensively in prior research is how various aspects

of PI or forms or types of PI are associated in experiencing events. In order to

specifically examine the role that the various forms of PI may play in influencing

perceptions and information management behaviors, the following research

questions were proposed:

RQ1: What specific forms of problematic integration were associated most

strongly with caregiving burden?

RQ2: What specific forms of problematic integration were associated most

strongly with sibling relational quality?

RQ3: What specific forms of problematic integration were associated most

strongly with the two forms of family communication patterns?

RQ4a: What specific forms of problematic integration were associated most strongly with the information management behavior of information sharing?

RQ4b: What specific forms of problematic integration were associated most strongly with the information management behavior of topic avoidance?

RQ4c: What specific forms of problematic integration were associated most strongly with the information management behavior of secret keeping?

Although a number of studies (e.g., Babrow & Kline, 2000; Gill & Morgan, 2011; Hines et al., 2001) have sought to extend the framework of PI theory as a means for understanding the difficulties inherent in communication during times of illness, no study to date has examined whether the underlying forms PI contribute to more destructive or constructive information management behaviors. The specific methods used in Study Two to operationalize PI (create a quantitative PI measure or the PIM) and to conduct a cross-sectional survey (including participant recruitment, procedure, and measurement) are described in the section below, followed by a discussion of the results.

Study Two – Method

Recruitment procedures in Study Two were very similar to those used in Study One. Because this was the first time that PI was operationalized via a survey measure, additional outreach was done to local senior living communities in an effort to increase the number of participants. The survey was built in Qualtrics, a secure online platform available through the researcher's university. Details of the new PIM developed from the results of Study One, including the sub-scales of Likelihood, Value, and Upsetness, and the other measures used in Study Two are discussed in the following sections.

Participants

A purposive sample of adults who had recently negotiated care for an aging parent with their sibling(s) was solicited from the national and local chapters of various professional and networking organizations. Additional participants were recruited via the researcher's personal and professional contacts (including senior housing executives, social work professionals, and home health care organizations in New Jersey), as well as through social media accounts and email listservs (see Appendix A). Some unknown overlap may have occurred with Study One participants. An IRB approved recruitment flyer was distributed electronically or physically posted at an organization's location (see Appendix J).

As in Study One, there were multiple criteria for inclusion in Study Two. Consistent with Merrill (1996) and Checkovich and Stern (2001), participants included adults over the age of 35 with one or more living siblings and an unmarried parent (i.e., divorced, widowed, or never married) or two parents to whom the participant or a sibling had provided direct assistance (versus advice or information). Provision of direct assistance was identified as Activities of Daily Living, health care decisions, financial matters, or living arrangements within the past twelve months. At least one sibling had to have contact (phone or face-to-face) with the aging parent no less than once per month in the past year.

Participants included 82 adults (12 males and 70 females) who were primarily in the 55-64 age range ($n = 50$) and the 45-64 age range ($n = 21$). Five additional participants were in the 35-44 age range and five others were in the 65-74 age range. The majority of participants were Caucasian ($n = 69$), while 8 identified as African American,

2 as Hispanic, and 3 as Other. Over half of the participants indentified as Christian ($n =$ 51), while the remainder identified as Jewish ($n = 7$), other denominations ($n = 7$) or no specific affiliation ($n = 17$). Over half of the participants reported relational status as married ($n = 58$), while others said they were never married ($n = 5$), divorced ($n = 10$), widowed ($n = 5$) or in a civil union ($n = 3$). Participants reported between 0 and 8 children ($M = 1.92$, $SD = 1.44$). The mean age of those children was 27.33 with a range from 7 to 52 years old ($SD = 9.23$). A large portion of the participants reported having graduate or professional degrees ($n = 51$), while 13 reported having a college degree, four an Associate degree, nine some college but no degree, and four a high school diploma. Participant income showed a relatively normal distribution: 0 - \$24,999 ($n = 6$), \$25,000 - \$49,999 ($n = 6$), \$50,000 - \$74,999 ($n = 17$), \$75,000 - \$99,999 ($n = 13$), \$100,000 - \$149,999 ($n = 15$), \$150,000 - \$249,999 ($n = 11$), greater than \$250,000 ($n = 8$), and 5 participants declined to report income.

A majority of participants were caring for one unmarried parent ($n = 59$); however, 23 participants were involved in the care of two aging parents. The ages of the parents receiving care ranged from 58 to 99 ($M = 84.16$, $SD = 6.87$). The living arrangements of Parent 1 were the following: with the participant ($n = 15$), with the participant's sibling ($n = 4$), in the parent's home ($n = 32$), in an independent living community ($n = 7$), in assisted living community ($n = 13$) or in another locale such as a nursing home or rehabilitation center ($n = 11$). The living arrangements of Parent 2 were similar with 3 living with the participant, 10 living in their own home, two in an independent living community, three in an assisted living community, and five living in another locale. Twenty-seven participants reported having one sibling, 23 had two

siblings, 13 had three siblings, and 29 reported four or more siblings (M = 2.63, SD = 1.72).

Procedure

Participants completed an anonymous online survey (n = 80) or a hardcopy survey (n = 6). There were no detectable differences between the results of the online and paper versions and thus they were combined for analyses. On-line participants were instructed to log-on to a secure website to access the survey. The survey was expected to take between 30 and 45 minutes to complete based on pilot testing; online participants took an average of 1 hour and 11 minutes (range from 17 minutes to 18 hours and 25 minutes, SD = 2 hours and 25 minutes). Completion times of the online survey were skewed because participants were able to stop the survey and return at a later time. However, even with that option, only 47% of those starting the survey completed it. Data are presented based on completed surveys. Completion times of the paper based surveys were not recorded. Upon completion of the survey, participants could enter a drawing for one of three $50 American Express gift cards.

Measures

At the outset of the survey, participants read an assent form (see Appendix K). The first section of the survey asked about the participant's background information, the participant's sibling(s) and contact with them, and the participant's parent(s), the parent's living arrangements, and contact with them. Following collection of this general information, participants were asked to respond to questions about the current health or living situation of their parent(s), the events that led to the caregiving situation, the

caregiving activities that they and their sibling(s) were doing, and the feelings they experienced about caregiving.

Following the collection of background data and caregiving information, participants were asked to respond to questions measuring sibling relational quality, patterns of information management (including information sharing, topic avoidance, and secret keeping), family communication patterns, and the newly created measure of Problematic Integration. For these measures, participants were asked to focus on their interactions with one specific sibling during caregiving. If they had more than one sibling, they were asked to choose the sibling where interaction during caregiving has been the most challenging. The following sections will review each measure.

Caregiving burden. Caregiving burden is defined as the psychological, physical, and financial costs of providing care to another individual (Zarit, Reever, & Bach-Peterson, 1980). Although Zarit et al. (1980) was not the first to identify the burden of home care to family members (i.e., Lowenthal, Berkman, & Associates, 1967; Sainsbury & Grad de Alarcon, 1970), Zarit et al. was the first to identify how specific behaviors contributed to burden. Zarit's (2006) Care Burden Interview (CBI) includes 29 items and measures the overall degree of burden reported by a caregiver. The CBI items were developed based on clinical experience with caregivers and previous studies and covered problem areas most frequently mentioned by caregivers (Zarit et al., 1980).

The level of overall burden measured in Zarit et al.'s (1980) study was less than expected considering the complexity of many of the cases. The mean score was 31 (range 1 to 66, *SD* = 13.3) out of a possible 84 on the CBI. Items on which the most burden was reported involved the caregiver's lack of time for self, the excessive dependency of the

patient on the caregiver, and the caregiver's fears about further deterioration in the patient (Zarit et al., 1980). The only item, however, significantly related to care burden was the frequency of family visits ($r = -0.48$, $p < 0.01$).

While the CBI is one of the most well known care burden scales, it does not have a clear domain structure nor does it necessarily correspond to various aspects of care burden (Miyashita et al., 2006; Hashimoto, 2005). These issues have limited CBI's use in subsequent analysis. For the present Study Two, three items were selected from Zarit et al.'s (1980) CBI based on face validity and the results of the interviews conducted in Study One. Additional items for the measure of caregiving burden used in Study Two were taken from Miyashita et al.'s (2006) Burden Index of Care and are described next.

Miyashita et al. (2006) developed a multidimensional scale by selecting items from pre-existing care burden scales. Analysis was performed to confirm that selected answers were not heavily weighted on either end of the 5-point scale and multidimensionality was tested by conducting exploratory factor analysis (Miyashita et al., 2006). Those items that included a low difficulty level and a high discrimination power were used to establish a multi-dimensional Burden Index of Caregiver (BIC) that contains 11 items (Miyashita et al., 2006).

Five factors were extracted as a result of the exploratory factor analysis performed on the 10 items, excluding the total care burden of the BIC, and named Time-dependent burden, Emotional burden, Existential burden, Physical burden, and Service-related burden (Miyashita et al., 2006). Service-related burden demonstrated a slight deviation in distribution and its Cronbach's alpha coefficient was low ($\alpha = .68$) (Miyashita et al., 2006). For the other four factors, however, internal consistency was good (0.84 to 0.89)

(Miyashita et al., 2006). The average total care burden score, an additional item in the

BIC, was 16.8 (*SD* = 8.9) (Miyashita et al., 2006).

Known groups validity was examined using the correlation between BIC total

score and reported hours spent on daily caregiving (Miyashita et al., 2006). The

correlation between reported caregiving hours and a feeling of care burden has been

previously raised in other studies (Arai, Kudo, Hosokawa, Washio, & Miura, 1997;

Bugge, Alexander, & Hagen, 1999). On average, the BIC total care burden score was

12.3 for less than 3 hours, 18.1 for 3 to less than 6 hours, 20.1 for 6 to less than 12 hours,

and 22.6 for 12 hours or more. Spearman's ρ was 0.47 (*p* < 0.001) (Miyashita et al.,

2006).

Caregiving Burden in the present study was measured by 10 Likert-type items

with seven-point responses ranging from *Never Feel* (1) to *Always Feel* (7) (see

Appendix L). As previously mentioned, based on face validity, three items were taken

from Zarit et al.'s (1980) Burden Interview; an additional seven items were taken from

Miyashita et al.'s (2006) Burden Index of Care. A Principal Component Factor Analysis

(Varimax rotation) was performed on the 10 items. Examination of the factor analysis

including scree plot revealed the presence of one factor. Item i was deleted due to poor

loading (below 0.5), and the factor analysis was rerun with the remaining nine items

producing a single factor solution. The single factor (eigenvalue = 4.88) explained 54%

of the variance with all items loading above 0.6 on the single factor. The factor was

labeled *Caregiving Burden* and consisted of items such as "I wish I could delegate some

aspects of caregiving" and "My physical health has suffered because of caregiving." The

reliability coefficient was good (α = .89). The remaining nine items in the scale were averaged (*M* = 3.40, *SD* = 1.36) with a higher score indicating greater feelings of burden.

Sibling relational quality. Sibling relational quality is typically measured by the dimensions of contact or closeness. To capture closeness in Study Two, Rubin's Love Scale (1970) was used in combination with Weber and Patterson's Emotional Support Scale (1991). Although Rubin's (1970) Love Scale has been widely applied to romantic partners, there are common elements among additional varieties of love, such as familial love. These elements include affiliative and dependent need, predisposition to help, and exclusiveness and absorption (Rubin, 1970). These are all elements that may be present in adult sibling relationships during caregiving.

Rubin (1970) initially developed the Love Scale by examining college dating couples, In that study, the Love Scale had one factor and showed a high internal consistency (α = .84 for women and .86 for men). The scale was tested against Rubin's Liking Scale and the two were found to be more highly correlated among men than women (*z* = 2.48, *p* < 0.02). The construct validity of the Love Scale was further attested to by the findings that love for one's romantic partner was only slightly correlated with love for one's same-sex friend (*r* = 0.18 for women, *r* = 0.15 for men). Rubin (1970) suggests that the love scale taps an attitude toward a specific other person rather than more general interpersonal orientations.

The communication of emotional support, however, is another important aspect of the sibling relationship and caregiving decisions. Therefore, this study connects sibling relational quality to the provision of emotional support and utilizes Weber and Patterson's (1991) Emotional Support Scale. Weber and Patterson (1991) developed their

scale by taking a number of items from the emotional support subscale of Buhrmester, Furman, Wittenberg, and Reiss' (1988) Interpersonal Competence Questionnaire and changing them to reflect communication based emotional support. In addition, Weber and Patterson (1991) selected items from the Buhrmester et al. scale that reflected social support (communication that is intended to help individuals work through their problems).

In a study of study undergraduate students in a romantic relationship, Weber and Patterson's (1991) initial factor analysis relied primarily on unrotated factor structures and scree plots to produce a three factor solution. However, two of the factors produced weak results. Items that marginally loaded were deleted and a second analysis was run on the remaining items, yielding a single factor with an eigenvalue of 7.3 ($\alpha = .93$). Weber and Patterson (1991) then explored the relationship between emotional support and relational solidarity, and the Pearson correlation ($r = 0.72$, $p < 0.0001$) lends evidence for scale validity.

Sibling Relational Quality in the present Study was measured by 10 Likert-type items with seven-point responses ranging from *Strongly Disagree* (1) to *Strongly Agree* (7) (see Appendix M). Based on face validity, five items were utilized from Weber and Patterson's Emotional Support Scale (1991) and five were utilized from Rubin' Love Scale (1970). Participants were instructed to think about their overall relationship with one particular sibling. A Principal Component Factor Analysis (Varimax rotation) was performed on the ten items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 1 was deleted due to poor loading (below 0.5), and the factor analysis was rerun with the remaining nine items producing a

single factor solution. The single factor (eigenvalue = 6.23) explained 69% of the

variance with all items loading above 0.5. The factor was labeled *Sibling Relational*

Quality and consisted of items such as "My sibling shows genuine concern for my

problems" and "My sibling makes an effort to make me feel better when I am down."

The reliability coefficient was excellent (α = .94).The remaining items in the scale were

averaged (*M* = 3. 85, *SD* = 1.82) with a higher score indicating greater relational quality.

Information management. To capture the three different types of information

management behaviors (i.e., information sharing, topic avoidance, and secret keeping),

different scales were developed to measure the constructs. The scales for the present

Study Two were developed based on three prior information management scales and the

specific themes that were identified in Study One for this context. The existing

information management measures do not fully capture aspects of the context, and they

were adapted for use. Each of the three prior information management scales is described

separately next.

The first information management scale that informed the scale development for

Study Two tapped components of information sharing or disclosure. Miller, Berg, and

Archer's (1983) Self-Disclosure in Conversation Scale for information sharing is often

used to examine disclosure differences according to the gender, level and type of

relationship (Greene, Derlega, Yep, & Petronio, 2003). Subjects indicated the extent of

disclosure on a scale ranging from 0 (discuss not at all) to 4 (discuss fully and

completely) (Miller et al., 1983). Participants were instructed to "think of a same-sex

friend and same-sex stranger and indicate to which you have disclosed to each person"

and responded to such items as "What is important to me in life," "My worst fears," and

"Things I have done which I am proud of" (Miller et al., 1983). A factor analysis

revealed that the 10 topics, whether they referred to a same-sex stranger (α = .93) or a

same-sex friend (α = .87), loaded on a single factor (Miller et al., 1983). The results of

analysis showed gender and target differences, with females disclosing more than males

and both genders disclosing more to friends than to strangers. The most disclosure was to

female friends (*M* = 27.85), followed by male friends (*M* = 23.01), male strangers (*M* =

15.65), and female strangers (*M* = 15.04) (Miller et al., 1983). An overall self-disclosure

score is calculated for each target person by summing the scores across the ten items

(Miller et al., 1983).

The second information management component in Study Two was topic

avoidance. Baxter and Wilmot (1995) used a grounded theory approach to develop a

Taboo Topics Scale, which assesses the negative relational meta-communication implicit

in certain topical categories. In the original experiment, 90 interviews were conducted in

which participants were asked "what topics, if any, are taboo in the relationship and why

is the given topic taboo." From the interviews, an analytical induction method was used

to categorize the topics generated in the interviews (Baxter & Wilmot, 1995). Through a

series of modifications and informal checks, seven categories or themes of taboo topics

were deemed a summary of the data. These categories include: state of the relationship,

extra-relationship activity, relationship norms, prior relationships, conflict-inducing

topics, negatively valenced self-disclosure, and miscellaneous topics (Baxter & Wilmot,

1995). A chi-square test determined no significant different between same-sex and cross-

sex relationship types (x^2 = 2.29, *p* = .33) (Baxter & Wilmot, 1995). A number of the

categories identified by Baxter and Wilmot (1995) were similar to those identified in

previous studies (e.g., Roloff & Ifert, 1998) by participants in Study One of the present research and were, therefore, used to construct the Taboo Topic scale in Study Two.

The final information management component in Study Two was secrets. Larson and Chastain's (1990) Self-Concealment Scale (SCS) for secret keeping assesses concealment of information that is seen as negative or distressing. The 10 items of the measure use 5-point Likert scales ranging from 1 (strongly disagree) to 5 (strongly agree) and refer to three areas: keeping things to oneself, possessing a personally distressing secret, and apprehension about concealed information (Larson & Chastain, 1990). Example items include "I have an important secret that I haven't shared with anyone," and "There are lots of things about me that I keep to myself." The reliability of the scale (α = .83) has been consistent across different samples, including human service workers and graduate students ((Larson & Chastain, 1990). Whereas the SCS is distinct from self-disclosure, the scale has been correlated with anxiety, depression, and similar symptoms (Greene et al., 2003) and that is why it was chosen for Study Two.

The three scales described previously informed the development of the measures of information management strategies used in this portion of the research. Study Two sought to retain some consistency between the measures, adapting from these prior scales but also including topics identified in Study One. The descriptions of specific scales developed for each information management strategy are described next.

Information sharing. Individuals may share information about themselves (personal self-disclosure) or about interactions with others (relational self-disclosure) (Greene, Derlega, & Mathews, 2006). Whatever the type of information shared, it can have enormous influence on and serious consequences for close relationships (Derlega et

al., 1993). Because elder care is a new context for studying information sharing, Study

Two set out to discover the type of information revealed by adult siblings, and the results

of Study One were used to formulate the item content.

     Information Sharing in the present study was measured with 14 Likert-type items

with seven-point responses ranging from 1 (*Never Share)* to 7 (*Always Share)* developed

by the author (see Appendix N). Participants were asked to report how often they share

general or caregiving related information with a particular sibling that was the focus of

the survey. However, because more than 10% of respondents chose not to answer Item i

(Information on my child's well-being or personal life), it was deleted and not used in

analyses. A Principal Component Factor Analysis (Varimax rotation) was performed on

the remaining 13 items. Examination of the factor analysis including scree plot and item

loadings revealed the presence of one factor. The single factor (eigenvalue = 8.21)

explained 63% of the variance with all the items loading above 0.6 on the single factor.

The factor was labeled *Information Sharing* and consisted of items such as "I share

information regarding our parent's finances" and "I share information about how stressed

I am regarding caregiving." The reliability coefficient was excellent (α = .95). The

remaining thirteen items in the scale were averaged (*M* = 4.11, *SD* = 1.78) with a higher

score indicating a greater likelihood to share information with this particular sibling.

     Topic avoidance. What is concealed and revealed in conversation has a profound

influence on both the depth and limits to intimacy in personal and family relationships

(Afifi & Guerrero, 2000; Caughlin, 2003; Petronio, 2002). The results of Study One were

combined with the taboo topics commonly identified in previous research by Baxter and

Wilmot (1985) and Burke, Weir, and Harrison (1976) (i.e., relationship norms, state of

the relationship, negative life experiences, personal failures, and conflict-inducing topics) to formulate items for Study Two. Again, because elder care is a new context for studying topic avoidance, the focus of Study Two was on the topics avoided versus the criteria for avoidance.

Topic avoidance in the present study was measured with 12 Likert-type items with seven-point responses ranging from 1 (*Never Avoid)* to 7 (*Always Avoid)* developed by the author (see Appendix O). Participants were instructed to think about how often they avoid caregiving related or general topics with a particular sibling. A Principal Component Factor Analysis (Varimax rotation) was performed on the 12 items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. The single factor (eigenvalue = 6.61) explained 55% of the variance with all items loading above 0.6 on the single factor. The factor was labeled *Topic Avoidance* and consisted of items such as "I avoid discussing my thoughts and feelings about our caregiving roles with my sibling" and "I avoid discussing politics or religion with my sibling." The reliability coefficient was excellent (α = .95). The twelve items in the scale were averaged (M = 3.95, SD = 1.57) with a higher score indicating greater topic avoidance.

Secret keeping. A similar rationale was used to construct the measure of *secret keeping* as *information sharing*. Once again, because elder care is a new context for studying *secret keeping*, the focus of Study Two was on secrets kept from a particular sibling during caregiving and the results of Study One were used to formulate the questions.

Secret keeping in the present study was measured with 14 Likert-type items with seven-point responses ranging from 1 (*Never a Secret)* to 7 (*Always a Secret) developed by the author* (see Appendix P). However, because more than 10% of respondents chose not to answer Item i (Information on my child's well-being or personal life), it was deleted and not used in analyses. A Principal Component Factor Analysis (Varimax rotation) was performed on the remaining 13 items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. The single factor (eigenvalue = 8.40) explained 64% of the variance with all items loading above 0.5 on the single factor. The factor was labeled *secret keeping* and consisted of items such as "I keep information regarding our parent's day-to-day health situation a secret from my sibling" and "I keep information about recent job or life struggles in my family a secret from my sibling." The reliability coefficient was excellent (α =.95). The thirteen items were averaged (*M* = 4.35, *SD* = 1.83) with a higher score indicating greater secret keeping.

Family Communication Patterns. To gauge the type of communication that has typically taken place in a participant's family of origin, the Revised Family Communication Patterns Scale (RFCP) was used. This 26-item scale was developed by Ritchie and Fitzpatrick (1990) and is a modified version of McLeod and Chaffee's (1972) Family Communication Patterns measure. The intent of the RFCP is not to distinguish between healthy and unhealthy family communication but rather to describe the many ways that families function (Graham, 2009).

Across numerous studies, the reliability estimates for the conformity and conversation orientation subscales of the RFCP have consistently produced acceptable

levels (α = .72 to .92) (e.g., Baxter & Clark, 1996; Fitzpatrick & Ritchie, 1994; Graham, 2009; Koerner & Fitzpatrick, 2002; Ritchie & Fitzpatrick, 1990). In addition, Fitzpatrick and Ritchie (1994) assessed the test-retest reliability of the RFCP scale across three different age groups and reported alphas close to 1.00 for the conformity orientation and .73 to .93 for the conversation orientation (Fitzpatrick & Ritchie, 1994; Ritchie & Fitzpatrick, 1990). Koerner and Fitzpatrick (2002) have suggested that evidence of the construct validity of the instrument is provided by the sum total of research conducted using the measure (e.g., Baxter & Clark, 1996; Graham, 2009; Koerner & Cvancara, 2002; Koerner & Fitzpatrick, 2002; Schrodt & Ledbetter, 2007).

Family communication patterns in the present study were measured by 14 Likert-type items with seven-point responses ranging from 1 (*Strongly Disagree)* to 7 (*Strongly Agree)* as developed by the author (see Appendix Q). Items were selected based on face validity with 7 items representing each of the FCP dimensions. Participants were instructed to "think about the communication that took place with your parent(s) while you were growing up." A Principal Component Factor Analysis (Varimax rotation) was performed on the 14 items. Examination of the factor analysis including scree plot and item loadings indicated the presence of two factors, consistent with those reported in earlier research (Chaffee, McLeod, & Wackman, 1966; McLeod & Chaffee, 1972; Ritchie, 1988).

The first factor (eigenvalue = 5.73) explained 44% of the variance with all items loading above 0.6 on this factor. The first factor was labeled Conversation Orientation and consisted of seven items such as "My parents often asked my opinion when the family was talking about something." The reliability coefficient was acceptable (α = .90).

A *Conversation Orientation* subscale was created by averaging the seven items ($M =$ 3.21, $SD =$ 1.61, range 1.00 to 6.71), with higher scores indicating more openness in family communication.

The second factor was labeled Conformity Orientation and consisted of seven items such as "My parents became irritated with my views if they were different from theirs." Item 10 was deleted due to poor loading (below 0.5) and the factor analysis was rerun. This factor (eigenvalue = 2.27) explained 17% of the variance with all items loading above 0.5 on this factor. The reliability coefficient was acceptable ($\alpha =$ .84). A *Conformity Orientation* subscale was created by averaging the remaining six items ($M =$ 4.98, $SD =$ 1.48, range 1.83 to 7.00), with higher scores indicating more conformity in family communication.

Problematic Integration. A new instrument, the Problematic Integration Measure (PIM), was developed to measure the various forms of an individual's perceived level of Problematic Integration with one target sibling during caregiving. The forms of PI include Ambiguity, Ambivalence, Divergence, and Impossibility (Babrow, 1998, 2002). The new instrument also measured Uncertainty, to capture its distinction from Ambiguity, and Transcendence, the new form of PI found in Study One. Each of the six forms is represented in the instrument, with a total of 32 items created based on prior research (Babrow, 1998, 2002), existing measures such as Mishel's Measure of Uncertainty in Illness (1981), and the data collected in Study One (see Table 6 for the Forms of PI and their associated items).

The new PI instrument presented various items representative of the caregiving situation (see Appendix R). For each item, participants were asked to respond to three

questions intended to capture the nature of PI: How likely is this statement to be true? How would you evaluate this statement? How upsetting is this statement? These evaluative aspects were labeled *Likelihood, Value*, and *Upsetness*. *Likelihood* employed an 11 point scale ranging from *Not Likely to be True* (0%) to *Definitely Likely to be True* (100%). This scale was recoded for analyses from *Not Likely to be True* (1) to *Definitely Likely to be True* (11). *Value* employed a seven point scale ranging from *Extremely Bad* (1) to *Extremely Good* (7). This scale was reverse coded for analysis so that responses ranged from *Extremely Bad* (7) to *Extremely Good* (1) in order to match the scaling of *Upsetness*. *Upsetness* employed a seven point scale with responses ranging from *Not Upsetting* (1) to *Very Upsetting* (7).

Initially, a Principal Component Factor Analysis (Varimax rotation) was performed independently on the three evaluative aspects of PI with all 32 items. The intention was to extract six factors matching the six forms of PI as designed in the survey. These factors, however, were not clean within any of the three evaluative aspects. This was not surprising given that the analyses were not powered adequately due to sample size, the number of items per scale was moderate, and there was no prior data. Factor analyses were then conducted separately for each of the six subfactors relative to the three evaluative aspects of PI. During this analysis, items were retained if the primary loading was above 0.5. The development of items for each of the six forms of PI and their associated responses are presented in the sections below, including how each form was developed and the resulting psychometrics for the aspects of Likelihood, Value, and Upsetness.

Ambiguity. According to PI Theory, Ambiguity is both a form of PI as well as a distinct construct within the category of Ambiguity. This distinction was confirmed in the results from Study One. Participants were unclear about the future direction of the relationship with their sibling(s) and they did not know what outcome was likely. As such, items designed to capture Ambiguity had to incorporate this sense of vagueness (see Appendix R), for example "My parents deteriorating health will affect my relationship with my sibling." The items were developed from Budner's (1962) Tolerance for Ambiguity Scale as well as Checton and Greene's (2012) measures of prognosis and symptom uncertainty in combination with the results from Study One.

Budner's (1962) 16 item scale employed 7-point Likert scales with results ranging from 1 (*Strongly Disagree)* to 7 (*Strongly Agree)*. With no published factor structure, the scale is considered one dimensional ($\alpha = .39$ to .62) but has low reliabilities. Checton and Greene's (2012) measures employed 5-point Likert scales with responses ranging from 1 (*Very Uncertain*) to 5 (*Very Certain*). In Checton and Greene's study (2012), Confirmatory Factor Analysis (CFA) revealed that four items formed a one-dimensional measure of self-focused prognosis uncertainty ($\alpha = .50$). CFA also revealed that four items formed a measure of partner focused prognosis uncertainty ($\alpha = .63$) and four items formed a measure of relationship-focused prognosis uncertainty ($\alpha = .79$). Two items were used to measure self-focused symptom uncertainty, partner-focused symptom uncertainty, and relationship-focused symptom uncertainty.

From all of the items in each scale, five items, three items from Budner's (1962) scale and two items from Checton and Greene's (2012) scale, were chosen based on face validity and matching the results of Study One. Sample items included "My sibling does

not understand the complexity of our parent's caregiving situation" and "Future changes in our parent's care will affect my relationship with my sibling." Ambiguity was measured relative to the three response categories (*Likelihood, Value*, and *Upsetness*) and psychometrics were run with the following results.

The first evaluative aspect of Ambiguity measured was *Ambiguity-Likelihood*. Examination of the factor analysis scree plot and item loadings revealed the presence of one factor. Item 10 was deleted due to poor loading (below 0.5) and factor analysis was rerun. The observed reliability improved ($\alpha = .65$), but Item 6 still loaded below 0.5. This item was deleted, factor analysis was rerun, and the reliability improved further ($\alpha = .70$). The single factor (eigenvalue = 1.88) explained 63% of the variance with the remaining items all loading above 0.5. A composite was created by averaging the *Ambiguity-Likelihood* scores for the remaining three items representing Ambiguity ($M = 5.60$, $SD = 3.06$) with a higher score indicating a greater perceived likelihood of these ambiguous situations occurring.

Ambiguity-Value was the next evaluative aspect of Ambiguity measured. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings indicated the presence of one factor. Item 10 was deleted due to poor loading. Factor analysis was rerun and reliability improved ($\alpha = .89$). The single factor (eigenvalue = 3.05) explained 76% of the variance with all items loading above 0.8 on the factor. A composite was created by averaging the *Ambiguity-Value* scores for the remaining four items representing Ambiguity ($M = 3.16$, $SD = 1.76$) with a higher score indicating a greater value attached to these ambiguous situations.

Ambiguity-Upsetness was the final evaluative aspect of Ambiguity that was measured. The factor analysis, reliabilities, and scree plot indicated the presence of one factor ($\alpha = .80$). Item 10 was deleted due to poor loading (below 0.5). Factor analysis was rerun and reliability improved ($\alpha = .85$). A composite was developed by averaging the *Ambiguity-Upsetness* scores for the remaining four items representing Ambiguity ($M = 2.94$, $SD = 1.80$) with a higher score indicating greater Upsetness about the ambiguous situations presented.

Uncertainty. According to PI Theory, Uncertainty is a distinct construct within the category of Ambiguity. This distinction was also confirmed in the results of Study One. Participants had a sense that their parent's needs would be different in the future but were uncertain as to what those changing needs would require and what impact those needs would have on their lives. In other words, participants knew that an outcome was likely, but they did not know the extent of the impact of that outcome. As such, questions meant to capture Uncertainty had to incorporate this conflicting sense of knowing without knowing.

The newly developed measure of Uncertainty (see Appendix R) was created by the author based on data from Study One and included items such as "My parent's health condition will deteriorate." In addition, items from Mishel's (1981) measure of Uncertainty in Illness were used as examples to structure survey questions related to caregiving uncertainty. Mishel's (1981) measure initially included a total of 62 statements, but was rewritten into 54 items. The preliminary scale initially included an equal number of positively and negatively worded items and was constructed on a five-point Likert scale.

Initial factor analysis in Mishel's (1981) study yielded a listing of 15 factors with an eigenvalue above 1.0. The scree test indicated that five factors accounted for 51% of variance (Mishel, 1981) and the number of items was reduced from 54 to 30. Mishel originally retained items that had a factor loading greater than 0.40. For the current Study Two, items with a factor loading greater than 0.59 were selected for the construction of the measure of Uncertainty.

A total of six items, five items from Mishel's (1981) scale and one item from a previously described Checton and Greene (2012) scale, were chosen based on face validity in relation to the results of Study One. The items included "My sibling is aware of how our parent's care needs will change in the future" and "I understand the purpose of each of our parent's treatments or medications." Uncertainty was measured relative to the three response categories (*Likelihood, Value*, and *Upsetness*) and psychometrics were run with the following results.

The first evaluative aspect of Uncertainty measured was *Uncertainty-Likelihood*. A Principal Component Factor Analysis (Varimax rotation) was performed on six items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 15 was deleted due to poor loading (below 0.3). Factor analysis was rerun and reliability improved, but item 13 still loaded below 0.3. This item was deleted and factor analysis was rerun with the remaining four items. The single factor (eigenvalue = 2.15) explained 54% of the variance with all remaining items loading above 0.5. The reliability coefficient was acceptable (α = .71). A composite was created by averaging the *Uncertainty-Likelihood* scores for the remaining four items

representing Uncertainty ($M = 7.28$, $SD = 2.59$) with a higher score indicating a greater likelihood of the uncertain events occurring.

 Uncertainty-Value was the next evaluative aspect of Uncertainty measured. A Principal Component Factor Analysis (Varimax rotation) was performed on the six items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 11 was deleted due to poor loading (below 0) and factor analysis was rerun. Reliability improved, but item 13 still loaded very low. This item was deleted, factor analysis was rerun and the reliability improved further ($\alpha = .70$). However, in this run, item 15 had a low loading and so it was deleted from analysis. Factor analysis was conducted once more with the remaining 3 items producing a single factor solution. The single factor (eigenvalue = 2.07) explained 69% of the variance with all items loading above 0.7 on the factor. The reliability coefficient was acceptable ($\alpha = .78$). A composite was created by averaging the *Uncertainty-Value* scores for the remaining three items representing Uncertainty ($M = 3.25$, $SD = 1.65$) with a higher score indicating a greater value attached to these uncertain situations.

 The final evaluative aspect of Uncertainty measured was *Uncertainty-Upsetness*. A Principal Component Factor Analysis (Varimax rotation) was performed on the six items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. All items loaded above 0.5, were retained for analysis, and resulted in an acceptable reliability ($\alpha = .72$). A composite was created by averaging the *Uncertainty-Upsetness* scores for the six items representing Uncertainty ($M = 3.15$, $SD = 1.29$) with a higher score indicating greater Upsetness about the uncertain situations presented.

Divergence. Five items related to Divergence were developed from the results of Study One. The items included "My sibling will step up to the caregiving challenge" and "I share similar values about caregiving with my sibling." Divergence was measured relative to the three response categories (*Likelihood, Value*, and *Upsetness*) and psychometrics were run with the following results.

The first evaluative aspect of Divergence measured was *Divergence-Likelihood*. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 1 was deleted due to poor loading (below 0.3). Factor analysis was rerun with the remaining four items producing a single factor solution. The single factor (eigenvalue = 3.09) explained 77% of the variance with all remaining items loading above 0.8. The reliability coefficient was good (α = .90). A composite was created by averaging the *Likelihood* scores for the remaining four items representing Divergence (M = 6.11, SD = 3.39) with a higher score indicating a greater perceived likelihood of these divergent events occurring.

Divergence-Value was the next evaluative aspect of Divergence measured. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings indicated the presence of one factor. Item 1 was deleted although it loaded above 0.5 in an effort to improve reliability. When factor analysis was rerun, the reliability improved to .92. This single factor (eigenvalue = 3.21) explained 81% of the variance with all remaining items loading above 0.8 on the factor. A composite was created by averaging the *Divergence-*

Value scores for the remaining four items representing Divergence (M = 3.82, SD = 1.93) with a higher score indicating a greater value associated with these divergent situations.

The final evaluative aspect of Divergence measured was *Divergence-Upsetness*. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 1 was deleted due to poor loading (below 0.5), and the factor analysis was rerun with the remaining four items yielding a single factor solution. This factor (eigenvalue = 2.94) explained 74% of the variance with all remaining items loading above 0.8 on the factor. The reliability coefficient was good (α = .88). A composite was created by averaging the *Divergence-Upsetness* scores for the remaining four items representing Divergence (M = 3.51, SD = 1.89) with a higher score indicating greater Upsetness about the divergent situations presented.

Ambivalence. Six items related to Ambivalence were developed from the results of Study One. The items included "I would be better suited than my siblings to be our parent's primary caregiver" and "I am willing to accept multiple solutions to the caregiving situation." Ambivalence was measured relative to the three response categories (*Likelihood, Value*, and *Upsetness*) and psychometrics were run with the following results.

The first evaluative aspect of Ambivalence measured was *Ambivalence-Likelihood*. A Principal Component Factor Analysis (Varimax rotation) was performed on the six items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 22 was deleted due to low loading. Factor analysis was rerun, but item 20 also had a low loading. This item was deleted and

factor analysis was rerun. Next item 19 was deleted due to poor loading (below 0.5), factor analysis was rerun, and reliability improved once more. Finally, item 18 was deleted. This item also loaded below 0.5 and, once factor analysis was rerun. This two item factor (eigenvalue = 1.58) explained 79% of the variance with the items loading above 0.8 on a single factor (α = .73). A composite was created by averaging the *Ambivalence-Likelihood* scores for the remaining two items representing Ambivalence (*M* = 8.06, *SD* = 3.04) with a higher score indicating a greater perceived likelihood of these ambivalent events occurring.

Ambivalence-Value was the next evaluative aspect of Ambivalence measured. A Principal Component Factor Analysis (Varimax rotation) was performed on the six items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 19 was deleted due to poor loading (below 0.5) and factor analysis was rerun. Item 17 also loaded below 0.5. This item was deleted, factor analysis was rerun. However, in this run, item 21 loaded poorly (below 0.5) and was deleted from analysis. Factor analysis was conducted once more and reliability improved further. The single factor (eigenvalue = 1.75) explained 58% of the variance with all items loading above 0.7 on the factor and an adequate reliability (α = .64). A composite was created by averaging the *Ambivalence-Value* scores for the remaining three items representing Ambivalence (*M* = 2.87, *SD* = 1.50) with a higher score indicating greater value associated with the situations.

The final evaluative aspect of Ambivalence measured was *Ambivalence-Upsetness*. A Principal Component Factor Analysis (Varimax rotation) was performed on the six items. Examination of the factor analysis including scree plot and item loadings

revealed the presence of one factor. Item 19 loaded below 0.5. However, when this item was deleted and factor analysis rerun, reliability decreased. Therefore, this item was retained for analysis. The single factor (eigenvalue = 2.48) explained 41% of the variance with all five items loading above 0.4 on the factor with an adequate reliability (α = .71). A composite was created by averaging the *Upsetness* scores for all five items representing Ambivalence (*M* = 2.46, *SD* = 1.23) with a higher score indicating a greater degree of Upsetness about the ambivalent events.

   Impossibility. Five items related to Impossibility were developed from the results of Study One. The items included "The outcomes of the caregiving situation are very predictable" and "My sibling and I cannot change our relationship at this stage." Impossibility was measured relative to the three response categories (*Likelihood, Value*, and *Upsetness*) and psychometrics were run with the following results.

   The first evaluative aspect of Impossibility measured was *Impossibility-Likelihood*. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 23 was deleted due to poor loading (below 0.5). Factor analysis was rerun reliability improved. The single factor (eigenvalue = 1.85) explained 46% of the variance with all remaining items loading above 0.6 on the factor and a good reliability (α = .84). A composite was created by averaging the *Impossibility Likelihood* scores for the remaining four items representing Impossibility (*M* = 6.64, *SD* = 2.47) with a higher score indicating a greater perceived likelihood of these impossible situations holding true.

Impossibility-Value was the next evaluative aspect of Impossibility measured. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 23 was deleted due to poor loading (below 0.5). Factor analysis was rerun and the results improved. The single factor (eigenvalue = 2.75) explained 69% of the variance with all items loading above 0.6 on the factor and a good reliability (α = .84). A composite was created by averaging the *Impossibility-Value* scores for the remaining four items representing Impossibility (M = 3.39, SD = 1.61) with a higher score indicating a higher value attached to these situations.

The final evaluative aspect of Impossibility measured was *Impossibility-Upsetness*. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. All items loaded above 0.6 and so were retained for analysis. The single factor (eigenvalue = 2.92) explained 58% of the variance with all items loading above 0.6 on the factor. The reliability coefficient was good (α = .82). A composite was created by averaging the *Impossibility-Upsetness* scores all five items representing Impossibility (M = 2.98, SD = 1.60) with a higher score indicating the greater feelings of Upsetness about these situations.

Transcendence. Items for Transcendence, a newly proposed form of PI, were also constructed from the results of Study One and included statements such as "The outcome of the situation is in the hands of a higher power" and "I am focusing what I feel is right for my parent and my life at this time." Transcendence was measured relative to the three

response categories (*Likelihood, Value*, and *Upsetness*) and psychometrics were run with the following results.

The first evaluative aspect of Transcendence measured was *Transcendence-Likelihood*. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 31 was deleted due to poor loading (below 0.5) and factor analysis was rerun. The results improved, but item 29 still loaded below 0.5. This item was deleted, factor analysis was rerun, and the remaining three items produced a single factor solution. The single factor (eigenvalue = 2.11) explained 70% of the variance with all items loading above 0.7 on the factor. The reliability coefficient was good (α = .79). A composite was created by averaging the *Transcendence-Likelihood* scores for the remaining three items representing Impossibility (M = 7.38, SD = 3.06) with higher scores indicating a greater likelihood of these situations of transcendence occurring.

Transcendence-Value was the next evaluative aspect of Transcendence measured; results similar to the *Transcendence-Likelihood* aspect were reported. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. Item 29 was deleted due to poor loading (below 0.5) and factor analysis was rerun. The results improved, but item 31 still loaded below 0.5. This item was deleted, factor analysis was rerun, and the results further improved yielding a single factor solution. The single factor (eigenvalue = 2.18) explained 73% of the variance with all items loading above 0.8 on the factor with a good reliability (α = .81). A composite

was created by averaging the *Transcendence-Likelihood* scores for the remaining three items representing Transcendence ($M = 2.94$, $SD = 1.69$) with a higher score indicating a greater level of value attached to these situations of transcendence.

The final evaluative aspect of Transcendence measured was *Transcendence-Upsetness*. A Principal Component Factor Analysis (Varimax rotation) was performed on the five items. Examination of the factor analysis including scree plot and item loadings revealed the presence of one factor. The single factor (eigenvalue = 2.13) explained 71% of the variance with all items loading above 0.8 on the factor and an adequate reliability ($\alpha = .76$). A composite was created by averaging the *Transcendence-Upsetness* scores for all five items representing Transcendence ($M = 2.72$, $SD = 1.43$) with a higher score indicating a greater perceived level of Upsetness about the situations of transcendence presented.

Summary of measures. Because this was the first time that Problematic Integration was measured quantitatively, measure development sought to capture the copious forms of PI (i.e., Ambiguity, Uncertainty, Divergence, Ambivalence, Impossibility, and Transcendence) as well as the various evaluative aspects of PI (i.e., Likelihood, Value, and Upsetness). Some of the forms performed well and retained all, if not most, of the items in the category. Others, however, did not perform well as they were constructed (such as *Ambivalent-Likelihood*) and should be revised in future research. Following the computation of psychometrics to establish scale structure, correlations were run to calculate the associations between the various measures in Study Two.

Study Two – Results

The hypotheses were tested by Pearson product-moment correlations between caregiving burden, relational quality, family communication patterns, information management behaviors (three types), and problematic integration. Zero order correlations were calculated, with the level of significance was set at $p \leq .05$ for all tests. The results of each variable are discussed in the following paragraphs and are presented in Tables 7-18.

Caregiving Burden

The first hypothesis predicted that the greater perceived level of caregiving burden, the greater the overall perceived level of problematic integration during elder care. Caregiving burden was significantly related to the overall score for Problematic Integration, $r = .49$ ($p < .01$). Caregiving Burden was positively related to two of the three broad aspects of PI: *Value* $r = .34$ ($p < .01$) and *Upsetness* $r = .46$ ($p < .01$). However, the relationship between caregiving burden and the remaining PI aspect of *Likelihood* was not supported. Thus, Hypothesis 1 was partially supported with the greater the perceived level of caregiving burden associated with greater the overall perceived level of *Value* of PI and *Upsetness* of PI. Table 7 summarizes the results of these correlations.

The first research question asked what forms of problematic integration were associated most strongly with caregiving burden. All three aspects of Ambiguity were positively related to Caregiving Burden, although at varying levels of strength: *Ambiguity-Likelihood* $r = .22$ ($p < .05$), *Ambiguity-Value* $r = .25$ ($p < .05$), and *Ambiguity-Upsetness* $r = .30$ ($p < .01$). However, only two of the aspects of Uncertainty, an

Ambiguity subdimension, were related to Caregiving Burden: *Uncertainty-Value r* = .27 ($p < .01$) and *Uncertainty-Upsetness r* = .39 ($p < .01$), but not *Upsetness-Likelihood*. All three aspects of Divergence were related to Caregiving Burden, but the direction of the relationship differed. *Divergence-Likelihood* was negatively related to Caregiving Burden, *r* = -.41 ($p < .01$), while *Divergence-Value, r* = .39 ($p < .01$), and *Divergence-Upsetness, r* = .38 ($p < .01$), were both positively related to Caregiving Burden). Two of the three aspects of Ambivalence were related to Caregiving Burden*: Ambivalence-Likelihood r* = .23 ($p < .05$) and *Ambivalence-Upsetness r* = .25 ($p < .05$), but not *Ambivalence-Value*. All three aspects of Impossibility were directly related to Caregiving Burden*: Impossibility-Likelihood r* = .36 ($p < .01$), *Impossibility-Value r* = .30 ($p < .01$), and *Impossibility-Upsetness r* = .46 ($p < .01$). Finally, all three aspects of Transcendence were related to Caregiving Burden, but the direction of the relationship differed. *Transcendence-Likelihood* was negatively related to Caregiving Burden, *r* = -.41 ($p < .01$), while *Transcendence-Value, r* = .34 ($p < .01$), and *Transcendence-Upsetness, r* = .43 ($p < .01$), were both positively related to Caregiving Burden.

The results for Research Question 1 suggest that higher levels of perceived caregiving burden are associated with higher levels of most measures of PI (14 of 18). Only two of the 18 measures were negatively associated with Caregiving Burden (*Divergence-Likelihood* and *Transcendence-Likelihood*), while two others (*Uncertainty-Likelihood* and *Ambivalence-Likelihood*) indicated no association. Table 8 summarizes the results of these correlations.

Relational Quality

The second hypothesis predicted that the greater the perceived level of sibling relational quality, the lower the overall perceived level of problematic integration during elder care. Relational quality was negatively related to the overall score for Problematic Integration, $r = -.57$ ($p < .01$). Relational quality was also negatively related to two of the three aspects of PI: *Value r = -.67* ($p < .01$) and *Upsetness r = -.58* ($p < .01$). However, although the association between Relational Quality and the remaining PI aspect of *Likelihood* was significant, it was a positive relationship $r = .41$ ($p < .01$). The second hypothesis was partially supported. Although higher levels of relational quality resulted in lower PI and its aspects of *Value* and *Upsetness*, relational quality showed a positive association with the aspect of *Likelihood*. Table 9 summarizes the results of the correlations.

The second research question asked what forms of problematic integration were associated most strongly with relational quality. All three aspects of Ambiguity were negatively related to Relational Quality: *Ambiguity-Likelihood r = -.47* ($p < .01$), *Ambiguity-Value r = -.62* ($p < .01$), and *Ambiguity-Upsetness r = -.62* ($p < .01$). All three aspects of Uncertainty were related to Relational Quality, but the direction of the relationship differed. *Uncertainty-Likelihood* was positively related to Relational Quality, $r = .40$ ($p < .01$), while *Uncertainty-Value* and *Uncertainty-Upsetness* were both inversely related to Relational Quality *Uncertainty-Value r = -.56* ($p < .01$) and *Uncertainty-Upsetness r = -.24* ($p < .01$). Just like Uncertainty, all three aspects of Divergence were related to Relational Quality, but with varied directionality. *Divergence-Likelihood* was positively related to Relational Quality, $r = .69$ ($p < .01$), while

Divergence-Value, r = -.66 (*p* < .01), and *Divergence-Upsetness, r* = -.64 (*p* < .01), were both negatively related to Relational Quality). All three aspects of Ambivalence were negatively related to Relational Quality, but at varying strength: *Ambivalence-Likelihood r* = -.21 (p < .05), Ambivalence-Value r = -.57 (p < .01), and *Ambivalence-Upsetness r* = -.37 (p < .01). All three aspects of Impossibility were inversely related to Relational Quality: *Impossibility-Likelihood r* = -.58 (*p* < .01), *Impossibility-Value r* = -.62 (*p* < .01), and *Impossibility-Upsetness r* = -.51 (*p* < .01). Finally, all three aspects of Transcendence were related to Relational Quality, but the direction of the relationship differed. *Transcendence-Likelihood* was positively related to Relational Quality *r* = .76 (*p* < .01), while *Transcendence-Value r* = -.68 (*p* < .01) and *Transcendence-Upsetness r* = -.49 (*p* < .01) were both negatively related to Relational Quality.

The results for Research Question 2 suggest that higher levels of perceived Relational Quality are associated with lower levels of most measures of PI (15 of 18). As adult siblings feel a greater sense of closeness and emotional connectedness to one another, they struggle less with the "what's likely" versus "what's wanted" integration. Only three of the 18 measures were positively associated with Caregiving Burden (*Uncertainty-Likelihood*, *Divergence-Likelihood* and *Transcendence-Likelihood*). Table 10 summarizes the results of these correlations.

Family Communication

The third hypothesis predicted that the greater the perceived openness of family communication, the lower the overall perceived level of problematic integration during elder care. The Conversation Orientation of Family Communication was not related to the overall scores for Problematic Integration, nor was the Conversation Orientation

related to the PI aspects of *Likelihood* or *Upsetness*. However, the Conversation

Orientation was negatively associated with the remaining PI aspect of *Value r = -*.28 (*p <*

.05). No relationship was shown for the Conformity Orientation of family communication

and the overall score of PI. The third hypothesis was not supported. Table 11 summarizes

the results of these correlations.

Research Question 3 asked what forms of problematic integration were associated

most strongly with family communication. The patterns of association differed depending

on whether the Conversation Orientation or the Conformity Orientation was being

considered. Only the Likelihood aspect of Ambiguity was related to the Conversation

Orientation: *Ambiguity-Likelihood, r = -*.29 (*p < *.01). None of the other aspects of

Ambiguity or any of the aspects of Uncertainty showed a relationship to the Conversation

Orientation. All aspects of Divergence showed a significant relationship to the

Conversation Orientation, but with varied directionality: *Divergence-Likelihood*, *r = *.24

(*p < *.05), *Divergence-Value*, *r = -*.23 (*p < *.05), and *Divergence-Upsetness*, *r = -*.24 (*p <*

.05). For Ambivalence and Impossibility, only the aspect of Value showed a significant

relationship to the Conversation Orientation, *Ambivalence-Value*, *r = -*.21 (*p < *.05) and

Impossibility-Value, r = -.26 (*p < *.05). The aspects of Transcendence showed the

strongest relationships with the Conversation Orientation: *Transcendence-Likelihood, r =*

.33 (*p < *.01), *Transcendence-Value, r = -*.36 (*p < *.01), and *Transcendence-Upsetness, r =*

-.20 (*p < *.05), suggesting that family's past conversational nature may yield fewer

problems integrating wants and expectations in the future.

Only one aspect showed any relationship to the Conformity Orientation. For

Uncertainty only the Likelihood aspect was related to the Conformity Orientation:

Uncertainty-Likelihood, $r = .20$ ($p < .05$). None of the aspects of Ambiguity, Ambivalence, Divergence Impossibility, or Transcendence were related to the Conformity Orientation. These results, that a family's conforming communication style had little affiliation with future problematic integrations, were surprising considering previous research on Family Communication Patterns. Table 12 summarizes the results of these correlations.

Information Management

In this research, the concept of information management was represented by three different strategies: information sharing, topic avoidance, and secret keeping. Each was analyzed relative to the various aspects and forms of PI. The results of each are described in the following paragraphs.

Information Sharing. Hypothesis 4a predicted that the lower the overall perceived level of Problematic Integration, the greater the information management behaviors of Information Sharing. Information sharing was negatively related to the overall scores for Problematic Integration, $r = -.38$ ($p < .01$). Information sharing was also negatively related to two of the three aspects of PI: *Value r = -.54* ($p < .01$) and *Upsetness r = -.41* ($p < .01$). However, the association between information sharing and the remaining PI aspect of *Likelihood* was positive $r = .42$ ($p < .01$). Therefore, Hypothesis 4a was partially supported. Although higher levels of Information Sharing resulted in lower PI and its aspects of *Value* and *Upsetness*, Information Sharing was positively associated with the aspect of *Likelihood*. Table 13 summarizes the results of the correlations.

The first part of Research Question 4 asked what forms of problematic integration were associated most strongly with the information management behavior of Information Sharing. All three aspects of Ambiguity were negatively related to Information Sharing: *Ambiguity-Likelihood r* = -.28 (*p* < .01), *Ambiguity-Value r* = -.43 (*p* < .01), and *Ambiguity-Upsetness r* = -.47 (*p* < .01). Only two aspects of Uncertainty were related to Information Sharing. *Uncertainty-Likelihood* was positively related to Information Sharing, *r* = .32 (*p* < .01), while *Uncertainty-Value* was negatively related to Information Sharing, *r* = -.44 (*p* < .01). All three aspects of Divergence were related to Information Sharing, but with varied directionality. *Divergence-Likelihood* was positively related to Information Sharing, *r* = .58 (*p* < .01), while *Divergence-Value r* = -.56 (*p* < .01) and *Divergence-Upsetness r* = -.55 (*p* < .01) were both negatively related to Information Sharing. All three aspects of Ambivalence were also related to Information Sharing, but at varying strength: *Ambivalence-Likelihood r* = -.23 (*p* < .05), *Ambivalence-Value r* = -.52 (*p* < .01), and *Ambivalence-Upsetness r* = -.27 (*p* < .01). Similarly, all three aspects of Impossibility were negatively related to Information Sharing: *Impossibility-Likelihood r* = -.42 (*p* < .01), *Impossibility-Value r* = -.49 (*p* < .01), and *Impossibility-Upsetness r* = -.35 (*p* < .01). Finally, all three aspects of Transcendence were related to Information Sharing, but the direction of the relationship differed. *Transcendence-Likelihood* was positively related to Information Sharing *r* = .69 (*p* < .01), while *Transcendence-Value* and *Transcendence-Upsetness* were both negatively related to Information Sharing *Transcendence-Value r* = -.59 (*p* < .01) and *Transcendence-Upsetness r* = -.35 (*p* < .01).

The results suggest that higher levels of Information Sharing are associated with lower levels of most measures of PI. As adult siblings share more with another, they

experience less problematic integration during elder care. Only three of the 18 measures were positively associated with Information Sharing (*Uncertainty-Likelihood*, *Divergence-Likelihood* and *Transcendence-Likelihood*). Table 14 summarizes the results of these correlations.

      Topic Avoidance. Hypothesis 4b predicted that the lower the overall perceived level of Problematic Integration, the less Topic Avoidance. Topic Avoidance was positively related to the overall score for Problematic Integration, $r = .37$ ($p < .01$). Topic Avoidance also was also positively related to two of the three aspects of PI: *Value r = .47* ($p < .01$) and *Upsetness r = .38* ($p < .01$). However, Topic Avoidance and the remaining PI aspect of *Likelihood* were negatively related $r = -.30$ ($p < .01$). Hypothesis 4b was partially supported. Table 15 summarizes the results of these correlations.

      The second portion of Research Question Four asked what forms of Problematic Integration were associated most strongly with the information management behavior of Topic Avoidance. All three aspects of Ambiguity were positively related to Topic Avoidance: *Ambiguity-Likelihood r = .32* ($p < .01$), *Ambiguity-Value r = .35* ($p < .01$), and *Ambiguity-Upsetness r = .35* ($p < .01$). Only one aspect of Uncertainty was related to Information Sharing: *Uncertainty-Value* was positively related to Topic Avoidance, $r = .35$ ($p < .01$), but not *Uncertainty-Likelihood* or *Uncertainty-Upsetness*. All three aspects of Divergence were related to Topic Avoidance, but with varied directionality. *Divergence-Likelihood* was negatively related to Information Sharing, $r = -.49$ ($p < .01$), while *Divergence-Value r = .46* ($p < .01$) and *Divergence-Upsetness r = .49* ($p < .01$) were both positively related to Topic Avoidance: *Divergence-Value* and *Divergence-Upsetness*. Only two aspects of Ambivalence were related to Topic Avoidance:

Ambivalence-Value r = .51 (*p* < .01), and *Ambivalence-Upsetness r* = .31 (*p* < .01), but

not *Ambivalence-Likelihood*. All three aspects of Impossibility were positively related to

Information Sharing: *Impossibility-Likelihood r* = .40 (*p* < .01), *Impossibility-Value r* =

.42 (*p* < .01), and *Impossibility-Upsetness r* = .33 (*p* < .01). Finally, all three aspects of

Transcendence were related to Topic Avoidance, but the direction of the relationships

differed. *Transcendence-Likelihood* was negatively related to Topic Avoidance *r* = -.56

(*p* < .01), while *Transcendence-Value r* = .50 (*p* < .01) and *Transcendence-Upsetness r* =

.30 (*p* < .01) were both positively related to Topic Avoidance).

The results suggest that higher levels of Topic Avoidance are associated with

higher levels of most measures of PI (13 of 18). As adult siblings avoid more with each

other, they experience greater problematic integration during elder care. Only two of the

18 measures were inversely related to Topic Avoidance (*Divergence-Likelihood* and

Transcendence-Likelihood). Three other measures were not related to Topic Avoidance

(*Uncertainty-Likelihood*, *Uncertainty-Upsetness*, and *Ambivalence-Likelihood*). Table 16

summarizes the results of these correlations.

Secret Keeping. Hypothesis 4c predicted that the lower the overall perceived

level of Problematic Integration, the less Secret Keeping. No relationship was found

between Secret Keeping and the overall score for Problematic Integration. However,

Secret Keeping was negatively related to the Value aspect of PI: *Value r* = -.31 (*p* < .01).

Significant relationships were also reported between the remaining aspects of PI, albeit at

a lower strength: *Likelihood r* = .26 (*p* < .05) and *Upsetness r* = -.22 (*p* < .05). Hypothesis

4c was partially supported. Although there was no relationship between Secret Keeping

and the overall level of PI, there was a relationship between Secret Keeping and its three

aspects of *Likelihood, Value*, and *Upsetness*. Table 17 summarizes the results of these correlations.

The third portion of Research Question Four asked what forms of Problematic Integration were associated most strongly with the information management behavior of Secret Keeping. All three aspects of Ambiguity were negatively related to Secret Keeping: *Ambiguity-Likelihood r* = -.24 (*p* < .05), *Ambiguity-Value r* = -.23 (*p* < .05), and *Ambiguity-Upsetness r* = -.26 (*p* < .01). Only two aspects of Uncertainty were related to Secret Keeping. *Uncertainty-Likelihood* was positively related to Secret Keeping, *r* = .23 (*p* < .05), while *Uncertainty-Value* was negatively related to Secret Keeping, *r* = -.27 (*p* < .01). All three aspects of Divergence were related to Secret Keeping, but with varied directionality. *Divergence-Likelihood* was positively related to Secret Keeping, *r* = .47 (*p* < .01), while *Divergence-Value r* = -.38 (*p* < .01) and *Divergence-Upsetness r* = -.34 (*p* < .01) were both negatively related to Secret Keeping). One aspect of Ambivalence was negatively related to Secret Keeping: *Ambivalence-Value r* = -.33 (*p* < .01). No other aspects of Ambivalence (*Likelihood* not *Upsetness*) were related to Secret Keeping. All three aspects of Impossibility were negatively related to Secret Keeping: *Impossibility-Likelihood r* = -.32 (*p* < .01), *Impossibility-Value r* = -.28 (*p* < .01), and *Impossibility-Upsetness r* = -.24 (*p* < .05). Finally, all three aspects of Transcendence were related to Secret Keeping, but the direction of the relationship differed. *Transcendence-Likelihood* was positively related to Secret Keeping *r* = .42 (*p* < .01), while *Transcendence-Value r* = -.34 (*p* < .01) and *Transcendence-Upsetness r* = -.27 (*p* < .01) were both negatively related to Secret Keeping).

The results suggest that higher levels of Secret Keeping are associated with lower levels of most measures of PI (12 of 18). As adult siblings keep more secrets from another, they experience less problematic integration during elder care. Similar to other results, three of the 18 measures were positively related to Secret Keeping (*Uncertainty-Likelihood*, *Divergence-Likelihood* and *Transcendence-Likelihood*). Three other measures were not related to Secret Keeping (*Uncertainty-Upsetness*, *Ambivalence-Likelihood,* and *Ambivalence-Upsetness*). Table 18 summarizes the results of these correlations.

Summary of Study Two Results

The results of Study Two support Babrow's (1992, 2001) conception of PI as a reference to a particular issue or object rather than a generalized state of mind. This reference is multi-faceted, comprised of probabilistic (*Likelihood*) and evaluative (*Value*) orientations mixed with an emotive (*Upsetness*) reaction. The direction of the relationship between the overall measure of PI and the various scales in Study Two reflected the strength and direction of the aspects of *Value* and *Upsetness* (see Table 19 for a summary of the correlations). The results of the associations between total PI and the aspects of *Value* and *Upsetness* with study variables trended in the same direction.

Alternatively, when there was no relationship between *Upsetness* and the various scales, there was no relationship between the overall measure of PI and the various scales. Additionally, when there was a weaker relationship between *Upsetness* and the various scales, there was no relationship between the overall measure of PI and the various scales. These results suggest that the aspect of *Upsetness* works differently from

the other aspects and an individual's reaction to an issue or object is what determines the level of Problematic Integration.

Examining the forms of PI relative to the various scales in Study Two highlights the significance of contextual and relational perceptions. When perceptions of Caregiving Burden were high, the aspects of PI (*Likelihood, Value and Upsetness*) for each form were predominantly positively related (RQ1). When perceptions of Relational Quality were good, the aspects of PI (*Likelihood, Value and Upsetness*) for each form were primarily negatively related. However, while the aspects of *Value* and *Upsetness* trended in the same direction for each form, the aspect of *Likelihood* differed for the forms of Uncertainty, Divergence, and Transcendence (RQ2).

Examining the forms of PI in Study Two also shows how the form of PI experienced associates with the information management behavior exhibited. For example, there was a negative relationship between Information Sharing and the forms of Ambiguity, Ambivalence, Impossibility, Divergence, and Transcendence and their three aspects (*Likelihood, Value and Upsetness*). There was a positive relationship between Topic Avoidance and the forms of Ambiguity, Ambivalence, Impossibility, Divergence, and Transcendence and their three aspects (*Likelihood, Value and Upsetness*). In other words, experiencing PI in any form decreases Information Sharing and increases Topic Avoidance. Secret Keeping exhibited the same negative relationship with the forms of PI as Information Sharing (see Table 20 for a summary of the relationship between the aspects of PI and the scales used in Study Two).

Alternative Calculations for PI

  This study is the first attempt to measure PI in a survey form, and as a result it is prudent to explore varying measurement structures as well as combinations for scaling. In an effort to measure PI concepts (i.e., forms), whether the project explored each individual item in the measure reflected a distinctive issue about which the participants might be experiencing PI. The original calculations (reported above) anticipated that the individual items would reflect the underlying six dimensions of PI. In this section, alternative calculations assumed that each item reflected a distinct, but varying issue towards which the respondent experienced diverging expectations and desire (*Likelihood* and *Value*). Thus, rather than presuming that an individual item in the PIM represented a *particular* form of PI, items were tested alternatively presuming to represent *some* form of PI. The reason for this alternative analysis was a concern that, although the items in the scale represented events or situations about which a participant might experience PI, the form of PI being experienced could differ depending on the participant, the participant's orientation to the event, and the other issues leading to (or "chaining" across) the event.

  This alternative exploration required calculating a new measure of Divergence that would act as proxy for an overall measure of PI. The first step in this approach was to recode the *Likelihood* variables for all 32 items so that 0% and 100% = 1, 10% and 90% = 2, 20% and 80% = 3, 30% and 70% = 4, 40% and 60% = 5, and 50% = 6, assuming *Likelihood* was an indicator of Uncertainty. The next step was to recode the *Value* variables for all 32 items so that 0 and 4 = 0, 1 and 5 = 1, 2 and 6 = 2, 3 and 7 = 3. Two new Divergence variables were then calculated, one for *Likelihood* and one for *Value*. See Table 21 for a summary of the results.

The first Divergence variable was created by multiplying the recoded *Likelihood* variables by the recoded *Value* variables, consistent with the argument that PI arises out of a combination of perceived *Likelihood* and perceived *Value* of an event. The multiplicative Divergence variable was positively related to Caregiving Burden $r = .36$ ($p < .01$), and negatively related to Relational Quality $r = -.60$ ($p < .01$). These results suggest that higher levels of perceived Caregiving Burden are associated with greater experiences with Divergence, while poorer perceived Relational Quality are associated with greater experiences of Divergence as a proxy for PI.

The multiplicative Divergence variable was negatively related to Information Sharing $r = -.47$ ($p < .01$) and Secret Keeping $r = -.31$ ($p < .01$), yet positively related to Topic Avoidance $r = .38$ ($p < .01$). These results suggest that lower levels of Information Sharing and Secret Keeping are associated with greater experiences of Divergence, or a sibling experiencing Divergence will share less information with other siblings. The results also suggest that higher levels of Topic Avoidance are associated with higher experiences of Divergence, or a sibling experiencing Divergence will avoid more topics with other siblings. These results are consistent with both the direction and relative size of the *Value* composite reported in the initial calculations.

The second Divergence variable was calculated to gauge the influence of the *Upsetness* variable by combining *Upsetness* to the *Likelihood* and *Value* variables. Here the original coding for *Upsetness* was retained and summed with the recoded *Likelihood* and *Value* variables. The additive Divergence variable was positively related to Caregiving Burden $r = .35$ ($p < .01$) and negatively related to Relational Quality $r = -.62$ ($p < .01$). These results also suggest that higher levels of perceived Caregiving Burden

are associated with greater experiences with Divergence, while poorer perceived

Relational Quality is associated with greater experiences of Divergence as a proxy for PI.

The additive Divergence variable was negatively related to Information Sharing r

$= -.45$ ($p < .01$) and Secret Keeping $r = -.24$ ($p < .01$), yet positively related to Topic

Avoidance $r = .41$ ($p < .01$). These results also suggest that lower levels of Information

Sharing and Secret Keeping are associated with greater experiences of Divergence, or a

sibling experiencing Divergence will share less information with other siblings. The

results also suggest that higher levels of Topic Avoidance are associated with higher

experiences of Divergence, or a sibling experiencing Divergence will avoid more topics

with other siblings. The results of the additive Divergence variable, similar to the

multiplicative Divergence variable, are consistent with the direction and relative size of

the *Value* and *Upsetness* composites reported in the initial calculations.

In this current research, three different methods for calculating PI were

undertaken. The initial calculation assumed that the individual items distinctly

represented one of the six forms of PI. Following a factor analysis, retained items were

used to formulate composites for the three aspects of PI asked about in the survey

(*Likelihood*, *Value*, and *Upsetness*). These three composites were used to calculate an

overall composite for PI.

The two additional calculations assumed that each item reflected some form of PI

rather than one particular form. Since PI is defined as diverging expectations and desire, a

new measure of Divergence was calculated as a proxy for PI using the recoded

Likelihood and *Value* variables. The first Divergence variable was created by multiplying

the recoded *Likelihood* and *Value* variables and the second Divergence variable was

created by adding the recoded *Likelihood* and *Value* variable to the original *Upsetness* variable. The three calculations yielded similar results.

Discussion

Study Two operationalized PI, which allowed for comparison with communication constructs. The quantifying of PI has dramatic implications for the theory as well as the contexts in which it is most often explored. For example, Uncertainty is a construct frequently included in research in the field of health communication (e.g., Afifi et al., 2006; Brashers, Hsieh, Neidig, & Reynolds, 2006; Hines et al., 2001; Mishel & Clayton, 2003). However, Uncertainty was the form of PI that showed weak or nonexistent relationships with the various contextual experiences and information management behaviors examined in Study Two. Testing the various forms of PI gives researchers and practitioners the opportunity explore what forms are the most "problematic" for individuals in different health situations and in different relationships (i.e., spouse-spouse, sibling-sibling, and doctor-patient).

The results of Study Two suggest that the three aspects of PI (*Likelihood, Value, and Upsetness*) have an additive versus multiplicative relationship between the aspects and the overall measure. This differs from other theories with probabilistic and evaluative dimensions, such as the Expectancy Value Theory (Fishbein, & Ajzen, 1975). The difference seems to be the aspect of *Upsetness* incorporated into PI. The strength and direction of *Upsetness* relative to the scales in Study Two corresponded directly to the strength and direction of the overall measure of PI and the scales. More fully understanding the *Upsetness* aspect of PI will lead to an even fuller understanding of PI

and how it relates to communication behaviors in relationships. The discussion section

next explores this and other Study Two results, in addition to Study One findings.

CHAPTER FIVE – DISCUSSION

This chapter will discuss the project findings, as well as the implications, limitations, and future directions of the research conducted for this dissertation. Implications include those for communication and information management theories as well as those for family caregivers and health practitioners. Limitations to the research include the similar demographic make-up of the participants and the lack of dyadic perceptions in the results. Additional limitations include the small sample size of the studies, the cross-sectional nature of the studies, and the operationalization of a complex process. Further refinement of the Problematic Integration measure (PIM) and an extension of the sibling relationship within the caregiving context are some areas identified as areas of future research. The following sections provide more detail, starting first with a review of findings, followed by a discussion of implications for theory, implication for practice, limitations of the study, and areas of future research.

Review of Findings

The present research produced some expected, as well as unexpected, results. Study One confirmed that, in addition to parent's health, characteristics of sibling relationships are a frequent concern during the elder care process. Yet, these concerns are framed differently within the context of PI. Worries about the parent are seen in the traditional lens of uncertainty, while worries about the sibling relationship are framed in the broader construct of ambiguity. For some caregivers, the ambiguity about what the sibling relationship may look like in the future was overshadowed by the expectations of what the relationship should be like during elder care. The quality of the sibling relationship during caregiving was strongly associated with feelings of caregiving

burden, information management behaviors, and aspects of PI in Study Two. The findings of each study are further discussed below.

Study One

The results of Study One suggested that the relational characteristic of emotional closeness was a critical part of siblings coping with the challenges of elder care. Those participants who were more positive about their sibling and their sibling's caregiving actions spoke of feeling supported and respected by their sibling. Those participants who were more negative about their sibling and their sibling's caregiving actions spoke of feeling abandoned or dismissed by their sibling. These results are consistent with previous research showing that increased feelings of spousal caregiving burden are associated with lower levels of spousal relational quality (Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011) and that relational quality serves as a protective factor for spousal caregivers (Gozzoli, Giorgi, & D'Angelo, 2013).

The results of Study One also supported Babrow's (1992) contention that Ambiguity is a broad construct comprised of the multiple, distinct concepts. Each concept poses different levels of information needs and different responses from individuals (Babrow, 1992; Babrow et al., 1998; Mishel, 1988). Whereas participants were Uncertain about their parents' changing caregiving needs, there were Ambiguous as to what the future will hold for the relationship with their sibling. Study One extends the claim that there are "many meanings of uncertainty" (Babrow et al., 1998). An event or situation may be interpreted in many different ways. Although individuals may be able to "put words" to the parent's health condition, Study One revealed that they might not be able to find the words to describe what they expected of the sibling relationship.

The concept of Divergence, which appeared in Study One, was not new to caregiving (e.g., Russo, 2010). The participants' mismatch of expectations was the source of conflict with their sibling(s) and greatly contributed to the stress of caregiving. There were other participants who were resigned to the fact that their sibling was never going to meet their ideals for a relationship or a caregiving participant. These individuals found peace with the caregiving experience, but this was rare in the present data. The idea of Transcendence shifts the response to PI, a major change for the theory and significant to the healthcare context. The assumption of PI theory is that a mismatch between expectations (what is believed to be so) and values (what we want to be so) results in "problems." However, the results of Study One showed that this is not always the case.

This new form of PI, Transcendence, should be explored to see if it is unique to the sibling relationship, elder care context, or some other facet of the study. Additionally, the question remains whether Transcendence is a form of PI or a response to PI. If it is considered a response to PI, is it a mechanism for coping with the "problems" inherent in elder care? Transcendence itself may not be a static state. If the "problems" change, individuals may respond differently. At one point in time, people may experience Transcendence, but at another point in time they may experience Divergence. One aspect of PI relies on a level of certainty about a sibling's behavior (both positive and negative) in order to make judgments about what to expect during the caregiving process. If someone is very certain about the future behavior of other family members, then he or she will have to choose how to respond to such certainty. A response includes not only whether to be upset about the pending behavior but also how to communicate one's emotional reaction and how to manage elder care knowing what sibling behavior is

likely. Further research could provide insight into what conditions lead to a state of Transcendence and how that state contributes to productive communication behaviors with family members during times of transition or challenge.

In Study One, participants reported using a number of information management strategies to manage the interpersonal exchanges with their siblings during caregiving. The avoidance strategies of curtailing interaction, restricting topics, and suppressing thoughts were most often used, but the strategy of secret keeping was also utilized. Although avoidance strategies were used to prevent conflict-inducing topics from being reintroduced within the family, the secret keeping strategy was more often used to protect the participant from disapproval about his or her caregiving methods. These results aligned with prior research on topic avoidance (e.g., Guerrero & Afifi, 1995) and secret keeping (Kelly, 1999), which suggested that individuals manage information to protect themselves from criticism.

Study Two

The results of Study Two suggest that there is a combinatorial relationship between three aspects of PI (*Likelihood, Value, and Upsetness*) and the overall measure of PI. This differs from other theories with probabilistic and evaluative dimensions, such as the Expectancy Value Theory (Fishbein, & Ajzen, 1975). The difference seems to be the aspect of *Upsetness* incorporated into PI. The strength and direction of *Upsetness* relative to the scales in Study Two corresponded directly to the strength and direction of the overall measure of PI and the scales. More fully understanding the *Upsetness* aspect of PI will lead to an even fuller understanding of PI and how PI relates to communication behaviors in relationships.

Problematic Integration. PI is a long standing theory in the field of Communication that has been applied to healthcare contexts. PI has been specifically applied to decisions about mammography screening (Babrow & Kline, 2000) and to coping with breast cancer (Ford et al., 1996) and HIV or AIDS (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000) diagnoses. PI has also provided a useful lens for exploring how expectant mothers manage and negotiate the uncertainties accompanying pregnancy (Matthias, 2009) and how individuals regard the role that genetics play in human health outcomes (Parrott et al., 2004). PI has been a useful framework for conducting a systematic analysis of the many meanings of uncertainty in health and illness experiences (Babrow et al., 1998). This framework gave structure to the items in Study Two. Study Two then went a step further by exploring the association between the many experiences of PI and various information management strategies relative to caregiving burden and relational quality.

Caregiving burden. The findings of this research revealed some new associations between caregiving and caregiving burden. Previous studies have shown that caring for someone with dementia is associated with higher levels of stress than caring for someone with functional impairment from another type of chronic illness (e.g., Clipp & George, 1993; Parks & Novielli, 2000). Participants in Study One whose parent had been diagnosed with a form of dementia discussed greater feelings of stress and burden than those whose parent had heart disease or mobility issues. This reported increase in challenges and uncertainties associated with a parent's cognitive decline were consistent with past research. What was different in Study One was the reported increased tension between these participants and their sibling(s) and greater ambiguity about their sibling

relationship compared to siblings in families with a parent suffering a chronic illness or general age-related health decline. This finding is similar to those on spousal caregiving. Spouses of those with Alzheimer's disease or Parkinson's disease report greater feelings of disappointment and sadness about the loss of the spousal relationship than other spousal caregivers (e.g., Davis et al., 2011).

The personality and behavioral changes associated with moderate to severe Alzheimer's disease, such as delusions, suspicion, or compulsive behaviors (ALZ, 2014), increase the burden associated with caregiving. As such, primary caregivers in this situation (in Study One) reported a greater need for respite and hoped that their sibling would be the one to provide it. When the sibling did not take over caregiving responsibilities, even for a short period of time, participants felt frustrated and dejected. The participant wondered "What does it mean to be a good sibling" and "What does it mean to be a good son/daughter"? These questions increased reported feelings of stress and burden as participants questioned whether this sibling was the type of person they would maintain a relationship with in the future.

The difference in uncertainties about parents' care needs and sibling relationship trajectories was also apparent in Study Two. Higher levels of perceived caregiving burden are associated with higher levels of most measures of PI. These results suggest that Caregiving Burden relates most strongly to how much participants valued an event and how much the occurrence of that event upset them. So, for example, the greater level of burden felt by caregivers, the more they might value respite care, and the more upset they may be if their sibling is not the one to provide it. A sibling not providing respite

may be a strong indication of the current and/or future state of the sibling relationship, which will be discussed further in the next section.

Relational quality. In Study One, many participants reported "How the relationship was, is how the relationship is," meaning that the feelings and perceptions that the siblings had when they were younger carried over to their later years when they were caregivers. This addressed Research Question 1, which asked what personal and relational qualities siblings bring to bear when coping with caregiving challenges. The relationship qualities present during elder, as well as the perceived challenges and uncertainties associated with a sibling relationship during elder care (RQ3) were those that existed prior to caregiving beginning. This suggests that siblings do not normally develop the skills and resources to meet life's new challenges together.

Study One and Study Two confirmed the association between caregiving burden and relational quality, something mass media has referred to as the "they're your parents too" (Russo, 2010) or "mom always liked you best" phenomenon (Kardasis, Larsen, Thorpe, & Trippe, 2011). If sibling rivalry or perceived parental favoritism existed in the past, then those feelings carried over to the present caregiving situation. The results of Study Two specifically indicated that better quality sibling relationships are associated with lower feelings of caregiving burden for the primary caregiver. However, it is not clear whether lower burden was due to feelings of pre-existing emotional closeness, a commonly studied relational quality variable, or current displays of social support and interactions providing caregiving assistance (Hobfoll, 1988).

Study Two highlighted how better quality sibling relationships are associated with lower experiences of most forms of problematic integration for the primary caregiver

(RQ2). Fifteen of the 18 measures were negatively associated with Caregiving Burden, suggesting that the closer the sibling relationship the more likely participants believe they know their sibling's responses to caregiving. As reported earlier, adult siblings struggle less with the "what's likely" versus "what's wanted" integration when they feel a greater sense of closeness and emotional connectedness to one another. These sentiments may change over time, however, prior PI research has not dealt with this longitudinally.

Sibling relational quality is typically measured by the dimensions of frequency of contact or closeness. The results of Study One and Study Two are reminders that the adult sibling relationship is a relationship that shares some qualities similar to romantic relationships. These shared qualities include affiliative and dependent need, predisposition to help, and exclusiveness and absorption (Rubin, 1970), qualities demonstrated during family caregiving. By studying these additional elements, adult sibling relationships were considered more completely in relationship to other concepts. Study Two did capture traditional measures of sibling contact (i.e., how often are you in contact with your sibling). However, the age-old adage "it's not quantity, but quality" applied here. Some participants had frequent contact with their sibling as they reported on the health and well-being of the parent, but many of these same participants described feeling overburdened by caregiving. The additional elements of emotional closeness and support and provisions of assistance, as measured in the Relational Quality scale, showed an association to caregiving burden, problematic integration and information management.

Information management. As expected in Study Two, better Relational Quality was associated with an increase in Information Sharing. This is consistent with prior

research (e.g., Checton & Greene, 2012; Schneider, Konijn, Righetti, & Rusbult, 2011) that demonstrated individuals who are close to their partner are more likely to perceive that their partner provides them with support, and therefore, are more likely to share health information with their partner. Also as expected better Relational Quality was associated with a decrease in Topic Avoidance. Previous research revealed that, across relationship targets, having a close relationship and needing to seek help were the top reasons for disclosure (Afifi & Steuber, 2009; Derlega et al., 2008; Magsamen-Conrad, 2012). Better relational quality is related to increased intentions to disclose (Brashers et al., 2000; Durham, 2008; Greene, 2009), yet there are situations where people disclose to those with whom they have poor relationships and these particular disclosure events are likely to have heightened uncertainty (Greene, 2009; Stiles, 1987). Elder care is one of those situations. The primary caregiver decides to disclose to other siblings not knowing the impact the information will have on the sibling relationship.

The lack of association between Secret Keeping and the total score of PI was unexpected considering past research (e.g., Caughlin & Vangelisti, 2009; Kelly, 1999, 2002; Vangelisti, 1994). Information Sharing and Secret Keeping also showed the same direction of association with the three aspects of PI, leaving the question of what may be contributing to this unexpected direction. One explanation may be that the participants in Study One were keeping both negative and positive information from siblings. Kelly and McKillop (1996) suggest that most secrets involve negative information that pertains to the secret keeper themselves. However, in the current research, some participants kept positive information about themselves secret as well. This included positive news about their lives, their spouses, and children.

Another explanation may be that caregivers have both individual and shared ownership of information during caregiving. Caregivers may claim ownership of their personal information (related to job, family, etc.) and establish privacy rules around this information (Petronio, 2002; Venetis et al., 2012). They can decide what personal information to disclose and to whom, and may decide to protect a sibling with whom they have a close relationship from any information that may upset the sibling.

Caregivers are also the shared owners of information related to both the caregiving process and their parents' health. Sharing other's health information is often labeled gossip because it is not personal information revealed by the discloser (Greene, 2009). However, primary caregivers, as direct participants in the caregiving process, are also owners of caregiving information, which in turn includes information about the parent and the parent's health and perhaps even finances. Once again, the caregiver may decide to protect a sibling with whom they have a close relationship and avoid sharing negative information by keeping secrets.

There are many complexities to caring for an aging parent, and caregivers' report numerous varied responses to the situation. Caregiver responses may present themselves as one of the forms of PI (Divergence, Ambiguity, Uncertainty, Ambivalence, Impossibility, or Transcendence) depending on the quality of family relationships, the parent's type of illness, and the resulting feelings of caregiving burden. In turn, PI and perceptions of the caregiving situation are related to the information management behaviors of information sharing, topic avoidance, and secret keeping.

Family communication. This research expected that a greater perceived prior openness of family communication would be associated with lower perceived level of

overall problematic integration during elder care. However, this expectation did not hold in the results. Only the PI aspect of *Value* was negatively associated with the FCP Conversation Orientation. This was surprising considering how prior FCP research has revealed that families with a high Conversation Orientation tend to openly address conflicts and engage in positive conflict resolution strategies (Koerner & Fitzpatrick, 1997). However, other research has described FCP as a mediator rather than a direct indicator of communication competence (Schodt, Ledbetter, Jernberg, Larson, Brown, & Glonek, 2009) suggesting that additional variables are associated with communication patterns. Elder care may be a new context to which the old communication rules no longer apply. Then again, the stress of the changing family structure (even the loss of decision structure with the impending death of the family head) may lead to chaos and an inability to follow the old rule. Such implications for theory will be further discussed in the following paragraphs.

Implications for Theory

This current research yields implications for a number of theories in the family, interpersonal, and health communication fields. These theories include those related to family stress and adaptation, relational attributions and expectations, and information and uncertainty management. Each will be discussed further in the following paragraphs.

Caregiving Burden

The current research, similar to other explorations of caregiving burden, constructed a scale by selecting items from pre-existing care burden scales (Zarit et al., 1980; Miyashita et al., 2006). However, this research also used the results of Study One to guide items selected for Study Two. This is an important consideration. An interest in

caregiving burden blossomed in the 1980s, first with Zarit et al. (1980) and then with others such as Montgomery, Gonyea, and Hooyman (1985), Vitaliano, Maiuro, Ochs, and Russo (1989), and Novak and Guest (1989). More recent research on caregiving burden has been done in Asian counties (Chou, Chu, Tseng, & Lu, 2003; Miyashita et al., 2006). To ensure that the caregiving burden items included in Study Two aligned with the participant sociological and demographic patterns (such as age, gender, and ethnicity), the results and topics of Study One were used to guide item selection.

Caregiving burden is an extension of family stress and adaptation theories, including Attachment Theory, Intergenerational Solidarity Theory, and Social Exchange Theory. The original purpose of Attachment Theory was to understand how parent-child interaction affects personality development (Ainsworth & Bowlby, 1992). The theory has since been applied to a variety of relationships across the life span. Cicirelli (1983, 1991) suggests that the bonds a child develops with family members early in life becomes the basis for the adult child's sustained relationship, assistance, and commitment with these family members. Many times participants talked of the caregiving relationship with their sibling being a mirror of the childhood relationship with their sibling. The results of this research showed the important role that current and historical sibling Relational Quality plays in reducing caregiving burden.

The strength of the attachments may even explain why some families are better able to assist other family members in times of crisis (Afifi & Nussbaum, 2006). Adult children become socialized to provide assistance and to cope in certain ways (Cicirelli, 1995). The Intergenerational Solidarity Theory (Bengston & Harootyan, 1994) suggests that solidarity is a multifaceted construct that involves not only cohesiveness, affection,

contact, and communication, but also familial norms and rules that govern caretaking

behaviors and the exchange of resources. Some participants expressed feelings of

attachment and solidarity with their siblings and approached caregiving as a team effort.

For other participants, however, solidarity was offset by feelings of independence. Family

Participants decided to what extent they needed a family relationship to fulfill a parent's

caregiving needs (Rusbult, Drigotas, & Verette, 1994). Some participants in Study One

decided that they needed (and expected) their sibling to assist, and that the outcome of

caregiving was influenced by their sibling's efforts. Other participants decided that they

did not need their sibling and they were going to manage the caregiving situation

independently, as they had done with many task throughout life.

Relational Quality

Studies of information management within a context of health communication

frequently include a measure of couples' relational quality (e.g., Checton & Greene,

2012). Similarly, research on Caregiving Burden most often considers spousal caregivers,

but not other immediate or extended family members. For spousal caregivers, the

relationship is altered by the illness of the spouse and the level of care that is needed.

However, for adults caring for aging parents, although the parent-child relationship is

altered, the sibling relationship remains intact. Prior to the current research, the question

remained about how sibling relational quality is associated with caregiving burden and

information management behaviors within the framework of PI.

Another framework for exploring the sibling relationship during elder care is

Attribution Theory (Heider, 1958), an attempt to understand how people process

information in order to understand an event or another person's behavior. Ways to

explain an action include a person's disposition, concurrent events, or personal responsibilities. However, which explanation is assigned will depend on the quality of interpersonal relationships. For example, if a sibling with whom a caregiver has a strong relationship is unable to visit the parent at the agreed upon time, the caregiver will determine that an external event was the cause for missing the visit. However, if the caregiver and the sibling have a poor relationship, the caregiver may attribute the cause to the individual. Feelings about a relationship influence and are influenced by the kind of attributions that an individual makes about his or her sibling's behaviors (Fincham & Bradbury, 1992). Those siblings low in relational quality tended to see disappointing behaviors as another example of the sibling's inability to be a "good" sibling.

The quality of the sibling relationship are be affected by whether the actions of the sibling were expected. Fundamental to Expectancy Violations Theory is the construct of interaction expectancies, an enduring pattern of anticipated behaviors (Burgoon, 1993). Siblings have a long history of interacting. This history shapes expectations about the communicators and their relationship. An individual who has made requests for assistance in the past to siblings with little response will not expect the sibling to respond to requests in the future. However, for some participants the caregiving situation was a new context which prompted different expectations. These expectations formed not by the sibling's past behaviors but rather by those the participant thought the sibling should emulate during caregiving. "A good sister" or "a real sibling" was now expected to respond to a request for help. When the sibling did not meet these new expectations and resorted to past behaviors, the sibling relationship suffered.

Family Communication

The degree to which members share a reality is a function of co-orientation (i.e., accuracy, agreement, and congruence of meanings) and a consequence of family environments that favor ideas (concept-orientation) or relationships (socio-orientation) (Koerner & Fitzpatrick, 2004; McLeod & Chaffee, 1972; Ritchie & Fitzpatrick, 1990). Ritchie and Fitzpatrick's (1990) RFCP is based on the assumption that for relatively enduring family communication patterns to develop, a shared social reality needs to occur among family members. Both Study One and Study Two, however, relied on only one family member to report perceptions of co-orientation. Participants were instructed to "Think of the sibling with whom things have been most difficult during this situation." When responding to this statement, participants described "not agreeing with my sibling" or "not understanding my sibling" in regards to care decisions. While important to gauge caregiver perspectives, hearing the perspectives of multiple family members would provide a more multi-faceted picture of a shared reality.

This process of shaping of a shared reality is accomplished through communication and ultimately comprises family communication patterns (Koerner & Fitzpatrick, 2004; Ritchie & Fitzpatrick, 1990). Co-orientation, as measured by the Conversation Orientation in the RFCP scale, was compared to the forms and aspects of PI in Study Two. The expectation was that participants reporting a high Conversation Orientation with their sibling(s) would report lower levels of PI. However, there was no association between PI and the RFCP Conversation Orientation in Study Two. Therefore, questions remain about what variables other than open communication are related to

lower levels of PI. Similar questions about PI may emerge for practitioners and are discussed below.

Information Management

The information sharing behaviors of family members have been explored from a broad perspective (e.g., Vangelisti, 1994; Vangelisti et al., 2001) that considered the family relationship between adolescents and parents. The information sharing behaviors of family members have also been studied following particular health diagnoses (e.g., Greene, Carpenter, Catona, & Magsamen-Conrad, 2013 and HIV; Bolund, 1990 and cancer; Checton & Greene, 2012 and heart disease) and examined the relationship between spouses/partners. The adult sibling relationship presented in the present research is a very different family dynamic than the relationships previously explored.

As such, asking participants to discuss *what* topics they revealed, avoided or kept secret from adult siblings during elder care was a new context, and yet the results were similar to prior research. The family secret topics discussed by participants in Study One mirrored many of those discussed in Vangelisti's (1994) study. These topics included marital or relational problems, personal finances, physical or mental health issues, personality conflicts, religion, and personal achievements. This new context is an area that allows the expansion of other information management research. For example, Greene's (2009) "Disclosure Decision-Making Model" could be extended beyond decisions about health disclosure to personal or caregiving decisions between adult siblings or adult children and their parents.

The "chilling effect," as described by Roloff and Cloven (1990), denotes a relational situation where one partner suppresses complaints about the other partner's

irritating behaviors out of fear of damaging the relationship. Quite often, a partner suppresses complaints if he or she believes the other partner has relational alternatives. However, sibling relationships are life-long affiliations, and, therefore, less of a "chilling effect" may occur or it may occur for other reasons. For example, a caregiver may avoid telling a sibling that he or she is not assisting with the parent as much as the caregiver would like because doing so may destroy the possibility of a future relationship with the sibling.

Alternatively, demand/withdraw, the marital pattern of communication in which one spouse nags or criticizes while the other avoids (Blood & Wolfe, 1960), may be present in adult sibling relationships during elder care. As one sibling repeatedly asks for more assistance from another sibling or continually criticizes the lack of assistance from a sibling, less assistance may be given as the other sibling chooses to avoid the requests or comments. This pattern of communication may contribute to greater experiences of PI for the sibling who is requesting assistance. As the requests go unanswered, there is an increased mismatch between what the requester desires and what is now expected of the respondent.

Problematic Integration

PI is one of many theories to address the concept of uncertainty within a health framework. Mishel's (1988) Uncertainty in Illness theory, for example, explains how patients cognitively process illness-related stimuli and construct meaning in these events. Uncertainty for Mishel (1988) focused on the inability of a patient to structure meaning because of a failure to form a cognitive schema (or subjective interpretation) for the illness, its treatment, and possible hospitalization. Babrow's (1992) PI theory, in contrast,

accounts for not only reason-based, cognitive mechanisms (the probabilistic orientation) but also emotion based, psychological mechanisms (the evaluative component). Brashers' (2001) Uncertainty Management Theory recognized that the construction of the meaning and experience of uncertainty is situational and people respond both psychologically and communicatively to the phenomena. For some individuals, uncertainty is a dangerous state that yields a negative emotional response, for other individuals, uncertainty is a preferred state that yields a positive emotional response (Brashers, 2001). Although all three theories acknowledge that uncertainty is a complex construct, PI theory includes a greater number of dimensions, making it well suited for examining the complex events associated with elder care.

In particular, PI has been applied to many situations dealing with later-life or end-of-life decisions. Hines et al. (2001) used PI to provide further insight into why communication fails to produce the desired outcomes for elderly dialysis patients and the nurses that care for them. Similarly, Planalp and Trost (2008) expanded on PI theory when they reported on the communication issues that arose for hospice volunteers, patients, and their families. Finally, Gill and Morgan (2011) sought to understand how older adults make sense of the challenges of aging when moving into an assisted living facility. In each instance, the area of focus (or the item highly valued) was different for the groups involved. For example, in Hines et al.'s study (1997) patients wanted coping advice to address emotional concerns, but nurses were providing medical information to address treatment options.

Similar to these previous studies, Study One considered a later-life context and described the PI being experienced. However, Study One only sought the perspective of

one group of actors in the situation, the adult child of a parent needing care. Study One did not seek the perspective of other actors in the situation to see if their areas of focus overlapped. Study Two extended the consideration of problematic integrations to the related communication strategies of family members during elder care. In addition to discerning what PI people experience in particular situations, this research also explored how the experience of PI relates to how people communicate and share information.

Two studies have explored PI within the context of elder care, a personally reflective essay by Babrow (2010) and a study linking PI and Attribution Theory (Polk, 2005). Yet others have attempted to quantify PI, such as Egbert's (2000) quasi-experimental design in which participants ranked the certainty of the hypothetical situations presented to them and Dennis et al.'s (2008) frequency counts of evaluative (positive and negative) and probabilistic (positive probability/certainty promotion and negative probability/certainty reduction) instances. The present research was the first to develop a quantifiable survey of multiple PI aspects and forms. Thirty-two items represented six forms of PI and three sub-questions gauged the probabilistic, evaluative, and problematic aspects of PI. The creation of a measure allows PI to be compared relative to other communication and relationship constructs, moving PI from something that is a "general perspective on communication" (Babrow, 2001, p. 554) to something that may be tested. The phenomenon that people form probabilistic and evaluative orientations to their world (Babrow, 1992, 1998, 2001) can now begin to be measured in addition to being described.

PIM is meant to capture participants' probabilistic and evaluative orientations with the sub-dimensions of *Likelihood* and *Value*. PIM also attempts to gauge the

mismatch between one's orientations by adding the sub-dimension of *Upsetness*. These three aspects or sub-dimensions in the measure are in addition to the six forms of PI (the five original forms of PI plus the additional form of Transcendence) represented by the 32 individual items. A quantitative index allows researchers to choose an additional form of measurement and analysis for studies involving PI. Qualitative studies can continue to gather patient, provider, and caregiver perspectives to deepen the understanding of complex healthcare situations. These deepened understandings can inform and shape the refinement of the quantitative index. Used together, these approaches can expand the breadth and reach of PI, not only in the field of Communication but the fields of Family Studies, Medicine, Psychology, Social Work, and others.

Implications for Practice

The results of Study One and Study Two have numerous implications for those serving the aging population, including health and communication educators, healthcare and aging professionals, and family and family service providers. Many of these providers can relate to sibling communication during elder care on a personal and professional level. Understanding components of the underlying tensions and how those tensions translate into specific communication behaviors is difficult.

Even more challenging is how to design interventions that neutralize years of family dynamics. During elder care, differences in perception may depend on the ways that family members construct uncertainty and other aspects of PI. Communication is thought to be essential to PI; however, the aspects and forms of PI are quite varied. Differences in each member's response to PI may be at the center of the family's conflict. The continued refinement and application of PI can guide individuals to successful

integration of their PI and move conversations forward. This research provides some initial insights for various areas of practice.

Health and Communication Scholars

Uncertainty has long been examined in the health and Communication literature. PI (Babrow, 1992, 1998, 2001) has been one of the few communication theories to provide a multi-faceted understanding of how individuals approach complex situations. Studies utilizing PI have shown that individuals may be uncertain about different parts of a situation, or may not be uncertain at all but rather ambiguous, ambivalent, or divergent due to different probabilistic and evaluative orientations. This has dramatic implications for family relationships and patient-provider relationships, not only from a health management perspective but also a conflict management perspective.

The more providers understand the problematic focus of patients the better able providers will be able to match the information needs of their patients and ensure patients' desired health outcomes. The more family members understand the problematic perspectives of other family members, they may better resolve conflict or at least come to a place of understanding that provides some members peace. Therefore, health and communication scholars need to further explore PI theory in a wide variety of contexts and teach that there are multiple responses to illness, not just uncertainty.

Health and Aging Professionals

One important result from this dissertation research is the confirmation that different players in the caregiving process bring different perspectives to the situation. Although this is not new to PI, it is newer to family scholars and the elder care context. These different perspectives come from various frames of references and result in various points of focus. For example, one sibling may be focused on the logistics of caring for the

parent (i.e., getting the parent to appointments), another may be focused on the financial

cost of fulfilling the care needs of the parent(s), all while the healthcare provider is

focused on the medical diagnosis of the parent. These multiple points of focus result in

many areas in which the family members and the professional staff may experience

problematic integration. Those in the caregiving process may be unable or unwilling to

acknowledge that others have alternative viewpoints, thereby heightening interpersonal

tensions.

The difficulty for health care professionals, social workers, and assisted living

staff is determining who "owns" the information within a family, and, therefore who is

able to receive and share the parents' health information. Although patients (i.e., parents)

may formally dictate who may request or receive their health information per the federal

Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule

(www.hhs.gov/ocr/privacy), not all patients assign additional names to their HIPAA

forms. In addition, although HIPAA regulates who may request the information, the Act

does not specify what the designee can then do with the information. A similar issue

arises with legal documentation. Powers of attorney or health care directives may state

the name of the person who may make financial or medical decisions, but may not

necessarily state who may request or receive information about the third party (i.e., the

parent). If families are not going to have conversations about information management

during elder care, direct service professionals need to be prepared to guide the families

through such discussions.

Reminding caregivers and service providers of potential differences is a step

forward in reducing tensions and caregiving burden and enhancing positive

communication behaviors. An ultimate goal of this line of research is to preserve the family as a critical "unit of care" for the aging adult. This research provides support for developing dyadic interventions that help siblings manage relational issues, caregiving burdens, and problematic integrations. These interventions could be between the provider and the cooperative sibling, or the provider and the uncooperative sibling. Although, this research provided the opportunity to both assess and quantify those differences, there were some limits to its results. The next section discusses those limitations.

Limitations

A number of limitations are present in Study One and Study Two. These include the sample (demographics and the sample size), the structure (the single versus dyadic perceptions and the cross-sectional nature of the studies), and the operationalization of a complex process. The paragraphs below provide more detail regarding each limitation.

Sample

A limitation for both Study One and Study Two were the demographics of the participants. By recruiting participants from the national and local chapters of various professional organizations, the respondents were primarily Caucasian women with college and professional degrees. This group of respondents may not experience the same challenges with their siblings during the caregiving process as other groups. In addition, the sample was biased towards those siblings with more productive relationships. Even though the interview protocol primed participants by asking them to "think of the sibling with whom things have been most difficult during this situation," the sample may under-represent those in even less productive or more productive relationships. For example, some individuals expressed an interest in participating in the studies but declined because

they worried that their sibling(s) might not approve of them sharing the family's "dirty laundry." Therefore, the results of Study One and/or Study Two may not be generalizable to a broader population.

Although the average age of participants in the current research is slightly above the national average for caregivers (57 year old in Study One versus 48 years old nationally), the current research does align with statistics about gender. Nationally, an estimated 66% of caregivers are female and, of that number, over 43% are caring for an older family member (National Alliance for Caregiving, 2009). All but one participant was female in Study One and 70 of 82 participants in Study Two were female. However, research suggests that the number of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors (Kramer & Thompson, 2002), including decreasing family size and changing cultural expectations. However, regardless of who is doing the caregiving, sibling relationships may still be problematic.

An extension of this study, which was comprised primarily of Caucasian women, would be to examine other racial and ethnic groups. Families of particular cultural backgrounds typically have defined roles regarding who will provide care (such as a daughter or a daughter-in-law) for an aging elder (e.g., Pinquart & Sorensen, 2005). Certain cultures also necessitate that elders live with and be cared for by family members rather than moving to senior living facilities (e.g., Herrera, Lee, Palos, & Torres-Vigil, 2008). In addition, families with higher incomes typically have more senior service and housing options available than those with lower incomes. These families can privately pay for the home health aides or an assisted living facility of their choosing. In Study One, personal incomes ranged from $20,000 to $150,000 annually. In Study Two,

household incomes were most often reported in the $75,000 to $99,999 range. Future research can explore the influence of culture, income, and various social and financial resources on the experience of PI.

Another limitation of Study One and Study Two are their sample sizes. Study One included 22 participants, which is consistent with many qualitative studies. Although qualitative analysis of Study One did reach saturation, a more diverse group of participants may yield additional insights into the caregiving topics explored. For example, interviews with additional diverse participants may provide a greater variety of events (i.e., injury, illness, death of a spouse, general health decline, etc.) that led to the elder care situation and provide more information about which aspects of the situation worry participants the most. This information from Study One was used to create the PI measure, and, therefore, could be used to refine the PI measure (PIM) in the future.

In Study Two, over 170 participants began the survey, yet only eighty-two participants completed the survey. Of those that completed the survey, only 79 were included for analysis due to missing data. A greater number of participants would have ensured that the testing of this new PI measure would have been powered adequately and supported different tests of the factor structure. However, the PI measure is a particularly challenging measure for participants to complete because it requires considerable time and attention. Some participants in the pilot study even described the PI measure as "taxing," saying the measure "made me think too much." Future refinements of the scale need to balance the complicated nature of PI theory with the cognitive load for participants.

Structure

Study One and Study Two gauged only the perceptions of one sibling involved in the caregiving of an aging parent. Most the individuals that responded to the calls for participation were the primary caregiver to a parent. Neither Study One nor Study Two directly asked other siblings in the family for their perceptions regarding the caregiving situation. However, it is possible that multiple members of the same family participated in Study Two, but the data was not paired. Therefore, the structure of these studies did not allow comparison of sibling perceptions.

A dyadic study would have allowed the opportunity to examine if sibling perceptions regarding the problematic aspects of caregiving aligned or diverged, and if they diverged along what particular dimensions of PI they did so. In addition, capturing the perspectives of different family members would have provided the opportunity to explore whether different family members experience the uncertainty of caregiving differently or construct different expectations around who is to be involved in caregiving and in what manger. Also, distance from the aging parents, including varying siblings' distance from the parent(s), may alter the construction of PI as those at a distance may experience more guilt about not meeting personal or family expectations about caring for aging parents. Different combinations of sibling interactions, including gender composition of the dyads, may also yield different experiences of PI.

Study One and Study Two were also cross-sectional and did not assess longitudinal aspects of the caregiving process. The present studies captured the perceptions of caregivers at one particular point in time (i.e., "Please describe the *current* health or living situation of your parent."), but these perceptions may change over time or

under different circumstances. For example, to be eligible to participate, an individual or a sibling had to have contact with and provide direct assistance to the parent within the past twelve months of the study. However, if the parent moves out of the house and into an assisted living facility, the adult child may no longer have to cook meals or monitor medications for the parent. If the adult child who had been primary caregiver becomes ill or takes a distant job, other members of the family may need to take on considerably more caregiving tasks. Each change will influence perceptions about the caregiving situation. The caregiving process is comprised of many moving parts that ebb and flow over the life of the caregiving situation, but this present research chose to only focus on particular pieces occurring at one point in time. For both Study One and Study Two, participants needed to have conducted caregiving activities within the past 12 months. Perceptions of the situation, expectations of siblings, and feelings of caregiving burden could be quite different at the onset of care, as well as months or years into or from the end of care.

How a person is thinking about an issue will depend on the chain of thoughts that leads the person to think of the issue and the way the issue is named or labeled. In other words, personal framing of an issue as well as the context in which the issue is situated will determine one's perceptions about it. As the caregiving process continues, personal circumstances, a parent's illness, and family relationships may all change and lead to different issues about and different ways in which PI is experienced. In particular, the sibling relationship during elder care and after the death of the ailing parent may be dramatically different. In turn, the state of the sibling relationship may be fixed, and, if so, could become a moderator for PI. A longitudinal study, in which participants would

be tracked throughout the stages of caregiving, may be able to capture some of these changes over time.

Operationalization of PI

Study Two was the first time that the theory of Problematic Integration had been operationalized utilizing a measurable, quantifiable survey utilizing PI (i.e., the PIM). However, this is a complicated construct to measure. PI by its nature is abstract and subjective. PI involves the probabilistic (will it occur) and evaluative (will the occurrence be good or bad) orientations around the likelihood or benefit of an event occurring (Babrow, 1992, 1998). The measure attempted to incorporate these orientations or aspects by asking participants to identify the Likelihood and Value they associate with each item. The measure also incorporated the additional aspect of *Upsetness*. This last aspect was an attempt to differentiate when participants experience PI (they see the mismatch between what is expected and what is valued as problematic) and when participants do not (they *do not* see the mismatch between what is expected and what is valued as problematic).

In addition to these multiple aspects, the prior theory identifies four forms of PI (Ambiguity, Divergence, Ambivalence, and Impossibility). Based on the literature (Babrow, 1992, 1998), a distinction was made in the scale between the concepts of Ambiguity and Uncertainty. An additional form of PI (Transcendence) was suggested in Study One and was included in the measure as well, for a total of six forms of PI. The results of Study One, along with items from previously developed measures of ambiguity (Budner, 1962) and uncertainty (Checton & Greene, 2012; Mishel, 1981) were used to construct the 32 item PIM.

Difficulty arose, however, when trying to assess whether these individual items truly represented each of the six form of PI. This is because any object of thought can be considered in multiple ways (e.g., at various levels of abstraction, with multiple nuances, meanings, etc.) and, therefore, its meanings are not finalizable. How a person happens to think about an issue or object depends on the language used to nominate that issue or object as something to be thought about (e.g., the chain of thoughts that happened to lead the person to think of the object, the way the object was named, or the way the object name was spun into surrounding language). Therefore, if each form of PI can arise for any specific belief, some question remains as to whether the sets of items tapped each of the six forms of PI.

Considering that PI arises not from probability judgment alone or from value judgment alone, and not necessarily with respect to any particular substantive issue, two types of calculations were done with respect to the aspects and forms of PI. The first is referred to as the additive (or primary) approach. Here, factor analyses were conducted separately for each of the six forms relative to the three evaluative aspects of PI. Those items that were retained were used to construct broad composites for each of the three aspects of PI, *Likelihood*, *Value*, and *Upsetness*. These three composites were also then added together to create an overall measure of PI.

In the additive approach, the direction of the relationship between the overall measure of PI and the various scales in Study Two reflected the strength and direction of the aspects of *Value* and *Upsetness*. Total PI and the aspects of *Value* and *Upsetness* trended in the same direction. Alternatively, when there was no relationship between *Upsetness* and the various scales, there was no relationship between the overall measure

of PI and the various scales. Additionally, when there was a weaker relationship between *Upsetness* and the various scales, there was no relationship between the overall measure of PI and the various scales. These results suggest that the aspect of *Upsetness* works differently than the other aspects.

The different performance of *Upsetness* contributed to the rationale for conducting an alternative PI analysis (the multiplicative approach). In this approach, Divergence was proposed as a proxy for PI and an overall Divergence variable was created by multiplying the recoded Likelihood variables and the recoded Value variables. The results here were similar to the original PI calculations, with higher levels of Caregiving Burden related to greater levels of PI and poor Relational Quality related to increased levels of PI. The information management behaviors of Information Sharing and Secret Keeping were negatively related to PI, while Topic Avoidance was positive related to PI.

No single operational definition of an abstract concept can encompass a concept completely, particularly one that has so many components or one that relies so much on personal meanings and experiences. However, in the additive approach, the original scaling was retained. Moreover, the variables contained within it were those that performed best during the analyses, and it included the measure of *Upsetness*. The analyses conducted in this research acknowledges that people make probabilistic and evaluative judgments about particular issues/objects, but they are making those judgments within particular frames of reference and those frames determine how "upset" someone is about those judgments around the item.

Although the abstract nature of PI can be viewed as a limitation, it also provides opportunities for future research to refine the language used for each item. The PIM represented a balance between content specific to the elder care context and a conceptualization of forms and aspects of PI theory. For example, could an intended idea be represented in a single statement of did the idea require more than one statement? It is also not clear if the item content statements or PI forms would have similar meanings at different points in time. A participant who is new to the caregiving context may be at a different place than one whose parent just moved to a hospice facility, and these participants may experience PI differently from a caregiver whose parent just fell or one whose parent is declining cognitively.

The PIM developed for this project only seeks to capture the PI as reported at one moment in time. A future opportunity for research includes revising the items used to represent each form of PI. One way to do this is by presenting the items to participants as longer narratives, as Egbert (2000) did, and asking participants to rate the certainty and value of the narratives in an effort to test the validity of the items as they relate to the various forms of PI. Another way is to restructure the response questions associated with each item. Instead of following each item with scales representing *Likelihood*, *Value*, and *Upsetness*, each item would be followed by scales representing broader assessments of the PI form being represented by the item. For example, to measure Ambivalence, more detailed response options (such as "I have slightly mixed feelings about this situation. I see a bit of good, but mostly bad or I see a bit of bad, but mostly good") would be presented to participants for ranking along a four point scale ranging from *Not Ambivalent* to *Very Ambivalent*. Additional areas of research could include recalculating

combinations of the three aspects of PI and tracking changes in experiences of PI across the caregiving process. As such, the items in PIM intended to measure Uncertainty, such as "I know how my parent's care needs will change in the future," could be reclassified as items under Ambiguity or Impossibility. Any new analysis could then be compared the original results of PIM.

Future Research

The results of Study One and Study Two establish future paths for research on PI and a number of other areas. The first path leads to a further refinement of the Problematic Integration scale and other paths lead to an extension of sibling relationships within the caregiving context. These future directions address both the implications and limitations of the two studies.

Problematic Integration

Future research is necessary to refine and retest the newly developed Problematic Integration measure (PIM). The individual items of the scale will need to be refined to more confidently ensure that those items intended to represent the individual forms of PI do so. During this process, some items may be reclassified under a different form of PI (for example, items reclassified under Uncertainty rather than Ambiguity) or dropped from the scale and new items may be included (for example, Ambivalence only retained two items and more are needed to strengthen the factor). In addition, the items that remain in the scale will need to rewritten in a more neutral language so that they may be used in outside of elder care and health communication contexts.

Future research should also attempt to replicate the results of this result with a different sample. Both additive and multiplicative calculations for analysis should be

conducted on this different sample. The scale will then need to be further tested for validity and reliability with a larger sample size than that in Study Two.

Caregiving Burden

A sibling's decision to assist with caregiving tasks may be viewed as a provision of social support, an interaction that provides assistance (Hobfoll, 1988). An avenue for future research is exploring the association between social support (Burleson, Albrecht, Goldsmith, & Sarason, 1994; Campbell, Marsden, & Hurlbert, 1986; Haines, Hurlbert, & Beggs, 1996; House, 1981; Walker, Wasserman, & Wellman, 1993; Wellman, 1992), Caregiving Burden, and Problematic Integration. Other questions to investigate include: does the sibling's greater provision of social support decrease feelings of caregiving burden, and, in turn, decrease experiences of problematic integration? And is the relationship between social support, caregiving burden, and problematic integration influenced by gender, ethnicity, and/or religion?

Another aspect of Caregiving Burden to explore in the future is feelings of caregiving burden and ambiguity of the primary family caregiver versus the ancillary family caregiver(s). There were frequent comments from primary caregivers in Study One that alluded to "my sibling does not understand." However, the study did not explore whether this misunderstanding was related to differences in communication behaviors or differences in caregiving perceptions. A dyadic study of caregiving burden could address this question.

Relational Quality

The adult sibling relationship is one that is often overshadowed by romantic partner, parent-child, or adolescent sibling relationships in the Communication and

Family Studies literatures. In Family Studies, parent-child and adolescent sibling relationships receive considerable focus as well. The parent-child literature often considers parent attachment styles and the relation to child development (e.g., Cohn, 1990), while the adolescent sibling studies examine sibling rivalry and conflict (e.g., Buhrmester & Furman, 1990). Although there is research examining the issue of reciprocity between parents and children later in life (e.g., Silverstein, Conroy, Wang, Giarrusso, & Bengtson, 2002), future research should explore the relationship between parenting style/technique and adult sibling rivalry.

Some participants in Study One discussed how parents had made the siblings individualistic and competitive as children. Some participants also discussed how a parent's mental illness or a family trauma shaped their childhood family relationships. The participants believed that these events, in turn, influenced their sibling interactions and perceptions of sibling closeness as adults.

In the fields of Communication and Family Studies, dating or married couples receive significant attention. Future research might apply a theory or model that is typically tested with couples, such as the partner interference parameter of the Relational Turbulence Model (Theiss & Solomon, 2006), to adult sibling relationships. The uncertainty that often surrounds the caregiving experience spills over and creates turbulence for the individual, the sibling (the other), and the sibling relationship, as well as for the relationships with their spouses. In Study One, spouses of siblings had an influence on the type and magnitude of PI experienced by caregivers, as well as their information management behaviors. A study of caregiver relationships compared to other family members could yield insights into how the Relational Turbulence Model operates

in a new context of family relationships (such as when a sibling spouse's create interference in the sibling relationship) versus romantic relationships. Adult sibling relationships could also prove an interesting new context for the theories of disclosure (e.g., Greene, 2009), family secrets (e.g., Caughlin & Vangelisti, 2009), privacy management (e.g., Petronio, 1992), and topic avoidance (e.g., Afifi & Guerrero, 1998).

Chronic Illness versus Cognitive Illness

The results of Study One and Study Two suggest that participants' whose parents were suffering a chronic illness were at different places in terms of perceptions of caregiving burden and problematic integration than participants whose parents were suffering a cognitive illness, such as Alzheimer's disease. Future research should further test the differences in caregiving burden and problematic integration among family caregivers whose loved one is suffering a chronic versus cognitive illness. With the rapid increase in diagnoses of Alzheimer's disease and other forms of dementia, health professional need additional information to support families in this caregiving situation. To date, education and support are focused on the individual caregiver, such as Understanding Dementia, Legal and Financial Planning for Persons with Dementia, etc. (ALZ.org/NYC). Research should further investigate the relational dimensions of dementia caregiving as a means for supporting the primary caregiver, as well as the family unit as a whole. In general, the severity and types of illness and disease progression would be important to further understand in relation to caregiving burden, information management, and problematic integration.

Longitudinal versus Cross-Sectional Design

Additional revelations in family research could come from following adult sibling caregivers over time. A longitudinal study would align with Babrow's arguments that perceptions of PI change continuously. A cross-sectional study only captures one point in time and misses the chaining (how one event influences perceptions of the next and the next, etc.) that occurs. Feelings of Caregiving Burden, Perceptions of Sibling Relational Quality, Perceptions of Problematic Integration, and Information Management Behaviors could be very different at the start of caregiving versus the height of caregiving versus soon after caregiving has ended or even later. For example, the results of these measures could also be very different when the parent is living alone in a house or apartment and the family provides the bulk of assistance versus when the parent has moved into a senior living community and the community provides much assistance.

For some families, the caregiving process is only months long. Yet, for other families the caregiving process is decades long with markedly different impact on the family and family structure. Many life events could occur for immediate and extended family members over that time period, and each change could have a different influence on who is involved in caregiving and how caregiving is administered. A longitudinal study would provide the opportunity to examine the fluctuating dynamics of family relationships within a changing space of caregiving. A result of such a study may be that caregivers who had experienced Transcendence at one point in the caregiving process may experience Divergence at another point in time as events and expectations changed.

Additional Areas of Research

Four additional future areas of research have emerged from conversations with health and senior service professionals since completing Study Two. The first area involves gathering parents' perceptions of their adult children's relationships during caregiving. The research could consider how parents experience PI during the caregiving process, how they make sense of their adult children's relationships, and how these perceptions are associated with the parent's feelings of burden and resulting health outcomes. Patients whose caregivers report higher levels of caregiving burden are more susceptible to abuse or neglect. Those caregivers who feel they receive inadequate support from other family member report higher levels of burden (Nerenberg, 2002). Therefore, sibling relationships during elder care may be indirectly associated with parent's health outcomes.

Alternatively, parents (who are cognitively healthy) may actively mediate the communication taking place between their adult children. Communication through a parent creates a very different communication exchange from one in which the adult children are negotiating elder care directly with each other. Future research should consider how the structure of communication is associated with the ability to effectively integrate the problematic aspects of events, and, in turn, how the structure of communication is related to subsequent information management behaviors of both the adult children and the parent.

The second potential area for research is a dyadic study of the problematic integration and information management behaviors between family and professional caregivers. Previous studies have qualitatively explored the PI of patients and health

providers (e.g., Hines et al., 2001) and reported that each group experienced PI

differently. Family and professional caregivers should operate as a team to deliver the

best care possible to the aging adult. However, these two groups are often at odds due to

different perceptions about roles and responsibilities and different perceptions about what

is best for the aging parent (Doremus, 2014). One question is whether this conflict stems

from family and professional caregivers experiencing PI differently compared to patients

and health providers.

Another suggested area of research is the role of family caregivers in the "Aging

in Community" initiatives being developed around the nation. These grassroots initiatives

create local systems of support and caring to enhance the well-being and improve the

quality of life of older adults in the community (Blanchard, 2013). However, while the

aging in community movement focuses on creating the "social architecture" for "health

aging" through formal senior services or informal neighborhood networks, it often leaves

the family out of the design. Yet, family members provide nearly 82% of the necessary

care for an elder family member (UCSF, 2014). Incorporating the family back into the

social architecture may not only ensure that the senior ages well, but also that their

children feel more social support, experience less caregiving burden, and maintain their

own well-being.

A final area of potential research is childhood sibling relationships when one

sibling has a chronic illness, such as cancer or cardiovascular disease. This topic was

suggested by a pediatric cardiothoracic surgeon at a large children's hospital on the East

Coast. The money, time, and attention given to the child patient often come at the

expense of the non-patient child. Even if for a short period of time, these differences in

time and attention may alter the childhood sibling relationship and carry over into

adulthood. As a participant said in Study One, "How you are as children, is how you will

be as adults." A longitudinal study of relational quality that captures the turning points in

the childhood sibling relationship (such as sibling or parent illness, parent loss of job, or

relocation) may give information about parent-child communication and sibling relational

development. These pieces of information relative to the status of the relationship as

adults may provide clues for how to effectively manage these difficult life events from a

sibling perspective.

<div align="center">**Summary**</div>

This study considered how individuals form the expectations, perceptions, and

meanings of their sibling relationships as they negotiate one common task associated with

later life stages. This research utilized Problematic Integration (PI) theory (Babrow, 1992,

2001) as a framework for assessing how adult siblings identify and evaluate the

ambiguities of caring for an aging parent. Study One conducted individual interviews

with adults currently negotiating elder care with their sibling to assess the caregiving

situation, sibling relationship, feelings of uncertainty, and communication behaviors. The

goal of Study One was not to test PI theory but to explicate its concepts within the elder

care context. The results confirmed that PI is experienced in different forms even by

those experiencing a similar life event.

In an effort to build on the data collected in the first study, Study Two

investigated how one adult sibling's expectations, perceptions, and meanings of the

caregiving situation influenced the information management behaviors enacted as they

attempt to integrate their varied problematic integrations. A new measure, the PIM, was

developed to operationalize the various aspects and forms of PI. The results showed that

a higher perception of Caregiving Burden was related to greater perceptions of PI, while

higher perceptions relational quality was related to lower perceptions of PI. Greater

information sharing was related to lower PI, higher topic avoidance was related to higher

perceptions of PI, and greater secret keeping was also related to lower perceptions of PI.

The creation of a PIM moves the theory forward and allows it to be compared with other

communication and relationship constructs.

Family and psychology scholars describe the sibling relationship as one of the

most important interpersonal relationships, for it is a lifelong affiliation that spans other

well documented relationships such as those of parents, friends, and married couples

(Cicirelli, 1995). Most research on siblings, however, has focused on their interactions

during childhood or adolescence. Less is known about the communication exchanges of

siblings in middle to late adulthood. This research increased understanding of adult

sibling relationship, particularly as they manage the information and complexities of

caring for an aging parent – a time when, to paraphrase Babrow, all things are in motion.

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Table 1

Participant Experiences with Uncertainty and Ambiguity as forms of Problematic Integration

Form of PI	Definition	Example
1. Uncertainty about Parent		
a. Uncertainty regarding parent mental health	Not knowing the outcomes associated with a parent's mental health	I was mostly worried about the early stages of dementia and my mom not remembering . . . how to do simple things like how to turn the heat up or work the toaster oven.
		The last six months she's going downhill really quickly. It's difficult watching her not be able to do everything she wants to do and she gets frustrated and she starts to cry.
		[My mom] is always worrying about her two sons. I wanted her retirement years to be more fun and relaxing, not filled with stress.
		I'm most worried about her being lonely and not having companionship.
b. Uncertainty regarding parent physical health	Not knowing the outcomes associated with a parent's health	I am worried about my mom's physical health. We worry that she's gonna trip and fall, break her hip, the classic thing that would happen to an older person.
		[I am most worried about] her mobility, just being able to get around and the possibility of her falling down and breaking a hip.
		I've been worried about medication management. Her medication [levels where] causing her confusion and balance problems.
c. Uncertainty regarding parent housing	Not knowing the outcomes associated with a parent's housing	What are we going to do? Where is she going to live? She won't be able to stay here forever. [We] will have to get her into some kinds of assisted living. I don't really know what that entails.

Table 1 (cont.)

Participant Experiences with Uncertainty and Ambiguity as forms of Problematic Integration

Form of PI	Definition	Example
		Her mental abilities are slipping so fast. I think she's going to need to move to another level of care and we don't know what we're going to do.
		I wanna abide by her wishes and I want her to be happy. But if it gets to the point where I can't physically care for her and know that she's safe when I'm not there, I would probably consider a nursing home.
		At some point there could be a conflict between our desire to get [our mother] into a place we feel might be more helpful and [the home health care agency's] desire to keep her in the home for a longer period of time.
d. Uncertainty regarding parent finances	Not knowing the outcomes associated with a parent's finances	For financial reason, we moved her out of one assisted living facility and into another.
		The only concern I had was whether mom's money would last to the end of her life.
2. Uncertainty about Self		
a. Uncertainty regarding mental health	Not knowing the outcomes associated with one's mental health	Her personality and everything else the dementia has just compounded. That's a lot of stress for me.
		I was calling her every day and I was starting to get a little over the edge stressed out and needed to have this check in with her.

Table 1 (cont.)

Participant Experiences with Uncertainty and Ambiguity as forms of Problematic Integration

Form of PI	Definition	Example
2. Uncertainty about Self		
b. Uncertainty regarding personal health	Not knowing the outcomes associated with one's health	That was the hardest part sometimes just being tired . . . I would run a lot for my mom but I was still working, managing my business and trying to fit everything in.
		I'm always afraid I won't be able to handle whatever comes next. I mean physically I just won't be able to handle it.
c. Uncertainty regarding personal housing	Not knowing the outcomes associated with one's housing	When we were looking at houses, I just kind of stopped and said I don't see the point. If we sell [my mother's] house, it makes sense for her to move in with us. But nobody wants to have that discussion.
		At some point, I would like to be able to move. I would only live here if there's gonna be [further] decline.
d. Uncertainty regarding personal finances	Not knowing the outcomes associated with one's finances	What it's meant is that I've had to take a second job. There's always stress about whether or not I'll . . . be able to cover her expenses in this type of independent living situation.
		I'm coming from a position of feeling less than [my brother] just because of my financial situation.
e. Uncertainty regarding personal knowledge	Not knowing the outcomes associated with a parent's mental health	I don't know how far I can take it before I'm not able to give her the proper care.
		The hardest part has been trying to communicate with the doctors. They do seem to really communicate with each other, but . . . they're not seeing the whole picture.

Table 1 (cont.)

Participant Experiences with Uncertainty and Ambiguity as forms of Problematic Integration

Form of PI	Definition	Example
		I've tried to understand what's going on medically and just sort of know a lot of Google sites. But there's really no way to know and there's not even any reason to know. I've kind of given up on being wise.
3. Ambiguity about Sibling	Not knowing the outcomes associated with siblings	I think of my mother moving to hospice or passing away and I think that our relationship is just going to deteriorate.
		It's just the little things I see in terms of my brothers. Maybe they'll just step up to the plate.
		We won't have my mother to talk about anymore, so I don't know. I would assume there will eventually be some weddings and some grandchildren. We might get together for those things. I'm really not sure.
		I could see thing changing in some ways, but it's hard for me to imagine.

Table 2

Participant Experiences with Divergence as a form of Problematic Integration

Form of PI	Definition	Example
Divergence with Sibling	Discrepancy between what want to happen and what believe will happen	You cannot realistically expect a sibling that you were not able to negotiate, or compromise, or talk to before to all of a sudden be supportive and helpful in such a situation.
		Just getting him to understand that his mother isn't going to last forever and he should show up occasionally.
		My friends and I joke about how "it's always the daughter, it's always the daughter" for some reason the daughter is the one expected to be the caregiver.
		I had hoped that he would participate more. Maybe pick her up for a visit with the kids; get her out of the house for a little bit and give me a little time to myself. But that doesn't happen enough.

Table 3

Participant Experiences with Transcendence as a form of Problematic Integration

Form of Resolution	Definition	Example
Transcendence of Situation	Unprotesting acceptance of the caregiving situation	I've had to lean on my personal theology that we're on this earth to do what we can in the best way that we can . . . and to leave the result of everybody else's choices with God.
		I'm dismayed at [my siblings'] response but it's not my responsibility to make that all right.
		I could continue [sending him emails] and feeling hurt every time or I could just say, "that's your decision and I'll respect that."
		This is my life. I'm in charge of mom and I'm okay with it.
		If I thought that [my sister] could instantly become more organized, I would have done that to her 40 years ago.
		At the end of the day, I've turned this whole thing over 'cause I have to live my life. My attitude is it's her house, her money, it's her life; she can do whatever she wants with it.

Table 4

Strategies for Avoiding Conflict with Family Members

Strategy	Definition	Example
1. Curtail Interaction	Limiting contact and/or communication with sibling	I don't really interact with him a lot to be honest with you, because he's very combative. I just don't need to deal with it, so honestly I try to interact with him as little as possible.
		I just look at [brother] as someone I don't get along with, who I don't agree with most of the time and that's someone I don't wanna have any kind of a relationship with.
2. Restrict Topics a. Restrict Topics about Caregiving	Averting talk about matters related to caregiving	Maybe the whole tension that we had was that I saw them as being male and older and that they should step in. And maybe they saw it as me being the female of the family and that I should be stepping into a certain role.
		I think my brother is concerned he's going to get stuck . . . paying for my mother. And there's a component where just because I'm a single woman does not mean I'm gonna go down to [SE state] to take care of my mother.
b. Restrict Topics about People	Averting talk about particular family members	We have . . . a quiet agreement that I'm not going to talk to [sister] about my mother and … I'm not gonna talk to my mother about [sister] either. [We avoid talking about] my brother 'cause my mother will always stand up for him. I don't think very highly of him; he left six kids and a wife.

Table 4 (cont.)

Strategies for Avoiding Conflict with Family Members

Strategy	Definition	Example
c. Restrict Topics about Issues	Averting talk about particular personal or political issues	You don't wanna poke the bear, so to speak. There are things I just avoid with him, like politics, because we have different views
		[The cottage] is an elephant in the room for sure and a lot of it also has to do with my mother creating a lot of emotional upset around it. If we sell the house, it's all of us involved and nobody wants to, for whatever reason, have that discussion.
		I never discuss anything that's happening to our house in terms of health problems or how [son] is excelling. I know that will not be received well.
		[My sister] went to AA and has stopped drinking. I don't think she has had a drink in 20 years. We sure couldn't talk about that for a long time.
		[My sister's] inability to get pregnant and to do all these things in the traditional way that I did them. We sure didn't talk about that for years.
		[We avoid] talking of anything that went on in our childhood
3. Suppress Thoughts		
a. Suppress Thoughts about Sibling	Holding back personal feelings and opinions about siblings' caregiving efforts	I might feel a little disappointed in my brother or my sister in terms of what they're doing. I'll say some things, but I won't say that much and I won't say it that clearly.

Table 4 (cont.)

Strategies for Avoiding Conflict with Family Members

Strategy	Definition	Example
a. Suppress Thoughts about Sibling (cont.)	Holding back personal feelings and opinions about siblings' caregiving efforts	I don't wanna make her feel bad, like feel like she's not doing her part or doing the right thing. So, I won't say to her "I'm disappointed that you're not seeing mom more."
		When I try to let him know how this affected me, he doesn't want to hear it; he just throws it back in my face. That's why I don't share with him.
		Oh, I keep my mouth shut when my mother starts taking how wonderful her other daughter is, how perfect and how hardworking. I just sit there and you know don't say a word.
b. Suppress Thoughts about Others	Holding back personal feelings about others in family	I would never say to [brother], "Gee your first wife was actually one of the nastiest people I've ever met . . . and don't you see . . . that your second wife . . . is doing something similar. I don't like how she puts you down."
		I never criticized [sibling's spouse] to my sister. So we didn't talk about him, we talked about her.
		I do feel some strain with my brother in law, I'm still a little . . . angry maybe at the way he treated [mother]. But I've never said that to him.

Table 5

Secrets Kept from Family Members to Prevent Conflict

Secret	Definition	Example
1. Participant		
a. Kept from Parent	Knowingly withheld information from parent	My mother … is really nervous about money, I mean really nervous about money. I decided that I'm hiring someone to come in that my mother knows already and telling her that the county is paying for it.
b. Kept from Sibling	Knowingly withheld information from sibling	I don't tell him she has these episodes that all of a sudden people are saying they are mild seizures.
		I'm careful not to tell my sister that I'm telling my mother a lie. My sister might feel it's very important not to lie to our mother and I feel that it's very important as a care giver to take care of yourself.
c. Kept from Family	Knowingly withheld information from family	There is nothing I really didn't wanna tell them, or chose not to tell them, other than, we're probably gonna move in about a year and a half, two years . . . I don't wanna worry anybody.
		For a couple of years I knew [my daughter] was a lesbian but the family didn't know.
2. Parent		
Kept from Family	Knowingly withheld information from family	[My mother] wanted to move [into an assisted living community]. She got frightened thinking that my father had died when he'd gone to sleep one afternoon. We didn't actually know the whole back-story. They started planning it without even including us.

Table 5 (cont.)

Secrets Kept from Family Members to Prevent Conflict

Secret	Definition	Example
Kept from Family (cont.)	Knowingly withheld information from family	My older brother was farming the family farm, which was a dairy farm, and he had such bad knees that he couldn't do the milking. So he gave it back to my dad and . . . he went into beef and crop farming. Then my younger brother got the farm . . . for a steal and my older brother never knew. When it came up in conversation one day, my older brother was blown away. It wasn't exactly a secret but something we didn't know.
3. Sibling		
Kept from Family	Knowingly withheld information from family	He had a malignant melanoma that he chose not to share with any of us until the surgery was all over. Uh, that was a biggie.
		[Sister] has not had heat in her house. I did not know this until last week.

Table 6

Forms of PI and Associated Scale Items for Study Two

Form of PI	Item #	Item
Divergence	1	I am content with the caregiving roles that I am performing.
	2	My sibling's level of involvement in our parent's care is
	3	I share similar values about caregiving with my sibling.
	4	My sibling understands my needs it the caregiving process.
	5	My sibling will "step up" to the caregiving challenge.
Ambiguity	6	My sibling does not understand the complexity of our
	7	Our parent's need for assistance has affected my relationship
	8	Future changes in our parent's care will affect my
	9	Our different opinions about our parent's needs are hurting
	10	Most of our important caregiving decisions are based on
Uncertainty	11	I know how our parent's care needs will change in the future.
	12	My sibling is aware of how our parent's care needs will
	13	I am prepared to deal with our parent's declining health.
	14	My sibling is prepared to deal with our parent's declining
	15	I understand the purpose of each of our parent's treatments
	16	My sibling understands the purpose of each of our parent's
Ambivalence	17	I would be better suited that my sibling to be our parent's
	18	My sibling would rather pay someone to provide care for our
	19	I am willing to accept multiple solutions to the caregiving
	20	My sibling is willing to accept multiple solutions to the
	21	I would choose for my parent to live closer to my than my
	22	Caregiving helps keep me and my sibling in contact.
Impossibility	23	The outcomes of the caregiving situation are very
	24	My sibling will not help with our parent's care.
	25	My sibling and I cannot change our relationship at this stage.
	26	My sibling will never change how he or she acts.
	28	Obtaining additional information about the caregiving
Transcendence	27	My sibling is doing the best he or she can in this situation.
	29	The outcome of the caregiving situation is in the hands of a
	30	I respect my sibling's caregiving decisions, even when I do
	31	I am focusing on what I feel is right for my parent and my
	32	My sibling and I are muddling through the caregiving

Table 7

Correlation for Aspects of PI and Caregiving Burden

Aspect of PI	Caregiving Burden
Likelihood	-.06
Value	.34**
Upsetness	.46**
TOTAL	.46**

*p < .05, **p < .01

Table 8

Correlation for Forms of PI and Caregiving Burden

Form of PI	Caregiving Burden
Divergence	
Divergence Likelihood	-.41**
Divergence Value	.39**
Divergence Upsetness	.38**
Ambiguity	
Ambiguity Likelihood	.22*
Ambiguity Value	.25*
Ambiguity Upsetness	.30**
Uncertainty	
Uncertainty Likelihood	-.14
Uncertainty Value	.27**
Uncertainty Upsetness	.39**
Ambivalence	
Ambivalence Likelihood	.23*
Ambivalence Value	.17
Ambivalence Upsetness	.25*
Impossibility	
Impossibility Likelihood	.36**
Impossibility Value	.30**
Impossibility Upsetness	.46**
Transcendence	
Transcendence Likelihood	-.21*
Transcendence Value	.34**
Transcendence Upsetness	.43**

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

Table 9

Correlation for Aspects of PI and Relational Quality

Aspect of PI	Relational Quality
Likelihood	.41**
Value	-.67**
Upsetness	-.58**
TOTAL	-.57**

*p < .05, **p < .01

Table 10

Correlation for Forms of PI and Relational Quality

Form of PI	Relational Quality
Divergence	
Divergence Likelihood	.69**
Divergence Value	-.66**
Divergence Upsetness	-.64**
Ambiguity	
Ambiguity Likelihood	-.48**
Ambiguity Value	-.62**
Ambiguity Upsetness	-.62**
Uncertainty	
Uncertainty Likelihood	.40**
Uncertainty Value	-.56**
Uncertainty Upsetness	-.24*
Ambivalence	
Ambivalence Likelihood	-.21*
Ambivalence Value	-.57**
Ambivalence Upsetness	-.37**
Impossibility	
Impossibility Likelihood	-.58**
Impossibility Value	-.62**
Impossibility Upsetness	-.51**
Transcendence	
Transcendence Likelihood	.76**
Transcendence Value	-.68**
Transcendence Upsetness	-.49**

*p < .05, **p < .01

Table 11

Correlation for Aspects of PI and Family Communication

Aspect of PI	Conversation Orientation	Conformity Orientation
Likelihood	.14	.08
Value	-.28*	.03
Upsetness	-.19	.06
TOTAL	-.22	.09

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

Table 12

Correlation for Forms of PI and Family Communication

Form of PI	Conversation Orientation	Conformity Orientation
Divergence		
Divergence Likelihood	.24*	-.07
Divergence Value	-.23*	.09
Divergence Upsetness	-.24*	.16
Ambiguity		
Ambiguity Likelihood	-.29**	.15
Ambiguity Value	-.14	.00
Ambiguity Upsetness	-.18	.13
Uncertainty		
Uncertainty Likelihood	.04	.20*
Uncertainty Value	-.17	-.09
Uncertainty Upsetness	.01	-.08
Ambivalence		
Ambivalence Likelihood	.05	-.13
Ambivalence Value	-.21*	.05
Ambivalence Upsetness	-.11	.07
Impossibility		
Impossibility Likelihood	-.13	.05
Impossibility Value	-.26*	-.03
Impossibility Upsetness	-.18	-.01
Transcendence		
Transcendence Likelihood	.33**	-.12
Transcendence Value	-.36**	.07
Transcendence Upsetness	-.20*	-.02

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

Table 13

Correlation for Aspects of PI and Information Sharing

Aspect of PI	Information Sharing
Likelihood	.42**
Value	-.54**
Upsetness	-.41**
TOTAL	-.38**

$^{*}p < .05,$ $^{**}p < .01$

Table 14

Correlation for Forms of PI and Information Sharing

Form of PI	Information Sharing
Divergence	
Divergence Likelihood	.58[**]
Divergence Value	-.56[**]
Divergence Upsetness	-.55[**]
Ambiguity	
Ambiguity Likelihood	-.28[**]
Ambiguity Value	-.43[**]
Ambiguity Upsetness	-.47[**]
Uncertainty	
Uncertainty Likelihood	.32[**]
Uncertainty Value	-.44[**]
Uncertainty Upsetness	-.07
Ambivalence	
Ambivalence Likelihood	-.23[*]
Ambivalence Value	-.52[**]
Ambivalence Upsetness	-.27[**]
Impossibility	
Impossibility Likelihood	-.42[**]
Impossibility Value	-.49[**]
Impossibility Upsetness	-.35[**]
Transcendence	
Transcendence Likelihood	.69[**]
Transcendence Value	-.59[**]
Transcendence Upsetness	-.35[**]

[*]$p < .05$, [**]$p < .01$

Table 15

Correlation for Aspects of PI and Topic Avoidance

Aspect of PI	Topic Avoidance
Likelihood	-.30**
Value	.47**
Upsetness	.38**
TOTAL	.37**

*p < .05, **p < .01

Table 16

Correlation for Forms of PI and Topic Avoidance

Form of PI	Topic Avoidance
Divergence	
Divergence Likelihood	-.49**
Divergence Value	.46**
Divergence Upsetness	.49**
Ambiguity	
Ambiguity Likelihood	.32**
Ambiguity Value	.35**
Ambiguity Upsetness	.35**
Uncertainty	
Uncertainty Likelihood	-.19
Uncertainty Value	.35**
Uncertainty Upsetness	.07
Ambivalence	
Ambivalence Likelihood	.16
Ambivalence Value	.51**
Ambivalence Upsetness	.31**
Impossibility	
Impossibility Likelihood	.40**
Impossibility Value	.42**
Impossibility Upsetness	.33**
Transcendence	
Transcendence Likelihood	-.56**
Transcendence Value	.50**
Transcendence Upsetness	.30**

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

Table 17

Correlation for Aspects of PI and Secret Keeping

Aspect of PI	Secret Keeping
Likelihood	.26**
Value	-.31**
Upsetness	-.22**
TOTAL	-.20**

*p < .05, **p < .01

Table 18

Correlation for Forms of PI and Secret Keeping

Form of PI	Secret Keeping
Divergence	
Divergence Likelihood	.47**
Divergence Value	-.39**
Divergence Upsetness	-.34**
Ambiguity	
Ambiguity Likelihood	-.24*
Ambiguity Value	-.23*
Ambiguity Upsetness	-.26**
Uncertainty	
Uncertainty Likelihood	.23*
Uncertainty Value	-.27**
Uncertainty Upsetness	.06
Ambivalence	
Ambivalence Likelihood	-.15
Ambivalence Value	-.33**
Ambivalence Upsetness	-.07
Impossibility	
Impossibility Likelihood	-.32**
Impossibility Value	-.28**
Impossibility Upsetness	-.24*
Transcendence	
Transcendence Likelihood	.42**
Transcendence Value	-.34**
Transcendence Upsetness	-.27**

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

Table 19

Correlations between PI Aspects and the Scales in Study Two

Scale	PI Total	PI Likelihood	PI Value	PI Upsetness
Caregiving Burden	.46**	-.06	.34**	.46**
Relational Quality	-.57**	.41**	-.67**	-.58**
Information Sharing	-.38**	.42**	-.54**	-.41**
Topic Avoidance	.37**	-.30**	.47**	.38**
Secret Keeping	-.20	.26*	-.31**	-.22*
Family Comm. Conversation	-.22	.14	-.28*	-.19
Family Comm. Conformity	-.09	.08	.03	.06

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

Table 20

Relationship between PI Aspects and the Scales Used in Study Two

Scale	PI Total	PI Likelihood	PI Value	PI Upsetness
Caregiving Burden	+ + +		+ +	+ + +
Relational Quality	– – –	+ + +	– – –	– – –
Information Sharing	– –	+ + +	– – –	– – –
Topic Avoidance	+ +	– –	+ + +	+ +
Secret Keeping		+ +	– –	– –
Family Comm. Conversation			– –	
Family Comm. Conformity				

Note: + + + r > .4, + + r > .2 to .3, – – – r > -.4, – – r > -.2 to -.3.

Table 21

Summary of Correlation between Alternative Calculations of PI and the Scales in Study Two

Scale	Divergence - Multiplicative	Divergence - Additive	PI Total - Alternative
Caregiving Burden	.36**	.35**	.47**
Relational Quality	-.60**	-.62**	-.57**
Information Sharing	-.47**	-.45**	-.38**
Topic Avoidance	.39**	.41**	.37**
Secret Keeping	-.31	-.24*	-.20
Family Comm. Conversation	-.30**	-.18	-.22
Family Comm. Conformity	.04	.03	.09

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

Note: Divergence, one of the six forms of PI, was proposed as a proxy for PI and an overall Divergence variable was created by multiplying the recoded *Likelihood* variables by the recoded *Value* variables. An alternative Divergence variable was calculated to gauge the influence of the *Upsetness* variable by adding *Upsetness* with the *Likelihood* and *Value* variables.

Appendix A
Participant Recruitment Channels

Email - Personal & Professional Contacts
- Friends, Family, and Neighbors
- Teachers and Staff at children's schools
- Assisted Living Communities
- Community Centers
- Mediation Centers
- Offices of Aging
- Places of Worship
- Snowball to other's networks

Email Listservs - Professional Organizations
- Association for Conflict Resolution (ACR) listservs
- BNI Playmakers listserv
- New Jersey Association for Professional Mediators (NJAPM) listserv
- New York City-Dispute Resolution (NYC-DR) listserv
- National Association of Women Business Owners-Central Jersey (NAWBO-CJ) listserv
- National Council on Family Relations (NCFR) listservs
- National Association of Professional Organizers (NAPO) listserv
- National Association of Senior Move Managers (NASMM) listserv
- Rutgers University listservs
- Westfield Area Chamber of Commerce

LinkedIn Groups
- ADR (Alternative Dispute Resolution) Group
- ADR (Alternative Dispute Resolution) Exchange Group
- ADR (Alternative Dispute Resolution) Family Group
- ELDEResolutions Group
- Fund for American Studies Group
- Lifelines Academy Group
- NAWBO-CJ (National Association of Women Business Owners-Central Jersey) Group
- NJ (New Jersey) Network Group
- NJAWBO (National Association of Women Business Owners) Group
- NVC (Nonviolent Communication) Mediation Group
- Retirement Options Group
- RU-SCI (Rutgers University School of Communication and Information) Group
- Senior Portal Group
- Stonehill College alumni Group
- UPENN (University of Pennsylvania) Fels alumni Group

Twitter

Appendix B
Study One Recruitment Flyer

Caring for Mom or Dad?
Dealing with your sibling?

Participate in a research study?

Researchers from Rutgers University are conducting a study titled

THE COMMUNICATION BEHAVIORS OF ADULT SIBLINGS WHILE CARING FOR AGING PARENTS.

We are looking for individuals that would be willing to discuss the caregiving

roles and tasks completed by them and/or their sibling(s), any uncertainties

they had about the situation and/or their relationships, and the types of

conversations that took place with their sibling(s). As a token of appreciation

for participating in the 30 – 45 minute interview, you will have the

opportunity to enter your name into a drawing for one of three $50 American

Express gift cards. If you think you would like to participate or would like to

know more about the study, please feel free to contact Teresa L. Keeler at

tlkeeler@rutgers.edu or Dr. Kathryn Greene at klgreene@rutgers.edu.

This flyer was approved by the Rutgers University IRB as of 10/01/12, Protocol #12-665M.

Appendix C
Study One Consent Form

Co-Principal Investigators: Dr. Kathryn Greene, Ms. Teresa L. Keeler
Institution: Department of Communication, Rutgers University,
        4 Huntington Street, New Brunswick, NJ 08901-1071
Phone: 732-932-7500 ext. 8115   Email: klgreene@rutgers.edu

<u>Purpose</u>: You have been asked to participate in a research project titled "The communication behaviors of adult siblings while caring for aging parents" conducted in the Rutgers University Department of Communication. The purpose of the study is to investigate adult siblings' communication with others regarding caring for an aging parent.

<u>What Will Happen</u>: During this project, you will be asked to discuss the caregiving roles and tasks completed by you and/or your sibling(s), any uncertainties you had about the situation and/or your relationships, and the types of conversations that took place between you and your sibling(s) during a 30 - 45 minute audiotaped interview. About 20 people will be interviewed.

<u>Confidentiality</u>: This research is confidential. Confidential means that the research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes demographic variables, socioeconomic variables, parental health, caregiving responsibilities, family resources, and uncertainty perceptions. Please note that we will keep this information confidential by limiting individuals' access to the research data and keeping it in a secure location.

The research team and the Institutional Review Board (a committee that reviews research studies in order to protect research participants) at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept a minimum of three years.

<u>Risk</u>: You will be asked to reflect on a time when a parent was injured or ill and you and your siblings had to negotiate care (either successfully or unsuccessfully) for that parent. If the interview brings up issues that create psychological distress of any sort, you may terminate the interview and we will provide a list of referrals for counseling. In the event that ongoing or imminent danger or abuse to self or others is reported during the interview, such information will be disclosed to the appropriate authorities

Participation in this study is voluntary. You may choose not to participate, and you may withdraw at any time during the study procedures without any penalty to you. In addition, you may choose not to answer any questions with which you are not comfortable.

Appendix C (cont.)

Benefit: Your participation in this project will help us understand the perceptions adults have and the decisions they make about conversing with their sibling(s) about caregiving. The results will add to our knowledge of the relationship between uncertainty and information management in times of transition. You will have the opportunity to obtain transcripts of your interview when they become available. Upon completion of the interview, your name will be entered (if you choose) into a drawing for one of three $50 American Express gift cards. However, you may receive no direct benefit from taking part in this study.

Alternative Procedures: There is no alternative procedure in this research project.

Further Information: If you have other questions concerning this project, please feel free to contact the Principal Investigator (PI) or the PI's faculty advisor via the above contact information or contact the IRB via the following means:

Rutgers University Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs, 3 Rutgers Plaza, New Brunswick, NJ 08901
Tel: 848-932-0150   Email: humansubjects@orsp.rutgers.edu

Your participation in this research is VOLUNTARY. Refusal to participate or withdraw during the research will incur no penalty.
Thank you for your participation.

Principal Investigator: _____ Date: _____

Participant's Name (print): _____

Participant's Signature: _____ Date: _____

This consent form was approved by the Rutgers University IRB as of 05/02/12,
Protocol #12-665M.

Appendix D
Study One Audiotape Addendum to Consent Form

I understand that this study involves the audio taping of the interview. Neither my name nor any other identifying information will be associated with the audiotape or the transcript. Only the researchers and their team will be permitted to hear to the tapes.

I understand that the tapes will be transcribed by the researcher. Transcripts of the interviews may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither my name nor any other identifying information (such as my voice) will be used in presentations or in written products resulting from the study.

I further understand that immediately following the interview I will be given the opportunity to review my transcript for accuracy.

Please check one of each pair of options.
      A.___ I consent to have my interview taped.
       ___ I do not consent to have my interview taped.

      B.___ I consent to have my taped interview transcribed into written form.
       ___ I do not consent to have my interview transcribed.

The above permissions are in effect until __June 2015__. Following that date, the tapes will be destroyed. Please check one of the following:

      C.___ I consent to the use of the written transcription in presentations and written products resulting from the study, provided that neither my name nor other identifying information will be associated with the transcript.

       ___ I do not consent to the use of my written transcription in presentations or written products resulting from the study.

_____   _____
Participant's Signature   Date

I hereby agree to abide by the participant's above instructions.

_____   _____
Investigator's Signature   Date

This addendum was approved by the Rutgers University IRB as of 05/02/12, Protocol #12-665M

Appendix E
Study One Demographic Information

Gender: ____ M ____ F

Approx. Age: _____

Race / Ethnicity: _____

Religion: _____

Marital Status: _____

Number of Children: _____

Age of Children: _____

Education Level: _____

Approx. Income: _____

Occupation: _____

Number of Siblings: _____

Appendix F
Study One Interview Schedule

I would like to ask some specific questions about caring for your parent.
1. Please describe the current health or living situation of your parent?
   a. What events led to this current situation (i.e., injury, illness, death of a spouse, general health decline, etc.)?
   b. How is your family dealing with this situation?
   c. What aspects of the situation are you most worried about?
2. Describe the caregiving roles and activities that you are doing.
3. Describe the caregiving roles and activities that your sibling(s) are doing.
   a. How are you and your sibling(s) coordinating these roles and activities?
   b. What is going well? What has been difficult?
   c. Were these roles expected? What did you hope to be different?

Think of the sibling with whom things have been most difficult during this situation.
4. Tell me about the quality of your relationship with that sibling.
5. Describe your major concerns about this sibling in regards to caregiving.
   a. How have these concerns affected your relationship with your sibling?
   b. Of the concerns identified, which ones do you feel are shared by your sibling?
   c. How are the concerns in this situation different from those you have had in the past?
   d. What are you and your sibling doing to address these concerns?
   e. Are you confident that you and your sibling can overcome these concerns?
6. What topics related to your sibling relationship do you avoid with your sibling(s)?
7. What thoughts or feelings about your sibling do you keep from your sibling(s)?
   a. Why do you keep this information from your sibling?
8. What thoughts or feelings about your sibling did you decide to share with your sibling(s)?
   a. Why did you share this information with your sibling?
   b. When did you share this information with your sibling?
   c. How was this information received by your sibling?

We are coming to the end of the interview. I have just a few more questions.
9. Moving forward, how do you foresee the relationship with your sibling?
   a. How do you feel about that?
   b. How might those feelings impact your caregiving activities?
10. What else would you like to share about the caregiving situation?
11. Is there anyone else you know that may be willing to participate in this study?

Thank you for taking the time to participate in this study. I'm turning off the recorder now.

You will now have the opportunity to find out how to get a summary of the study results and to enter into the drawing for one of three American Express gift cards.

Appendix G
Study One Debriefing Form

Thank you for taking the time to participate in this interview. Your comments provide valuable information for us to better understand adults' perceptions of the relationship with their sibling(s) during caregiving. Because most people will provide some level of care to an aging parent during their lifetime, understanding not only how people manage the uncertainties of their relationships but also how they share information regarding their relationships with their siblings is critically important.

After participating, some individuals may be interested in seeing a transcript of their interview or finding out more information (e.g., results and implications). If so, we would be glad to provide a copy of your transcript or the project results when they become available in several months. Please provide your home or email address below and return this form to us.

We would like to thank you once again for your participation. We greatly appreciate your time, effort and assistance in this study.

<u>Note</u>: Only complete if you would like to receive a summary of the results in a few months.

Home Address: _____or Email: _____

_____

_____

Dr. Kathryn Greene, Principal Investigator
Department of Communication
Rutgers, the State University of New Jersey
4 Huntington Street
New Brunswick, NJ 08901
Tel: 732-932-7500 ext. 8115
Email: klgreene@rutgers.edu

This form was approved by the Rutgers University IRB as of 05/02/12, Protocol #12-665M

Appendix H
Study One Drawing Entry Form

Sibling Study
Department of Communication
Rutgers University

Upon completion of participation in this study, your name may be entered into a drawing for one of three $50 American Express gift cards. Please choose whether you would like to be entered into the drawing or whether you decline.

_____ I choose to be entered into the drawing.

_____ I decline entrance into the drawing

If you choose to be entered into the drawing, please write your contact information below. This information will kept separate from the interview transcript.

Name: _____

Address: _____

_____

Phone: _____

Email: _____

This form was approved by the Rutgers University IRB as of 05/02/12, Protocol #12-665M

Appendix I
Study One Regional Counseling Resources

Dear Participant:

Thank you for participating in this study. If you believe that the questions asked in this study bring up issues that create psychological distress of any sort, we encourage you to seek counseling. Below is a list of resources that you may use to find a counselor in your area.

New Jersey Geriatric Care Managers
c/o National Association of Professional Geriatric Care Managers
Phone: 520-881-8008
www.njgcm.org

New Jersey Chapter of the National Association of Social Workers
Phone: 732-296-8070
www.naswnj.org

New Jersey Psychological Association
Phone: 973-243-9800
www.psychologynj.org

New York City Chapter of the National Association of Social Workers
Phone: 212-668-0050
www.naswnyc.org

New York State Psychological Association
Phone: 518-437-1040
www.nyspa.org

Pennsylvania Chapter of the National Association of Social Workers
Phone: 717-232-4125
www.nasw-pa.org

Pennsylvania Psychological Association
Phone: 717-232-3817
www.papsa.org

Appendix I (cont.)

Sincerely,

Dr. Kathryn Greene and Teresa L. Keeler
Co-Primary Investigators
Department of Communication
Rutgers, the State University of New Jersey
4 Huntington Street
New Brunswick, NJ 08901
(732) 932 - 7500 ext. 8115
klgreene@rutgers.edu
tlkeeler@rutgers.edu

This form was approved by the Rutgers University IRB as of 05/02/12, Protocol #12-665M

Appendix J
Study Two Recruitment Flyer

Caring for Mom or Dad? Dealing with your sibling?

Participate in a research study?

Researchers from Rutgers University are conducting a study titled "The communication behaviors of adult siblings while caring for aging parents." We are looking for individuals who would be willing to answer questions regarding the caregiving activities completed by them and/or their sibling(s), any uncertainties they had about the situation and/or their relationships, and the types of conversations that took place with their sibling(s).

The survey should take between 30 and 45 minutes to complete and can be accessed at http://comminfo.rutgers.edu/siblingsurvey. As a token of appreciation, you will have the opportunity to enter into a drawing for one of three $50 American Express gift cards at the end of the survey. Please contact Teresa at 908-403-7319 or tlkeeler@rutgers.edu if you have any questions or would prefer to take the survey via paper and pencil.

This flyer was approved by the Rutgers University IRB on 10/01/12, Protocol #12-665M.

Appendix K
Study Two Online Consent Form

Co-Principal Investigators: Dr. Kathryn Greene, Ms. Teresa L. Keeler
Institution: Department of Communication, Rutgers University,
            4 Huntington St., New Brunswick, NJ 08901
Phone: (848) 932-8715 or (908) 403-7319 or
Email: klgreene@rutgers.edu or tlkeeler@rutgers.edu

Purpose: You have been asked to participate in a research project titled "The communication behaviors of adult siblings while caring for aging parents" conducted in the Rutgers University Department of Communication. The purpose of the study is to investigate adult siblings' communication with others regarding caring for an aging parent.

What Will Happen: You will be asked to fill out a survey about the caregiving roles and tasks completed by you and/or your sibling(s), any uncertainties you had about the situation and/or your relationships, and the types of conversations that took place between you and your sibling(s). The survey will take between 30 and 45 minutes to complete. Up to 300 people will be surveyed.

Confidentiality: This research is anonymous. Anonymous means that the research records cannot be linked to you individually. Some of the information collected about you includes demographic variables, socioeconomic variables, parental health, caregiving responsibilities, family resources, and uncertainty perceptions. We will limit access to the data to the research team and store it in a secure location. The research team and the Institutional Review Board (a committee that reviews research studies in order to protect research participants) at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept a minimum of three years.

Risk: You will be asked to reflect on a time when a parent was injured or ill and you and your siblings had to negotiate care (either successfully or unsuccessfully) for that parent. If the survey brings up issues that create psychological distress of any sort, you may stop answering any questions. If you contact us, we will provide a list of referrals for counseling. In the event that ongoing or imminent danger or abuse to self or others is reported during the survey, such information will be disclosed to the appropriate authorities

Participation in this study is voluntary. You may choose not to participate, and you may withdraw at any time during the study procedures without any penalty to you. In addition, you may choose not to answer any questions with which you are not comfortable.

Benefit: Your participation in this project will help us understand the perceptions adults have and the decisions they make about conversing with their sibling(s) about caregiving.

Appendix K (cont.)

The results will add to our knowledge of the relationship between uncertainty and information management in times of transition. You will have the opportunity to obtain general results from the surveys when they become available. Upon completion of the survey, your name will be entered (if you choose) into a drawing for one of three $50 American Express gift cards. However, you may receive no direct benefit from taking part in this study.

Alternative Procedures: There is no alternative procedure in this research project.

Further Information: If you have other questions concerning this project, please feel free to contact the Principal Investigator (PI) or the PI's faculty advisor via the above contact information or contact the IRB via the following means:

> Rutgers University Institutional Review Board for the Protection of Human Subjects
> Office of Research and Sponsored Programs, 3 Rutgers Plaza, New Brunswick, NJ 08901
> Tel: 848-932-0150   Email: humansubjects@orsp.rutgers.edu

Your participation in this research is VOLUNTARY. Refusal to participate or withdrawal during the research will incur no penalty. Thank you for your participation.

By filling out this survey, I agree that my responses may be used for research purposes.

This consent form was approved by the Rutgers University IRB on 04/12/13, Protocol #12-665M.

Appendix L
Study Two Caregiving Burden Scale

Think of your caregiving situation. How often do you experience any of the following feelings about providing care to your parent(s)?

	Never Feel			Sometimes Feel			Always Feel
	1	2	3	4	5	6	7
a. I feel stressed trying to attend to my parent(s) as well as my job, family, and other activities	o	o	o	o	o	o	o
b. I do not have enough time for myself because of caregiving.	o	o	o	o	o	o	o
c. I wish I could delegate some aspects of caregiving to others.	o	o	o	o	o	o	o
d. I am completely overwhelmed by caregiving.	o	o	o	o	o	o	o
e. I am experiencing hardship because caregiving does not give me a sense of satisfaction.	o	o	o	o	o	o	o
f. Caregiving is difficult because I cannot find meaning in what I am doing.	o	o	o	o	o	o	o
g. I desperately need a break to regroup from caregiving.	o	o	o	o	o	o	o
h. My physical health has suffered because of caregiving.	o	o	o	o	o	o	o
i. I feel that my parent relies on me to cover many caregiving expenses.	o	o	o	o	o	o	o
j. I am struggling to have enough money to assist my parent and support myself or family.	o	o	o	o	o	o	o

Appendix M
Study Two Sibling Relational Quality Scale

Think about your overall relationship with this particular sibling and respond to the following questions.

	Strongly Disagree 1	2	3	Somewhat Agree 4	5	6	Strongly Agree 7
a. I feel responsible for my sibling's well-being.	o	o	o	o	o	o	o
b. I find it easy to ignore my sibling's faults.	o	o	o	o	o	o	o
c. I would do almost anything for my sibling.	o	o	o	o	o	o	o
d. One of my primary concerns is for my sibling's welfare.	o	o	o	o	o	o	o
e. I would forgive my sibling for almost anything.	o	o	o	o	o	o	o
f. My sibling helps me cope with problems concerning other friends or family members.	o	o	o	o	o	o	o
g. My sibling shows genuine concern for my problems.	o	o	o	o	o	o	o
h. My sibling says and does supportive things for me when I am feeling down.	o	o	o	o	o	o	o
i. My sibling makes an effort to make me feel better when I am sad.	o	o	o	o	o	o	o
j. My sibling makes it very easy to discuss my personal feelings and concerns.	o	o	o	o	o	o	o

Appendix N
Study Two Information Sharing Scale

How often do you **SHARE general or caregiving related information** with this particular sibling?

	Never Share			Sometimes Share			Always Share
	1	2	3	4	5	6	7
a. Information regarding our parent's finances.	o	o	o	o	o	o	o
b. Information on our parent's day-to-day health situation.	o	o	o	o	o	o	o
c. Information about our parent's recent medical treatments.	o	o	o	o	o	o	o
d. Information regarding our parent's future housing change.	o	o	o	o	o	o	o
e. Information regarding my recent caregiving decisions.	o	o	o	o	o	o	o
f. Information about how stressed I am regarding caregiving.	o	o	o	o	o	o	o
g. Information regarding my financial situation.	o	o	o	o	o	o	o
h. Information on my well-being or personal life.	o	o	o	o	o	o	o
i. Information on my child's well-being or personal life.	o	o	o	o	o	o	o
j. Information about if I were to move or relocate.	o	o	o	o	o	o	o
k. Information on recent job or life struggles in my family.	o	o	o	o	o	o	o
l. Information about what is most important to me in this caregiving situation.	o	o	o	o	o	o	o
m. Information about what I am most scared about in this caregiving situation.	o	o	o	o	o	o	o
n. Information on how I cannot do the things I want in this caregiving situation.	o	o	o	o	o	o	o

Appendix O
Study Two Topic Avoidance Scale

How often do you **AVOID caregiving related or general topics** with this particular sibling?
(*You deliberately choose not to bring the topic up with your sibling.*)

	Never Avoid 1	2	3	Sometimes Avoid 4	5	6	Always Avoid 7
a. Thoughts or feelings about my sibling.	o	o	o	o	o	o	o
b. Thoughts or feelings about my relationship with my sibling.	o	o	o	o	o	o	o
c. Thoughts or feelings about my sibling's spouse.	o	o	o	o	o	o	o
d. Thoughts or feelings about other family members.	o	o	o	o	o	o	o
e. Thoughts or feelings about our caregiving roles.	o	o	o	o	o	o	o
f. Thoughts or feelings about our parent's finances.	o	o	o	o	o	o	o
g. Thoughts or feelings about our parent's health and well-being.	o	o	o	o	o	o	o
h. Thoughts or feelings about our parent's recent treatments or medications.	o	o	o	o	o	o	o
i. Thoughts or feelings about my personal finances.	o	o	o	o	o	o	o
j. Thoughts or feelings about my personal health and well-being.	o	o	o	o	o	o	o
k. Thoughts or feelings about my personal milestones and / or celebrations.	o	o	o	o	o	o	o
l. Thoughts or feelings about politics or religion.	o	o	o	o	o	o	o

Appendix P
Study Two Secret Keeping Scale

How often do you **KEEP general or caregiving related secrets** from this particular sibling? (*A secret is information that is important that your sibling not find out; you actively work to keep this information hidden from your sibling.*)

	Never Share			Sometimes Share			Always Share
	1	2	3	4	5	6	7
a. Information regarding our parent's finances.	o	o	o	o	o	o	o
b. Information on our parent's day-to-day health situation.	o	o	o	o	o	o	o
c. Information about our parent's recent medical treatments.	o	o	o	o	o	o	o
d. Information regarding our parent's future housing change.	o	o	o	o	o	o	o
e. Information regarding my recent caregiving decisions.	o	o	o	o	o	o	o
f. Information about how stressed I am regarding caregiving.	o	o	o	o	o	o	o
g. Information regarding my financial situation.	o	o	o	o	o	o	o
h. Information on my well-being or personal life.	o	o	o	o	o	o	o
i. Information on my child's well-being or personal life.	o	o	o	o	o	o	o
j. Information about if I were to move or relocate.	o	o	o	o	o	o	o
k. Information on recent job or life struggles in my family.	o	o	o	o	o	o	o
l. Information about what is most important to me in this caregiving situation.	o	o	o	o	o	o	o
m. Information about what I am most scared about in this caregiving situation.	o	o	o	o	o	o	o
n. Information on how I cannot do the things I want in this caregiving situation.	o	o	o	o	o	o	o

Appendix Q
Family Communication Patterns Scale

Think about the **communication that took place with your parent** while you were growing up.

	Strongly Disagree			Somewhat Agree			Strongly Agree
	1	2	3	4	5	6	7
a. My parents often asked my opinion when the family was talking about something.	o	o	o	o	o	o	o
b. My parents encouraged us to challenge their ideas and beliefs.	o	o	o	o	o	o	o
c. My parents often said things like "You should always look at both sides of an issue."	o	o	o	o	o	o	o
d. I usually told my parents what I was thinking about things.	o	o	o	o	o	o	o
e. In our family we talked about feelings and emotions.	o	o	o	o	o	o	o
f. We often talked as a family about things we had done during the day.	o	o	o	o	o	o	o
g. In our family, we often talked about our plans for the future.	o	o	o	o	o	o	o
h. In our home, my parents usually had the last word.	o	o	o	o	o	o	o
i. My parents became irritated if my views were different from theirs.	o	o	o	o	o	o	o
j. If my parents did not approve of something, they did not want to know of it.	o	o	o	o	o	o	o
k. When I was at home, I was expected to obey my parents' rules.	o	o	o	o	o	o	o
l. My parents often said things like "My ideas are right. You should not question them."	o	o	o	o	o	o	o
m. My parents said things like "There are some things that should not be talked about."	o	o	o	o	o	o	o
n. My parents often said things like "A child should not argue with adults."	o	o	o	o	o	o	o

Appendix R
Study Two Problem Integration Measure

1. I am content with the caregiving roles that I am performing.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

2. My sibling's level of involvement in our parent's care is appropriate.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

3. I share similar values about caregiving with my sibling.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

4. My sibling understands my needs in the caregiving process.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

5. My sibling will "step up" to the caregiving challenge.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

6. My sibling does not understand the complexity of our parent's caregiving situation.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

7. Our parent's need for assistance has affected my relationship with my sibling.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

8. Future changes in our parent's care will affect my relationship with my sibling.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

9. Our different opinions about our parent's needs are hurting my relationship with my sibling.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

10. Many of our most important caregiving decisions are based on insufficient information.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

11. I know how our parent's care needs will change in the future.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

12. My sibling is aware of how our parent's care needs will change in the future.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

13. I am prepared to deal with our parent's declining health.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

14. My sibling is prepared to deal with our parent's declining health.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

15. I understand the purpose of each of our parent's treatments or medications.

	NOT Likely to be True									Definitely Likely to be True	
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

16. My sibling understands the purpose of each of our parent's treatments or medications.

	NOT Likely to be True									Definitely Likely to be True	
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

17. I would be better suited than my sibling to be our parent's primary caregiver.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

18. My sibling would rather pay someone to provide care for our parent than provide care him/herself.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

19. I am willing to accept multiple solutions to the caregiving situation.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

20. My sibling is willing to accept multiple solutions to the caregiving situation.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

21. I would choose for my parent to live closer to me than to my sibling.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

22. Caregiving helps keeps me and my sibling in contact.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

23. The outcomes of the caregiving situation are very predictable.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad					Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting					Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

24. My sibling will not help with our parent's care.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad					Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting					Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

25. My sibling and I cannot change our relationship at this stage.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

26. My sibling will never change how he or she acts.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

Appendix R (cont.)

27. My sibling is doing the best he or she can in this situation.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

28. Obtaining additional information about the caregiving situation will not make a difference.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

29. The outcome of the caregiving situation is in the hands of a higher power.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

30. I respect my sibling's caregiving decisions, even when I do not agree with them.

	NOT Likely to be True										Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

31. I am focusing on what I feel is right for my parent and my life at this time.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o

32. My sibling and I are muddling through the caregiving situation the best we know how.

	NOT Likely to be True									Definitely Likely to be True
	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
a. How likely is this to be true?	o	o	o	o	o	o	o	o	o	o	o

	Extremely Bad						Extremely Good
	1	2	3	4	5	6	7
b. How would you evaluate this?	o	o	o	o	o	o	o

	NOT Upsetting						Very Upsetting
	1	2	3	4	5	6	7
c. How upsetting is this?	o	o	o	o	o	o	o