ADAPTING TO THE NEW NORMAL:
THE PROCESS OF RELATIONAL CHANGE AFTER STROKE WITHIN ROMANTIC DYADS

BY

BRYAN ABENDSCHEIN

DISSERTATION

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Communication
in the Graduate College of the
University of Illinois at Urbana-Champaign, 2018

Urbana, Illinois

Doctoral Committee:

Professor Leanne Knobloch, Chair
Professor John Caughlin
Professor John Lammers
Professor Monica McDermott
Associate Professor Brian Ogolsky
Ms. Dawn Henry

ABSTRACT

Brain injury can introduce serious life changes for the survivor and those responsible for care. Stroke, a specific form of brain injury, has been shown to impact communication (e.g., Fridriksson, Fillmore, Guo, & Rorden, 2015) and alter behavior (e.g., Fann, Uomoto, & Katon, 2000), both of which have individual and relational consequences (see Anderson & Keating, 2017). The current study extends the literature on life after stroke by highlighting the shared experiences of relational partners post-stroke. For this study, I gathered sensitizing concepts from the uncertainty in illness theory (Mishel, 1988), the uncertainty management theory (Brashers, 2001), and relational turbulence theory (Solomon, Knobloch, Theiss, & McLaren, 2016) to investigate how couples navigated the illness trajectory after a stroke. I focused specifically on the experience of uncertainty and relational changes that individuals associated with the stroke. I utilized the pragmatic iterative approach (Tracy, 2013) to analyze the interviews I collected from 22 stroke survivors and 22 caregiving partners (complete couples $N = 20$). My results led to a model of relational changes after stroke within romantic dyads that showed couples often experienced a shift in how they saw themselves, their partner, and the relationship after the stroke. Survivors and caregiving partners also reported an ongoing sense of uncertainty that they associated with the stroke. For couples in this study, managing life after stroke involved a process of acceptance and adaptation. These findings challenge existing theory by highlighting the dyadic experience of illness and the similarities between how survivors and their partners navigate life after a stroke. The current study also suggests that more education about stroke in general, and the influence on couples specifically, is needed at the professional and community levels.

ACKNOWLEDGEMENTS

I must acknowledge that this journey was not a solo endeavor. My undergraduate advisor John Katsion set me on this path nearly two decades ago and he is still one of the biggest supporters of my academic success. April Trees, my advisor at SLU, continues to live up to the moniker of advisor and I am grateful to be a part of her academic family. Additionally, the guidance, assistance, and encouragement from my dissertation committee has been invaluable. I learned a great deal from John Caughlin who allowed me to be his unofficial mentee in teaching and research. John Lammers was really the first person to introduce me to the wealth of collaborative potential within health communication. I am grateful that he always pushed me to think more critically and speak up about the contribution of my research. Brian Ogolsky has been a constant encourager and helped me to understand that collaboration begins by forming relationships. Monica McDermott was an amazing guide through the qualitative analysis process and taught me that researchers have to make a plan and then be ready to adapt when that plan changes. Dawn Henry helped me to see the stroke community through her extraordinarily compassionate eyes and she has been a constant encourager of my research. Above all, I have to thank my advisor, Leanne Knobloch. She has read and reread my papers, met with me when I needed encouragement, and helped me to become an independent scholar. My academic identity has been shaped by her thoughtful mentorship and the ongoing investment she makes in each of her students.

I would not be where I am today without the advice and guidance of April Trees and John Katsion – mentors in every sense of the word. In addition to the academic leadership provided by so many in my life, successfully navigating graduate school would not have been possible without the support of my friends. My crew from SMS, the Captain and the Major, have believed

in me for nearly 20 years, even as I continued to fail. I often find it hard to believe how our lives have changed, but your support has never wavered. My sincere thanks to Ray Carty, my first boss and still my role model when it comes to showing up and doing what needs to be done. At the University of Illinois, my mates in Pod J and 2013 cohort companion Nikki have rejoiced with me during victories and let me be moody when I was stressed. Additionally, it was Wasserman who went above and beyond as a friend and colleague. I sent her thousands of texts and hundreds of drafts and we are STILL friends who can look back and know that we shared the Ph.D. journey together. Finally, my dear friend and fellow wizard, Audrey. I appreciate your friendship and constant encouragement no matter how many miles are between us. I genuinely appreciate the opportunity to live an honest life with you all.

This process would have been much more difficult without the unrelenting support of my family. My in-laws have been a constant source of encouragement despite me being in graduate school for nearly a decade! John, Margaret, Esther, and Jesse, thank you! My sister, Melanie, has always done her best to keep me grounded by constantly reminding me, in a loving way, that I am an idiot:) Above all, my parents have always believed that I could succeed even when that seemed unlikely in my eyes. They have demonstrated that belief through an ongoing and selfless investment in my life. I have tried to model my personal and professional personas after your example and will always be proud to have you as my parents.

Ana, what can I say? You are my best friend and have shared every step of this journey with me. We may never come this way again, so let’s see what we can see.

Fortitudine Vincimus

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION.....1

CHAPTER 2: LITERATURE REVIEW 6

CHAPTER 3: METHOD 30

CHAPTER 4: RESULTS 46

CHAPTER 5: DISCUSSION 93

REFERENCES.....136

APPENDIX A: CONSENT FORM 161

APPENDIX B: INFORMED CONSENT DISCUSSION GUIDE.....167

APPENDIX C: EMAILS TO GROUP ADMINISTRATORS.....168

APPENDIX D: STUDY FLYERS 170

APPENDIX E: INTERVIEW PROTOCOL 172

APPENDIX F: EMAILS TO POTENTIAL PARTICIPANTS 176

APPENDIX G: REMINDER EMAILS 179

APPENDIX H: THANK YOU EMAIL 181

APPENDIX I: PAYMENT INFORMATION (QUALTRICS SURVEY).....182

APPENDIX J: DESCRIPTION OF STUDY SAMPLE 183

CHAPTER 1: INTRODUCTION

The National Institute of Neurological Disorders and Stroke (NINDS, 2018), a division of the National Institute of Health, recently reported that nearly 5.3 million individuals in the United States are currently living with the ongoing effects of a brain injury, with 1.7 million new injuries reported each year. *Brain injury* is an umbrella term for events and illnesses that primarily affect the brain, ranging from blows to the head to Alzheimer's disease. Stroke is a specific form of brain injury that occurs when there is a loss of oxygenated blood to the brain due to either a clot, known as an *ischemic* stroke, or a ruptured vessel, referred to as a *hemorrhagic* stroke (Mayo Clinic, 2018). On average, 800,000 strokes occur each year in the United States, with ischemic stroke being the most common and making up 87% of all reported cases (American Stroke Association, 2018a). Additionally, the Centers for Disease Control and Prevention (CDC) reports that 75% of strokes occur in people who have never had a stroke before (Mozaffarian et al., 2015).

Stroke is often a life-changing medical condition with far reaching implications. The United States spends over $36 billion a year on stroke related treatment through health expenditures, productivity loss, and long-term disability (Go et al., 2014). To address the growing prevalence of stroke related issues, the National Institutes of Health (NIH) reported that $288 million were spent on stroke research grants in 2015. Many of the NIH funded studies were focused on prevention and management of the physical obstacles associated with stroke such as paralysis and aphasia (see NINDS, 2018; e.g., Shoamanesh et al., 2016; Sullivan, Walenski, Love, & Shapiro, 2017). Although the physical outcomes of stroke have received a great deal of attention (e.g., Hesketh, Long, & Bowen, 2011; Kelly-Hayes et al., 1998; Ross & Wertz, 2002), the occurrence of a stroke can also contribute to interpersonal challenges as relational partners

manage the cognitive and communicative issues that often accompany this brain injury (Esptein-Lubow, Beevers, Bishop, & Miller, 2009; Winkler, Bedford, Northcott, & Hilari, 2014).

Stroke as a Cause of Relational Change

Scholarship located at the intersection of health research and relationship research links a broad array of medical conditions and social components. Medical researchers have investigated how individuals attempt to manage the various stressors associated with both chronic and acute conditions including cancer (Wortman & Dunkel Schetter, 1979), HIV (Alonzo & Reynolds, 1995, Brashers et al., 2000), heart attacks (Stewart, Davidson, Meade, Hirth, & Makrides, 2000), and dementia (Unson, Flynn, Glendon, Haymes, & Sancho, 2015). Stroke survivors face the possibility of long-term paralysis, speech impediments, and/or cognitive impairments (DeLaune & Brown, 2001; Tham et al., 2002). The effects of individually-situated stressors are not, however, confined to the stroke survivor.

Relational changes are commonly associated with times of serious illness. Relationship level stressors are salient in couples suffering from cancer (Weber & Solomon, 2008), infertility (Steuber & Solomon, 2008), and depression (Knobloch & Delaney, 2012). The combination of research that explores the outcomes of illness from medical and relational perspectives reveals that periods of illness can contribute to changes at both the individual and the relational levels. For example, changes may influence interpersonal behaviors, including avoiding specific topics of discussion (Venetis, Magsamen-Conrad, Checton, & Greene, 2014) or managing new relational roles (Banks & Pearson, 2004). Banks and Pearson (2004) found that during the lengthy recovery from a stroke, young partners wrestled with the challenges of new household responsibilities and altered relational activities, both of which added additional stress to the rehabilitation process. In a study of how stroke may affect couples across the lifespan, McCarthy

and Bauer (2015) used qualitative data to show that there may be practical, emotional, and relational changes for both partners due to stroke. Additionally, scholars have also worked to frame stroke as a dyadic issue that impacts the lives of both the survivor and caregiver (McCarthy, Powers, & Lyons, 2011), although the perceived changes may be viewed differently by each partner (McCarthy & Lyons, 2015). Since the potential outcomes of stroke include partner effects and relational changes (Abendschein, 2018; Hesketh, Long, & Bowen, 2011; Lurbe-Puerto, Leandro, & Baumann, 2012; Scarinci, Worrall, & Hickson, 2009), it is important to include the perspectives of survivors and partners in research that explores how people negotiate illness-related challenges.

Stroke as a Stimulus for Uncertainty

Uncertainty is a normal, yet often influential, part of the illness experience (Babrow, Kasch, & Ford, 1998). Scholars have moved from a largely individualistic, highly contextualized perspective of uncertainty to a process driven approach that highlights the ways people encounter, appraise, and manage uncertainty (Brashers, 2001; Budner, 1962; Mishel, 1988). *Uncertainty*, as defined in this project, follows Mishel's (1984) conceptualization in her uncertainty in illness theory as a person's ability to make sense of, or appraise, the meaning of stressful stimuli. Managing the various uncertainties that emerge across the illness trajectory is a complex process (Mishel, 1990). Scholars have put forward theories that seek to explain various responses to periods of uncertainty (e.g., Brashers, 2001; Mishel, 1988; Solomon & Knobloch, 2004), but as Brashers (2001) noted, "the appropriateness and effectiveness of responses used to manage [uncertainty] are likely to vary across contexts and situations" (p. 481).

Stroke may spark serious life changes that heighten uncertainty for both survivors and caregivers (Brandon, 2013). For example, the physical and cognitive outcomes of a stroke can

affect an individual's ability to move effectively and/or communicate clearly (Kelly-Hayes et al., 1998). These stressors are often major hurdles for individuals and can contribute to feelings of uncertainty, isolation, and depression (Abendschein, 2018). Stroke is a medical condition replete with uncertainty as questions about various topics take shape over time (e.g., "Will I ever be able to walk again?" "How can we have a relationship if I can't understand what she is saying?"). The uncertainties that arise after a stroke may contribute to the already traumatic experience of putting a life back together, which can take years and require changes to relational goals and norms (Banks & Pearson, 2004). Studying how people manage uncertainties they associate with stroke is important because their responses to uncertainty have both individual and relational consequences.

Illness-related stressors influence relational behaviors and contribute to experiences of uncertainty. For example, partners report struggling to manage conflicting schedules (Weber & Solomon, 2008), co-construct new relational norms (Abendschein, 2018), and adapt to altered communication patterns (Carlsson, Hartelius, & Saldert, 2014). Although medical researchers and social scientists have begun to develop and utilize theory to explore the intersection between interpersonal communication and illness-related stressors (Brashers et al., 2000; Harvey-Knowles & Faw, 2016; Mishel et al., 2009), researchers must continue to look beyond the pathology of illness to the relational implications involved with the occurrence, treatment, and recovery from stroke.

Conclusion

Studies that exist at the intersection of relationship research and therapeutic medicine have the potential to produce more nuanced knowledge of individual and relational health outcomes associated with stroke. A better understanding of how people communicate to adapt to

the combination of illness and relational stressors in the wake of a stroke is, to date, underexplored. Therefore, the goal of my dissertation is to investigate relational change and uncertainty management within romantic couples after a stroke. I conducted in-depth, semi-structured interviews to gather narrative accounts of how people perceive their relationship after a stroke and how they navigate various sources of uncertainty. I utilized Tracy's (2013) *pragmatic iterative approach* to data analysis that allowed me to alternate "between emic, or emergent, readings of the data and etic use of existing models, explanations and theories" (p. 184). In the chapters that follow, I outline sensitizing theories, discuss their key assumptions, and unpack their guiding concepts that shaped this study. Each theory (a) contributed a unique element to my study's conceptual framework regarding appraisal and management of uncertainty within a relationship, and (b) led to a research question to advance theory, research, and practice. I used qualitative data to build a theoretical model that maps the process of how people conceptualize their relationship and manage the uncertainties they associate with stroke.

CHAPTER 2: LITERATURE REVIEW

Discussions concerning relational change and individual abilities after a stroke are prevalent among stroke survivors and caregivers (Abendschein, 2018). Research has found that one potential outcome of major medical conditions, such as stroke, is an increase in relationship-level stressors caused by altered routines and new responsibilities for care. Times of transition may also give rise to relational uncertainty and shape the way individuals communicate with each other (Carlsson et al., 2014; Nagy & Theiss, 2013). Additionally, how a couple manages the challenges that arise during life-changing events can have implications for both relational satisfaction and relational duration (Badr & Acitelli, 2005; Weber & Solomon, 2008). Other studies have shown that an individual's "personal disposition [and] global orientation to life," also known as one's sense of coherence, can also influence the relational experience after a stroke (Forsberg-Wärleby, Möller, & Blomstrand, 2002, p. 128). Exploring the connections between how partners conceptualize stressors and how they view the influence of those stressors on their relationship may help scholars better understand the ramifications of stroke beyond the individual health outcomes (Acitelli, 1988; Brashers et al., 2000; Cahill, LoBiondo-Wood, Bergstrom, & Armstrong, 2012).

Survivors, partners/caregivers, and the medical community often discuss the aftermath of stroke in terms of a person's physical or cognitive ability, but there is more to the equation. The potential outcomes of a stroke also include health and relational changes for partners. Individuals must navigate new roles, altered norms, and communication difficulties (Blonder, Langer, Pettigrew, & Garrity, 2007; O'Connell & Baker, 2004). The unique relational dynamic created from both partners negotiating illness-related stressors makes it important to consider the dyadic consequences of stroke as well (e.g., Grawburg, Howe, Worrall, & Scarinci, 2014; Hesketh et al.,

2011). In the sections that follow, I discuss the sensitizing concepts and theories that informed this project. I also offer corresponding research questions shaped by gaps in the literature that guided this study.

Stroke as an Individual and Relational Phenomenon

Stroke is a type of brain injury that can have ramifications for individuals and relationships beyond physical and mental impairment (Radcliffe, Lowton, & Morgan, 2013). Restricting blood to any part of the brain can cause long-term consequences, but the effects of stroke vary due to a number of factors, including the specific infarct area, the type of stroke, and even the treatment received (Narushima, Chan, Kosier, & Robinson, 2003). Research indicates that individual outcomes of a stroke may include impaired speech (Fridriksson, Fillmore, Guo, & Rorden, 2015), increased aggression (Fann, Uomoto, & Katon, 2000), limited memory (Tatemichi et al., 1994), and clinical depression (Jorge, Robinson, Starkstein, & Arndt, 1993). Relationally, stroke may correspond with role adjustments (Banks & Pearson, 2004), partner satisfaction (Blonder et al., 2007), and relational changes (Hunt & Smith, 2004). The ability to differentiate and assess the ways a stroke can change relational communication might help researchers design more targeted interventions for both stroke survivors and their partners. In the subsections that follow, I elaborate on the effects of stroke at both the individual and the relational levels.

Individual effects of stroke. The most prevalent outcome of a stroke related to one's ability to speak is aphasia. *Aphasia* is a physical symptom of brain injury that impairs a person's capacity for language and is experienced by approximately 30% of patients after a stroke (National Aphasia Association, 2017; Papathanasiou, Coppens, & Patagas, 2016). There are four categories of aphasia based on the patient's communication ability: (a) *global aphasia* is the

most severe and is marked by a person's complete inability to communicate; (b) *expressive aphasia* or *Broca's aphasia* is marked by a person's struggle to articulate thoughts verbally; (c) *receptive aphasia* or *Wernicke's aphasia* is recognized as an individual's inability to understand what is being said; and (d) *anomic aphasia* is when a person has difficulty using the right words for various objects (Fridriksson et al., 2015; Jordan & Kaiser, 2013; NINDS, 2016). Although much is known about the structural implications of aphasia on communication ability, research on how the condition affects relationships and how the outcomes differ from those introduced by diminished cognitive functioning (i.e., dementia) is still developing (Carlsson et al., 2014; Fotiadou, Northcott, Chatzidaki, & Hilari, 2014; McGurk, Kneebone, & Pit ten Cate, 2011).

Location of the stroke in the brain is important. The outcomes of a stroke are different depending on whether the injury occurred in the right or left hemisphere of the brain (Foerch et al., 2005). In fact, the American Stroke Association (2018a) broadly articulates the main differences between left / right side brain injuries. They note that the outcomes of a stroke on the right side of the brain can result in left side paralysis, impaired vision, and a more engaged behavioral style. A stroke on the left side of the brain can contribute to right side paralysis, impaired communication, and a more reserved behavioral style. The distinction between left / right stroke location is important to note because different locations can contribute to different physical, social, and cognitive effects.

Two intertwining themes surrounding the cognitive implications of stroke are vascular dementia and depression (Khan, Kalaria, Corbett, & Ballard, 2016). *Dementia* has different diagnostic criteria based on the source one consults, but in the broadest sense the concept is understood to encompass any measurable mental decline over time (Erkinjuntti, Østbye, Steenhuis, & Hachinski, 1997; Gustafson, 1996). Specifically, *vascular dementia* is diminished

cognitive ability related to cerebral infarctions, which are areas of the brain that have died because they were deprived of oxygenated blood (Román, Erkinjuntti, Wallin, Pantoni, & Chui, 2002). The cognitive and emotional effects of vascular dementia appear to be significant, but are not thoroughly cataloged. *Depression* is also a commonly diagnosed disorder in people who have suffered a stroke (Jorge et al., 1993), yet the ramifications of such a diagnosis have been framed as a moderator for other stroke related issues. For example, studies have linked major depression in stroke survivors to slower recovery times (Kimura, Robinson, & Kosier, 2000), increased social anxiety (Jorge et al., 1993), and greater mental impairment (Narushima et al., 2003). The literature indicates that the mental and emotional effects of stroke might be far-reaching and long lasting (Godwin, Swank, Vaeth, & Ostwald, 2013; Lurbe-Puerto et al., 2012; Swardfager & MacIntosh, 2016; Wolfe, 2000).

The occurrence of severe brain trauma, including stroke, can introduce personality changes while still leaving the individual able to function physically. The disconnect between a person fading away mentally while remaining tangibly present is one example of *ambiguous loss* (Boss, 2004). Ambiguous loss is defined as unresolved grief from either (a) someone being physically present, but psychologically absent, or (b) someone being physically absent, but psychologically present (Boss, 2010). Researchers have found that ambiguous loss exists in post-brain injury relationships as a multifaceted experience where people may struggle with both the loss of a securely established relational connection and the loss of the future the couple had planned (Godwin, Chappell, & Kreutzer, 2014; Kreutzer, Mills, & Marwitz, 2016). For example, Boss (2010) interviewed partners of dementia patients and found that the "ambiguity surrounding the psychological loss" due to the disease led to anxiety, depression, and a "roller coaster experience" for the caregiving *partner* that exacerbated an already difficult situation (p. 138).

Stroke *survivors* may also struggle with ambiguous loss as they work to retain or regain their sense of self (Murray & Harrison, 2004) or individual identity (Radcliffe et al., 2013). The unknowns that can be introduced by stroke may lead people to wrestle with questions about their own, as well as their partner's, health and wellbeing.

Research suggests that serious cognitive or physical changes due to illness can have a negative effect on the health of a partner. In 2001, the World Health Organization (WHO) introduced the idea of *third-party disability* in the International Classification of Functioning, Disability and Health (ICF) as an area for future research. Third-party disability refers to the diagnosis of an illness in one partner as the result of the medical condition of the other partner (World Health Organization, 2001). It was not until 2009 that researchers attempted to explore third-party disability by linking a hearing impairment in one person to a similar disability in a partner (Scarinci et al., 2009). Likewise, the coexistence of physical and cognitive effects of a stroke and new or worsening health conditions in a partner have been documented, but not yet causally linked (Grawburg et al., 2014). For example, Grawburg et al. (2014) found that individuals attributed several medical conditions, "including depression, anxiety, vertigo, ulcer, hypertension, and mental health changes" (p. 1187), to living with a partner diagnosed with aphasia, often after a stroke. The medical community recognizes that illness impacts partners in profound ways, so scholars continue to examine how an individual's health has implications for his or her partner.

Relationship effects of stroke. Communication ability influences relational assessments after a stroke. Maintaining interpersonal connections is important, but the loss of speech or comprehension of language makes interacting difficult for both partners and may even change the way partners view one another or perceive each other's actions (Croteau & Le Dorze, 2001).

For example, a study by Croteau and Le Dorze (2001) found that when people with aphasia were compared to others without the disorder, those with aphasia were found to have less ambition, struggle with organization, and be liked less. Clark and Stephens (1996) found a connection between the wellbeing of stroke patients and how helpful they perceived their partner's actions to be. When they perceived their partner's actions as unhelpful, stroke survivors reported perceiving themselves and their spouses more negatively. Additionally, McGurk and Kneebone (2013) conducted a review of the literature on informal caregivers of people living with aphasia and found that communication difficulties, role changes, and relational issues were common stressors among stroke survivors and their partners. Their study showed that the stressors associated with caring for a partner might also negatively influence perceptions of the relationship, especially when there are other elements present including negotiating healthcare or seeking social support.

How people manage stroke-related stressors has important ramifications for relationships. Altered routines and new responsibilities for care may be directly linked to both cognitive and communicative functioning (Blonder et al., 2007; Epstein-Lubow, Beevers, Bishop, & Miller, 2009), as well as the way individuals interact within the relationship (Weber & Solomon, 2008). In fact, how couples talk about, or frame, the challenges that arise during life altering events can have implications for whether or not they are able to manage, or co-own, those stressors (Badr & Acitelli, 2005; Mishel, 1988; Weber & Solomon, 2008). In addition, a study on family caregivers and stroke survivors showed that when stressors outnumber instances of satisfaction in the relationship, both partners experienced a decrease in well-being (Kinney, Parris Stephens, Franks, & Norris, 1995). Researchers have also found that both survivors and caregivers are at an increased risk for "post-stroke depression" (PSD; McCarthy, Lyons, & Powers, 2012). Stress due

to life changes can influence relationships in different ways including quality of life changes (Tellier, Rochette, & Lefebvre, 2011), outlook on the future (McCarthy & Bauer, 2015), shared relational identity (Radcliffe et al., 2013), and a changing dynamic in the relationship (Han & Haley, 1999). Research on the relational consequences associated with stroke may help scholars differentiate outcomes due to stroke and those due to other factors (e.g., Fotiadou et al., 2014). This line of research also advances theory development and practical treatment focused on how partners negotiated life after stroke as a couple.

Unraveling the interconnectedness of individual and relational questions that emerge in the wake of a stroke is necessary for developing future research as well as tailored interventions. The process of understanding how romantic partners explain the process of navigating life before, during, and after stroke begins with examining the effects that they associate with stroke. The way couples talk about their response to stroke, the hardships, the victories, and the changes is an important first step in developing a theoretical model of the relational process. The following research question addresses the first component of this project:

RQ1: What do survivors and partners report as the effects of stroke, if any, on their relationship?

Uncertainty Theories and Sensitizing Concepts

Uncertainty is central to the experience of illness (Babrow et al., 1998). In fact, the ways uncertainty affects people during times of illness has a long history of scientific inquiry and clinical application. In the mid-twentieth century, the literature framed uncertainty as an amorphous construct, largely based on contextualized, individual experiences (e.g., Budner, 1962). The uncertainty in illness theory (UIT) broadened the theoretical scope to include an *appraisal process* that was situated as a central construct between the *antecedents* and *outcomes*

of illness-related stressors (Mishel, 1981, 1984, 1988). Brashers (2001) proposed the uncertainty management theory (UMT) as an elaboration of the process people go through as they select communicative strategies to *manage* their uncertainty from various sources. He noted that theories of uncertainty management should recognize that "uncertainty is multilayered, interconnected, and temporal," all of which may influence the communication competence of those seeking to manage their uncertainty (p. 481). Solomon et al. (2016) focused on how relationships change over time through the relational turbulence theory in which *relational uncertainty* is articulated as a specific form of uncertainty (Knobloch & Solomon, 1999). Each of the aforementioned theories and concepts offers an important sensitizing element to this project: UIT theorizes about the process people go through as they encounter and *appraise* the unknowns associated with illness (Hong & You, 2016; Mishel, 1988, 1990), UMT offers a way to frame the communicative element of how people manage specific *sources* of uncertainty (Brashers, 2001; Brashers, Basinger, Rintamaki, Caughlin, & Para, 2016), and relational turbulence theory emphasizes the dyadic interplay of *relational issues* over time. In the subsections that follow, I discuss the sensitizing elements of each theory to show how they contributed to the construction and implementation of this research project.

Uncertainty in illness theory. UIT emphasizes the relationship between uncertainty and stress (Mishel, 1988, 1984, 1990). *Uncertainty* was conceptualized by Mishel (1988) as neutral, neither inherently good or bad. She defined the construct as one's inability to make sense of, or appraise, the meaning of illness-related events. The more that people are able to make sense of contextualized events, or stimuli, the less uncertainty they experience. Central to the theory is Mishel's (1988) notion of *uncertainty appraisal*, which outlined how individuals evaluate and respond to questions they classify as a danger or an opportunity. A *danger* appraisal means that

the uncertainty is undesirable and thus leads to behaviors aimed at reducing the uncertainty. In contrast, uncertainty appraised as an *opportunity* leads to behaviors that either increase or maintain uncertainty. An appraisal of uncertainty as an opportunity has been studied in individuals with chronic illnesses where a negative outcome is likely (i.e., negative certainty), so uncertainty about a diagnosis or timeline of the illness is preferred (Mishel, 1988, 1990). Empirically, Mishel (1981) framed uncertainty as a measurable process of cognitive appraisals and specific behaviors that come about in response to stressful life experiences associated with illness. The *model of perceived uncertainty in illness* maps the progression of uncertainty as it is shaped by environmental stimuli, influences cognitive appraisals, and inspires behavioral adaptation (Figure 2.1). Mishel (1988) also noted that uncertainty is a cognitive and behavioral process shaped by the individual and may be considered as harmful (i.e., uncertainty should be decreased) or helpful (i.e., uncertainty should be maintained).

***Model of perceived uncertainty in illness*.** The model of perceived uncertainty in illness involves a temporal progression individuals navigate as they encounter, evaluate, and act upon experiences of uncertainty in illness (Mishel, 1988; Figure 2.1). First, the *stimuli frame* contains individual and contextual variables that act as antecedents to the appraisal of uncertainty. Mishel (1988) presents three components of the stimuli frame: symptom pattern, event familiarity, and event congruency. *Symptom pattern* refers to the degree to which the individual is able to discern a pattern of symptoms based on regularity, intensity, and duration. Patterns related to symptomatology have been linked to the experience of uncertainty (Mishel & Braden, 1988). When there is a regularity to symptoms, the illness seems less mysterious and patients experience less uncertainty. In contrast, when the symptoms fluctuate in duration or intensity, the lack of consistency may lead to greater uncertainty, or an appraisal of the uncertainty as

dangerous. Closely related to symptom pattern is *event familiarity*, an element of the stimuli frame that refers to contextual elements or experiences within a specific healthcare environment. New physicians, different tests, or even a change in medicine can increase novelty and lead to a change in how a person appraises uncertainty (Budner, 1962; Mishel, 1981). For example, the experience of having an MRI for the first time may generate increased levels of uncertainty since the experience is new and unfamiliar. The third element of the stimuli frame, *event congruency*, is the degree to which an event matches an individual's expectations. If, for example, a cancer patient is told that the chemotherapy drug will not cause hair loss, but then the patient begins losing hair, the experience may lead to an increase in uncertainty since the outcome did not align with expectations. Connected to the three elements of the stimuli frame, and conceptualized as an antecedent to an uncertainty appraisal, is *cognitive capacity*. Mishel (1988) draws from Mandler (1979) to make the case that stress and pain can affect cognitive ability and thus make it more difficult to understand and manage information associated with event related stimuli. The stimuli frame and cognitive capacity work together as an evaluative mechanism of internal and external cues that directly influence a person's appraisal of illness-related events (Mishel, 1988).

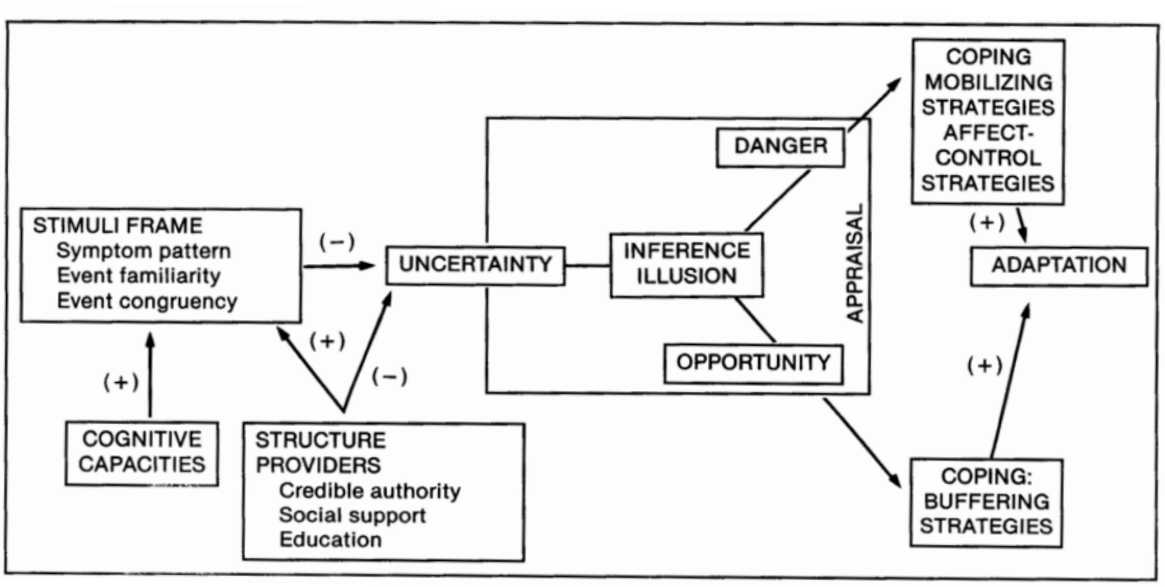


Figure 2.1. Model of Perceived Uncertainty in Illness (Mishel, 1988).

The model of perceived uncertainty in illness also includes *structure providers* as antecedents to stimuli interpretation and uncertainty appraisal. Mishel (1988) identifies three structure providers: credible authority, social support, and education. *Credible authority* is the degree to which a healthcare professional is trusted or instills confidence in patients. The more credible a healthcare professional appears, the more the stimuli frame is enhanced, which leads to less uncertainty. For example, if an individual experiences intermittent headaches, but is tested and deemed healthy by a medical professional, the patient may give less credence to the stimuli of symptom pattern and experience less uncertainty based on the credibility of the physician's diagnosis. Another structure provider is *social support*, or the network in which individuals share information, receive clarification, and maintain emotions in an effort to make sense of an illness (Goldsmith, 2015; Mishel, 1988). Friends and family act like a sounding board to confirm, deny, or alter elements of the stimuli frame and in doing so influence the appraisal of uncertainty (e.g., "You've had a CT scan and that is very similar to an MRI. There is nothing to worry about."). Finally, *education* is listed in Mishel's (1988) model as providing structure to the uncertainty

appraisal process. Education, according to UIT, allows individuals to situate experiences within a broader context and decipher more complex stimuli. The structure providers in the model of perceived uncertainty in illness offer a moderating effect between stimuli and how people evaluate uncertainty.

The next step in the temporal order of Mishel's (1988) model of perceived uncertainty in illness is the appraisal itself (see Lazarus & Folkman, 1984). Individuals determine if uncertainty is potentially harmful or helpful during the appraisal process. Uncertainty appraisals are first filtered through the cognitive processes of inference and illusion. *Inference* refers to the assessments people make about stressful situations based on the confidence they have in their skills or resources to approach and manage uncertainty (Mishel, 1988). Inferences allow individuals to conceptualize stressful events as manageable based on individual characteristics (e.g., "I can do this because I'm a strong person"). In contrast, *illusion* is a cognitive activity that refers to beliefs that are a product of redefining uncertainty to focus exclusively on the positive. Illusion is often associated with negative uncertainty, or knowing things are not going to get better. Uncertainty, when viewed through illusion, offers a way to generate optimism by ignoring negative possibilities and constructing an alternate reality of hope (e.g., "The results were inconclusive. If they can't find the tumor that must be a good thing."). It is through the frames of inference and illusion that individuals appraise uncertainty as danger, something to be reduced, or opportunity, something to be maintained or increased (Mishel, 1988,1990).

Once an appraisal is made, the next step is to take appropriate action. Implementing specific strategies that help people adapt to experiences of uncertainty is a necessary element of sense making (Mishel, 1990). The bifurcated response to uncertainty as a danger or opportunity influences the action strategies people utilize. Mishel (1988) argued that an appraisal of

uncertainty as dangerous could lead individuals to employ one of two sets of coping strategies: mobilization or affect control. *Mobilization* strategies focus on taking charge of the uncertainty through "direct action, vigilance, and information seeking" (Mishel, 1988, p. 230). A first response to uncertainty characterized as dangerous is to reduce the uncertainty by taking charge, staying engaged, or learning more about the stressors. A secondary method, *affect control*, utilizes "faith, disengagement, and cognitive support" (Mishel, 1988, p. 230). Uncertainty appraised as an opportunity leads to different behaviors. Maintaining the desired level of uncertainty might encourage individuals to use *buffering* strategies, including avoiding information to cope with ongoing uncertainty. Mishel (1988) noted that individuals who are able to successfully use mobilizing, affect control, or buffering strategies to manage their uncertainty appraisals will achieve *adaptation*, or an adjustment of one's "defined range of usual behavior" (p. 231). The process of uncertainty in illness involves both the cognitive work to appraise the uncertainty and the enactment of specific behaviors in an effort to adapt to the unknown (Mishel, 1990).

Appraisal precedes action, so an important aspect of my dissertation project is to explore the potential avenues of cognitive appraisals that people make when confronted with uncertainty. Identifying the mobilization strategies that survivors and partners choose to employ will help scholars and healthcare professionals better understand the resources couples may need after a stroke. A model of relational actions that flow from managing stressors associated with the stroke begins with an exploration of the appraisals people make. My second research question addresses the role of appraisals:

RQ2: How do survivors and partners appraise uncertainty after a stroke?

***Reconceptualized uncertainty in illness theory*.** Chronic uncertainty, according to Mishel (1990), changes people. UIT was designed to study how individuals construct meaning during acute phases of an illness (Mishel, 1988), but was found to be lacking in application among people with chronic illnesses. Mishel (1990) responded to critiques that UIT only focused on episodic uncertainty and not the experience of living with ongoing uncertainty by proposing the reconceptualized uncertainty in illness theory (RUIT). The model of perceived uncertainty in illness was reevaluated and the *outcomes portion* (i.e., from appraisal to adaptation) was tweaked to reflect the possible effects of chronic uncertainty. UIT originally approached the uncertainty appraisal as a onetime process. According to UIT, people's ability to manage illness-related stimuli is influenced by their cognitive capacity and contextual structures (Mishel, 1988). The theory does not, however, make allotments for uncertainty appraisals to change over time. RUIT contains all of the elements of UIT, but it elaborates on how individuals respond to prolonged exposure to uncertainty by achieving a *new state* that involves a more complex view of reality (Mishel, 1990). When people are required to manage stress for a prolonged period, Mishel (1990) argues, "patients attempt to integrate the experience of chronic uncertainty into their self-structure" (p. 260). In other words, chronic uncertainty leads people to fundamentally change their self-concept. Reevaluating uncertainty and changing one's outlook, as outlined in RUIT, is necessary if ambiguity has become a way of life and not simply a momentary experience.

***Limitations*.** UIT does not contain a mechanism to consider how multiple sources of uncertainty interact as couples engage in the appraisal process. Mishel (1988) envisioned a theory that encompassed how individuals, specifically, managed one source of uncertainty generated by illness-related stressors. RUIT was used to expand the model to include chronic illness as a source of ongoing uncertainty (Mishel, 1990), but neither UIT or RUIT allowed for

uncertainty appraisals or management to be influenced by other sources of uncertainty, or the interaction between partners throughout the process. Research using UIT explicitly focuses on how people generate uncertainty appraisals directly related to illness and how those appraisals change over time (e.g., Unson et al., 2015; White, Barrientos, & Dunn, 2014). Neither theory allows for much deviation from the expressed goal of understanding how people make sense of their own illness-specific stressors. There is, however, a great deal more to consider when studying the uncertainty management process, even in the context of illness. Research on the illness trajectory, for example, has shown that individuals often struggle with multiple stressors including navigating a new identity (Weber & Solomon, 2008), engaging in social support (Fisher, 2010), and managing relational uncertainty (Harvey-Knowles & Faw, 2016). The lack of attention to multiple stressors that might be associated with the illness trajectory, or how partners navigate the potentially turbulent time, has encouraged scholars to continue to expand, explore, and apply the central tenets of UIT (Brashers, 2001).

Uncertainty management theory. UMT, also known as the theory of communication and uncertainty management, has been used to explore various sources and responses to uncertainty directly and indirectly related to illness. Brashers (2001) focused on how *communication behaviors* influence uncertainty appraisal and coping strategies during times of illness. For example, UMT has been used to study how individuals encounter, make sense of, and manage uncertainty associated with HIV treatment (Brashers et al., 2000), cervical cancer (Cohen et al., 2016), organ transplant (Scott, Martin, Stone, & Brashers, 2011), and cystic fibrosis (Dillard & Carson, 2005). UMT shares some central tenets with UIT, but also diverges in its focus on multiple potential sources of uncertainty and the communicative behaviors people use to manage that uncertainty.

Uncertainty is not inherently negative or positive, making it a complex experience. Scholars have repeatedly rejected the notion that uncertainty is somehow negatively valenced, and thus prefer to represent the construct as a cognitive state that requires attention (Brashers, 2001; Budner, 1962; Lazarus, 1974; Mishel, 1984). Both UIT and UMT frame uncertainty as the "inability to determine meaning" (Mishel, 1988, p. 225), which creates an experience of "ongoing appraisal and management" (Brashers & Hogan, 2013, p. 1242). Whereas the authors of UIT attribute uncertainty exclusively to illness-related stimuli, UMT was constructed to explore the complexity of uncertainty from multiple sources.

***Sources of uncertainty*.** The idea that illness was a standalone stressor was short lived. Babrow et al. (1998) proposed challenging the framework of thinking about uncertainty in illness as unidimensional. Around the same time, Brashers, Neidig, Reynolds, and Haas (1998) began to explore the possibilities of various sources of uncertainty individuals may encounter across the illness trajectory. They expanded the conceptualization of uncertainty in illness to contain "physical, psychological, and social sources of uncertainty" (p. 74). Brashers et al. (2003) used data gathered from interviews with HIV patients to show that there were in fact medical, personal, and social sources of uncertainty associated with illness. The research team found that *medical* sources of uncertainty include ambiguous elements situated within the healthcare context including appointments, tests, and treatments. *Personal* sources of uncertainty emerged as individuals managed diverse and often conflicting roles that can include being both a patient and being an employee. Finally, the *social* sources of uncertainty associated with having HIV involved navigating the stigma of the disease and not knowing what information to share with others. Uncertainty within interpersonal health situations is a complex experience that arises from various sources.

Brashers et al. (2003) conceptualized uncertainty as emerging from medical, personal, and social sources, but investigating the unique sources of uncertainty people associate with stroke will help scholars focus their attention on specific areas. The sources of uncertainty are important to identify as both a critical element of a theoretical model and to better understand how people think about the uncertainties they associate with stroke. The following research question is meant to probe that aspect of uncertainty management:

RQ3: What sources of uncertainty, if any, do individuals report experiencing after a stroke?

Experiencing uncertainty is just one aspect of the uncertainty management process. UIT and UMT both emphasize illness-related stressors as the antecedents for various uncertainty appraisals and the specific behaviors driven by those different appraisals (e.g., information seeking / avoiding). Brashers and colleagues (2000), for example, placed an emphasis on exploring the communicative strategies individuals use to manage various aspects of the appraisal process. In fact, the two assumptions that guided the seminal study by Brashers et al. (2000) were built on the idea that uncertainty is an evaluative process that leads to various behaviors. The reason people consider their uncertainty is to find meaning (Mishel, 1884, 1988), and once appraised, communication is used to conceptualize uncertainty within a desired frame (Brashers, 2001). In other words, uncertainty management is an intentional, evaluative process toward a specific goal.

Within UMT, uncertainty can be appraised as dangerous, as an opportunity, or as inconsequential. The addition of the third category, *inconsequential*, deviates from UIT's two categories by adding more tracks to the appraisal process. Scholars utilizing UMT in their work have emphasized the importance of information as a tool to help people evaluate their

uncertainty (Brashers & Hogan, 2013). For example, if uncertainty about a specific diagnosis is appraised as dangerous (i.e., uncertainty is undesirable), an individual might seek information from experts about what to expect as the illness progresses in an effort to *reduce* uncertainty. If, however, the uncertainty of a particular diagnosis is appraised as an opportunity (i.e., uncertainty is desirable), an individual may seek information about success stories and avoid information that would disrupt their "fragile optimism" (Mishel, 1988, p. 231). The first step is the appraisal of uncertainty, and the next step is managing information to achieve a particular goal to support the appraisal: reduce, increase, or maintain one's current level of uncertainty.

***Limitations*.** UMT expanded the notion of uncertainty associated with illness as being multi-layered (Brashers, 2001), but continued to focus on individual outcomes. Researchers have, however, begun to explore the idea that managing illness-related stressors is a dyadic process with relational implications. For example, in studies where partners discussed the physical and cognitive effects of illness as *co-owned*, relational satisfaction increased and led to more favorable assessments of their relationship overall (e.g., Acitelli & Badr, 2005). The way couples discuss stressors during times of illness may influence uncertainty appraisals and mediate the adaptation phase as noted in UIT (Mishel, 1988). The individual is an important aspect of the uncertainty management process, but without considering the relationship between partners, scholars may be missing part of the equation.

Relational turbulence theory. As relationships encounter periods of change, whether positive or negative, planned or unplanned, there is an opportunity for relational reorganization (e.g., Harvey-Knowles & Faw, 2016; Knobloch & Theiss, 2012). To better understand experiences of transition in relationships, *relational turbulence theory* focused on substantive changes to the relational structure initiated within the dyad or by an external source (Solomon et

al., 2016). Studies have shown that as relationships change, *interdependence* between partners, which includes assessments of influence, interference, and facilitation from partners, may change as well (Knobloch & Solomon, 2002, 2004). The result of disrupted interdependence in a relationship has also been found to create a polarizing effect on partners' relational appraisals, emotions, and behaviors leading to the experience of relational turbulence (Knobloch & Solomon, 2004; Solomon & Knobloch, 2001, 2004). According to relational turbulence theory, *relational turbulence* is "a global and persistent evaluation of the relationship as tumultuous, unsteady, fragile, and chaotic that arises from the accumulation of specific episodes" (Solomon et al., 2016, p. 18). The *relational turbulence model* (RTM), the forerunner of relational turbulence theory, was originally designed to explain how relational changes are appraised by partners who were moving beyond casual dating toward greater degrees of interconnectedness. The model was expanded over time to encompass other life transitions that occur throughout romantic relationships (e.g., Knobloch, Ebata, McGlaughlin, & Ogolsky, 2013; Nagy & Theiss, 2013), and defined relational turbulence as an umbrella term used to describe "tumultuous experiences" (Solomon & Knobloch, 2004, p. 796) including conflict (Weber & Solomon, 2008), depression (Knobloch et al., 2013), and frustration (Steuber & Solomon, 2008).

Relational turbulence theory differs from RTM in three ways. First, relational turbulence theory does not treat relational uncertainty and interference from a partner as equivalent, but recognizes their unique influences on the way partners think and behave. Second, the potential for causal links between communication and intrapersonal responses is an overt and important element of the theory. Third, unlike RTM, relational turbulence theory takes the entirety of the relationship into consideration and assumes that small changes or stressors can accumulate over time and shape relational assessments (Solomon et al., 2016). The introduction of the theory

sought to clarify certain elements of RTM, but "time and the accumulation of research will determine whether relational turbulence theory provides a fitting and useful account for the experience of turmoil, both episodically and as a global relationship quality, within romantic associations" (Solomon et al., 2016, p. 33).

The more established relational turbulence model has proven useful for exploring a variety of transitions and will thus be used to unpack the sensitizing concepts and frames that follow. RTM has been employed to study stressors that occur when family dynamics change (Abendschein & Trees, 2018), cancer treatment begins (Weber & Solomon, 2008), military deployment ends (Knobloch, McAninch, Abendschein, Ebata, & McGlaughlin, 2016), and long-distance relationships continue (Ellis & Ledbetter, 2015). The conceptual and operational framework provided by RTM has been tested in studies on how partners interact and discuss their relationship during various life transitions (e.g., Knobloch & Theiss, 2011), how periods of change influence appraisals of relational satisfaction (Theiss & Knobloch, 2014), and how couples navigate both anticipated and unanticipated transitions (Harvey-Knowles & Faw, 2016; Knobloch et al., 2016).

***Relational uncertainty*.** Unlike UIT and UMT, RTM moves the conversation on uncertainty into the dyad. *Relational uncertainty* refers to the questions about relational involvement specific to one's self, one's partner, and the relationship (Knobloch & Solomon, 1999). Although the three sources are included in the construct of relational uncertainty, each is distinct. First, *self uncertainty* refers to questions people have about their own thoughts, attitudes, or behaviors regarding the relationship. Second, *partner uncertainty* stems from questions about the partner's thoughts, attitudes, and behaviors regarding the relationship. Third, *relationship uncertainty* arises from questions about the current state of a relationship (Berger & Bradac,

1982). Questions about one's involvement in the relationship, a partner's involvement in the relationship, or the current relational climate can all be sources of relational uncertainty as couples encounter times of transition (Solomon & Knobloch, 2004).

Relational uncertainty can make transitions turbulent. Research shows that as individuals experience heightened levels of relational uncertainty, they are more prone to evaluate a partner's irritating behavior as negative (Solomon & Knobloch, 2004), avoid direct communication (Theiss & Solomon, 2006), appraise messages as hurtful (McLaren, Solomon, & Priem, 2012), or view the relationship as damaged (Theiss, Knobloch, Checton, & Magsamen-Conrad, 2009). Further, Knobloch and Delaney (2012) found that relational uncertainty exists alongside other health-related sources of uncertainty, such as depression. The occurrence of a stroke, for example, often generates various physical uncertainties (e.g., "Will I fully recover the use of my arm?") along with relational uncertainties (e.g., "Does my partner still want to be with me?") that may introduce consequences for the relationship (Abendschein, 2018). During times of transition, couples often face various sources of relational uncertainty that can contribute to experiences of turbulence.

Research indicates that relational uncertainty exists across relationship types, but the content varies based on context. Relational uncertainty occurs in various forms of close relationships including dating relationships (McLaren et al., 2012), marital relationships (Knobloch & Theiss, 2012), and even sibling relationships (Bevan, Stetzenbach, Batson, & Bullo, 2006). The substance of questions in particular relationships, however, depends on the interpersonal circumstances (e.g., Knobloch, 2008). For instance, marital partners experience questions ranging from larger relational issues, including levels of commitment, to the more tangible needs including who is responsible for the household chores (Knobloch, 2008).

Research has also revealed that couples struggling with infertility, for example, wrestled with issues of blame and fitting their relationship into the normative makeup of a family (Steuber & Solomon, 2008). Weber and Solomon (2008) found that couples navigating a breast cancer diagnosis reported that relational uncertainty emerged from conflicting identities of one's self before and after a diagnosis, as well as conversations on how to co-own the illness. As these studies illustrate, relational uncertainty is common during times of change, but the content varies in different contexts. The following research question addresses this issue in a post stroke relationship:

RQ4: In what ways, if at all, do couples experience relational uncertainty after stroke?

***Interference from a partner*.** A second mechanism of relational turbulence is interference from a partner (Knobloch & Solomon, 2004; Solomon et al., 2016). RTM builds on the ideas set forth by Berscheid's (1983) emotional investment perspective that links intimacy and relational interdependence. As partners integrate their lives together, the result is an opportunity for increased influence, interference, and facilitation of a partner's everyday activities or individual goal achievement. Knobloch and Solomon (2004) unpack Berscheid's (1983) conceptualization of *interference from a partner* as instances where a person disrupts or blocks their partner's daily activities or goals. In contrast, *facilitation from a partner* is recognized as a person's ability to interject and help a partner accomplish daily tasks or achieve specific goals. Berscheid (1983) ties both constructs to a partner's influence such that interference and facilitation from a partner can increase in frequency and potency as relationships develop and become more interconnected (Steuber, Priem, Scharp, & Thomas, 2014). The authors of RTM apply Berscheid's (1983) logic to periods of transition by arguing that as relationships develop and become more dyadically

focused, interdependence increases and may lead to appraisals of the relationship as tumultuous due to increased interference from a partner (Solomon & Knobloch, 2004).

Various types of relational transitions can give rise to interference from a partner. For example, research on reintegrating schedules after a military deployment (Knobloch & Theiss, 2012), constructing a definition of family (Steuber & Solomon, 2008), or transitioning to an empty nest (Nagy & Theiss, 2013) all reveal that interference from a partner can exist in a myriad of relational transitions. Additionally, individuals may find that the stress of a major medical event can lead to greater opportunities for partners to interfere with each other's daily activities. Studies have shown that couples struggling with a major medical diagnosis including cancer or infertility reported high levels of interference from a partner as relational needs and the rigors of treatment collided (Steuber & Solomon, 2008; Weber & Solomon, 2008). If interference from a partner exists during times of medical related stress, then people may also experience interference from a partner associated with stroke, but the content of that hindrance is unknown. Consequently, I propose the following research question:

RQ5: In what ways, if any, do individuals experience interference from a partner after stroke?

***Limitations*.** Uncertainty also exists outside the dyad. UMT was originally used to explore the sources of uncertainty specifically related to individuals experiencing a major medical event, and RTM was initially created to better understand how relationships navigate times of transition. The focus on illness in UIT, the individual in UMT, and the relationship in RTM offers the opportunity to explore the intersection of these theories as people work to navigate their relationships after a stroke. All three elements are likely to be important, but their

inclusion in this study as sensitizing theories allows an examination of potential connections between them with respect to the ways people encounter and manage uncertainty.

Conclusion

Stroke has the potential to alter relationships. To better understanding that process I focus on five areas to frame this study. First, it is important to catalog the possible effects of stroke on relationships, as articulated by both stroke survivors and partners of stroke survivors. Second, the uncertainty appraisal process that survivors and partners go through in response to stroke is important to understand because different assessments may lead to different actions. Third, the various sources of uncertainty that exist in a post stroke relationship must be identified to help scholars and practitioners focus on the most salient areas. Fourth, the potential issues of relational uncertainty people associate with stroke should be investigated as a first step in developing a plan to help couples navigate the transition. Finally, interference from a partner can impact relationships and occur in many ways, but may manifest differently within relationships after stroke. Attending to these issues was the core focus of my dissertation. To that end, I gathered data that helped me build a model depicting how people encounter stressors, conceptualize uncertainties, and confront changes. In the next chapter I discuss how I went about collecting and analyzing the data to build a model of the relational effects people associate with stroke.

CHAPTER 3: METHOD

The central purpose of this study was to build a theoretical model of the communicative process people go through as they encounter and navigate stressors associated with stroke. I used Tracy's (2013) *pragmatic iterative approach* to examine several research questions that probe the relational issues and uncertainty management processes partners navigate after a stroke: (RQ1) What do survivors and partners report as the effects of stroke, if any, on their relationship? (RQ2) How do survivors and partners appraise uncertainty after a stroke? (RQ3) What sources of uncertainty, if any, do individuals report experiencing after a stroke? (RQ4) In what ways, if at all, do couples experience relational uncertainty after stroke? (RQ5) In what ways, if any, do individuals experience interference from a partner after stroke? In-depth interviews with stroke survivors and caregiving partners allowed me to investigate the issues individuals associate with stroke (Weiss, 1994). Gathering qualitative data from interviews is the first step toward a better understanding of how people think about themselves and manage relational changes after a stroke. The pragmatic iterative approach helped me to be mindful of emergent themes as well as existing concepts and theoretical frames during data collection and analysis (Tracy, 2013). As a final step, I created a theoretical model of how survivors and partners conceptualize the relational outcomes of stroke. In the sections that follow, I describe the study design and data analysis procedures.

Study Design

My study design involved gathering qualitative data, analyzing it using constant comparative techniques, and building a model of thematic interactions. I began with in-depth, semi-structured interviews to gather narrative data on the relational experiences participants associated with stroke. Researchers who have sought to understand how people communicate in

the wake of a serious medical event have successfully utilized interviews to explore uncertainty management strategies after an organ transplant (Scott et al., 2011), relational changes after a communication-debilitating illness (Donovan-Kicken & Bute, 2008), the complex experience of being a stroke survivor (Murray & Harrison, 2004), and the influence of illness on identity across the life span (Kundrat & Nussbaum, 2003). Within the literature on how relational partners experience a stroke, the most common type of interview is one with an individual participant (e.g., Grawburg et al., 2014; Thompson & Ryan, 2009) that focuses on just one side of the dyadic experience (e.g., Hunt & Smith, 2004; Pawlowski, 2006). Individual interviews conducted with participants who are stroke survivors as well as those who are partners of stroke survivors illuminated the relational aspects of the experience. The topics discussed by both groups in terms of relational changes, sources of uncertainty, and communication issues all emerged as elements of the final model of the relational processes associated with stroke. Further, in-depth, semi-structured interviews allowed me, or a member of my research team, to interject with guiding prompts and follow-up questions to better understand the individual's experience within the relationship over time (Baxter & Bullis, 1986). The back and forth that took place between the interviewer and the participant made the in-depth interview format well suited for this type of preliminary inquiry.

Recruitment and inclusion. I recruited couples for this project by connecting with people through social media sites, local medical facilities, and word of mouth. First, there are active online communities that offer a platform for stroke survivors, partners, caretakers, and researchers to interact. In fact, in an exploratory study I gathered data from various online forums to begin understanding how people think their relationship has been affected by stroke (Abendschein, 2018). I capitalized on the fact that large online communities exist for stroke

survivors and caregivers by contacting the administrators of those sites and asking if I could post a recruitment message or if they would relay the message to their users (Appendix C). Several national and international organizations responded to my request by asking if they could interview me for their site and write an article about my project. These opportunities opened doors across the country and allowed me to network with gatekeepers in the stroke community. I also posted a message on Facebook pages that offer support for stroke survivors and caregivers as another way to reach people across the U.S. (Appendix D). Second, over the last few years I have established contacts at local hospitals and traumatic brain injury (TBI) support groups. I have attended monthly support group meetings to better understand the needs of TBI survivors, build trust in the community, and share what I have learned throughout this project. I have also had the opportunity to make professional connections with scholars at the University of Illinois who are formally and informally investigating areas that align with the focus of my study. I asked these scholars for their advice about how to best advertise my study. I also asked them to share my flyer within their social and professional networks (Appendix C). Third, an existing community of stroke survivors and caregivers made recruitment through word of mouth, or snowball sampling, an effective avenue to reach participants. To stimulate this procedure, I sent the recruitment flyer with the thank you email to participants and encouraged them to share it with others. Multiple avenues of recruitment allowed me to increase the visibility of my study and connect with participants across the U.S.

To be eligible for inclusion in this study, participants had to meet several criteria. First, individuals had to be in a romantic relationship in which at least one partner was a stroke survivor (i.e., a person who has suffered one or more strokes). Second, participants had to be willing to engage in an audio recorded interview that took place in person or over the phone.

Third, the stroke survivors had to be able to speak (even if that communication was limited) since the interviews were recorded for transcription purposes. Individuals who had aphasia were included in the study as long as they could express their thoughts in a timely manner. For several of the interviews, partners or family members were present to offer clarification if necessary and they were only involved in the conversation at the request of the participant. Everyone who was involved or present at an interview was consented through the University of Illinois IRB approved consent process. Fourth, participants had to be physically able to engage in an interview lasting 60-90 minutes. Living with a brain injury is demanding and physically draining for both partners (American Stroke Association, 2018a; Hunt & Smith, 2004; O'Connell & Baker, 2004; Tellier et al., 2011), so I was sensitive to that during the interviews and made sure to let participants know that we could end our conversation at any time. Finally, it was crucial that individuals could read and understand the consent document. Cognitive impairment is a common and serious outcome of stroke (Ebrahim, Nouri, & Barer, 1985). For that reason, I took steps to ensure that the potential vulnerabilities of the participants, including their possible cognitive deficiencies, were addressed through a two-step informed consent procedure. I sent participants a consent form through Qualtrics and asked that they read and complete the document prior to our scheduled interview (Appendix G). Sending the consent form prior to the interview was a strategy to help aid understanding by allowing individuals to read it several times, or with a partner if necessary. If an individual did not complete the document at least one day prior to our interview, I sent another email with the link to the consent form and a reminder that he or she needed to read and complete the form ahead of our interview (Appendix G). If the email did not prompt action, I called the participant at the time of our interview and said that the consent form needed to be read and completed (i.e., mark "agree to participate" or "I choose not

to participate") before we could have our conversation. Additionally, I began each interview by going over the key points in the consent document to further ensure understanding and agreement (i.e., the interview will be recorded, participants can end the interview at any time without penalty, and participants can skip questions they don't want to answer). A similar model of assessment was approved by the University of Illinois Institutional Review Board for a previous protocol (#16235) in which I asked to interview stroke survivors. I constructed these five inclusion criteria to ensure that participants were protected and to construct a sample capable of producing a data set that reflected the central focus of this study.

Participants. The sample for this project was evenly split between stroke survivors and caregiving partners as well as representing males and females equally (Table 3.1). Specifically, the sample consisted of 44 individuals involved in a romantic relationship post-stroke (i.e., 22 = stroke survivors; 22 = partner caregivers). Included in the sample were 20 complete couples (i.e., both partners participated in the study) and 4 people who participated without their partner (i.e., 2 = stroke survivors; 2 = partner caregivers). Stroke survivors ranged from 27 to 68 years old at the time of their stroke (M = 46) and 32 to 72 years old at the time of the interview (M = 53.11). Four participants did not disclose their age. Individuals lived in 10 different states.

Table 3.1

Description of Study Sample

Category	Counts	*M*
Participants	44	-
Complete couples	20	-
Stroke survivors	22	-
Caregiving partners	22	-
Males (in study)	22	-
Males (survivors)	11	-
Females (in study)	22	-
Females (survivors)	11	-
Age at stroke in years (survivors)	27 – 68	46
Age at interview in years (survivors)	32 – 72	53.11

The sample for this study follows a growing call to action in stroke research to broaden the scope of investigation to include groups and issues that are underrepresented in the literature, such as partner's perspectives, dyadic effects, and young stroke survivors (e.g., Banks & Pearson, 2004; Buschenfeld, Morris, & Lockwood, 2009; McCarthy & Lyons, 2015). The lived experiences of couples managing life after a stroke are central to this project and extend previous research that isolated the perspective of either the stroke survivor (Thompson & Ryan, 2009), a spouse (Croteau & Le Dorze, 2001; Quinn, Murray, & Malone, 2014), or a caregiver (McGurk et al., 2011). Through individual, in-depth interviews, I sought to engage both partners about their

relational story and the effects of the stroke on them personally as well as their relationship. A description of the relational issues, victories, and challenges following the stroke contributed to a theoretical model of the common experiences that shaped the illness-trajectory associated with stroke. Additionally, the average age for a first-time stroke survivor in the U.S. is 55 years old (American Stroke Association, 2018a; Mozaffarian et al., 2015). The mean age in this study for the 18 stroke survivors who disclosed their age at the time of their first stroke was 46 years old (for a complete breakdown of year of stroke and age at stroke see Appendix J). The sample in this study is unique in its inclusion of so many young stroke survivors, but it addresses an understudied group while still offering insight into the post-stroke experience of the larger, more diverse population.

Additionally, the sample in my study contains several individuals who are stroke support group coordinators and those who have written books about their experience after stroke. The inclusion of participants who have reflected on their lived experience with stroke offers a degree of expertise in this area that allowed me to explore difficult topics in more detail during our interviews. Individuals who mentor others going through the recovery process after a stroke are uniquely situated to speak to the shared experiences of survivors and caregivers. The expertise that comes from thoughtfully reflecting on one's own stroke or helping others to manage life after such an event also meant that those individuals were able to clearly articulate the relational experience that resonated across interviews.

Data Collection

I used individual, semi-structured interviews to collect accounts of how romantic partners managed the stressors they associated with stroke. Researchers have used an interview format to gather data from survivors or caregivers in the past (e.g., Banks & Pearson, 2004; Pawlowski,

1998), but some have done so without considering both voices in the relationship (e.g., Hunt & Smith, 2004; Thompson & Ryan, 2009; Winkler et al., 2014). This study took a different approach by interviewing both partners individually to make sure that both views were represented in the final model. The inclusion of survivors and partners allowed for multiple perspectives and a richer understanding of the individual and shared stressors couples associate with stroke.

Interviews were recorded and took place in person or over the phone. Participants were given the opportunity to engage in private, simultaneous interviews with me and my research team (in person or by phone). Although several couples met with us in person and we were able to conduct individual interviews at the same time in two different rooms, most of the couples chose to be interviewed by phone and each partner selected a different time for their interview. Without the ability to always separate partners into different rooms, I was not able to ensure that the interviews were private. In fact, several participants told me that they invited their partner or a family member to be in the room while they were on the phone to help them with their memory, speech, or for support. All individuals who were known to be present during an interview were CITI trained members of the research team or consented to participate using the IRB approved consent document (Appendix A).

To arrange the interviews, I began by reaching out to potential participants through social media sites, local facilities, and snowball sampling. If a person was interested or knew of others who may want to participant, I sent an email with information about the study and the eligibility requirements (Appendix F). In that email, I asked for the email address of the person's partner, so I could reach out directly regarding the study. I actively recruited for couples, but I did enroll several individuals (n = 4) who met all the other requirements for the study but whose partner

was unable or unwilling to participate. After a couple or individual expressed interest in participating, we negotiated a time when we could hold the interview(s).

Collecting dyadic data through individual interviews required special attention and coordination. For example, after the initial introduction emails and consent process, I often scheduled both interviews through one partner. Further, I worked with six undergraduate research assistants over two semesters to help with data collection so that couples could schedule interviews at the same time. Although many of the interviews were nonsimultaneous and conducted over the phone, we held several interviews on the campus of a large Midwestern university where both partners could participate at the same time. As I interviewed one partner, one of my undergraduate research assistants interviewed the other partner in a different room. To prepare for this responsibility, team members were thoroughly trained on the interview protocol and practiced their interview skills prior to meeting participants.

Once a time and location were determined, I sent each participant a reminder email (Appendix G) with a link to an informed consent document on Qualtrics that the individual was asked to review and complete prior to the interview. At the agreed upon time and location, I began with introductions and then reviewed the informed consent document (see Appendix A). The consent form included information on eligibility (e.g., the participant must consent for audio recordings to be collected), procedures, and confidentiality. Next, I offered a brief overview of the consent document to ensure the participant understood the key points (Appendix B). Following the consent discussion, I began the semi-structured interview protocol (Appendix E). I sent a thank you email to the participant immediately after the interview (Appendix H). The email included a link to a survey on Qualtrics where I gathered the required information the university needed to process the $20 Amazon e-gift card incentive (Appendix I).

After each interview, I memoed about the interaction by writing my initial thoughts, notes, and questions related to the interview and how those elements may impact the study. When the interview was conducted by another research team member, I asked him or her to memo about the interaction and then we met to discuss the memo and the interview. The memos were a tangible way to track the process of data collection, to highlight any changes that needed to be made, and to reflect on the study overall. In other words, the interview protocol was reviewed regularly and certain prompts were highlighted as the salient issues began to emerge across interviews. During our weekly meetings, my team and I discussed our memos and remained open to the possibility that new concepts, experiences, and/or concerns may emerge that should be added to the interview protocol to use with other couples. Throughout the process, all recordings, transcripts, and notes were kept confidential and participants were assigned pseudonyms for data analysis and reporting of the results.

Data Analysis

To analyze the data set, I employed multiple cycles of analysis as specified by the pragmatic iterative approach (Tracy, 2013). First, each interview that was recorded was also transcribed and I used the resulting documents as the foundation for my reflexive data analysis procedures. Tracy (2013) notes that iterative analysis occurs through a process of data immersion, ongoing contemplation, and collaboration with others. In contrast to grounded theory, pragmatic iterative analysis allows for themes to emerge from the data, while at the same time encouraging "reflection upon the active interests, current literature, granted priorities, and various theories the researcher brings to the data" (p. 184). Throughout data analysis, I engaged in data immersion where I read and reread the transcribed interviews to get a sense of what was happening across the data set (Tracy, 2013). The driving motivation at this initial stage was to

explore connections and narratives that emerged within the data set or were connected to my various sensitizing concepts. This iterative process meant that as my research team and I were conducting interviews, transcribing recordings, or reading the transcriptions, we were also reflecting on connections within the interviews and with larger theoretical constructs. We met weekly to talk about what we saw emerging from these data and to make sure we were capturing the most salient experiences of couples managing their relationship after a stroke. Finally, the coding procedure was an ongoing, reflexive process as well. Coding links data collection and the resulting theoretical model (Charmaz, 2014). In other words, it is through coding that I worked with the growing data set, narrowed the focus, and interrogated various interactions. Tracy (2013) outlined two cycles of the coding process that I used to guide my analysis procedures.

Primary-cycle coding. The first stage involved what Tracy (2013) called *primary-cycle coding*. During this phase, my research team and I reviewed a subset of the data and assigned words and/or short phrases that described each line of text, also known as line-by-line coding (Glaser, 1992; Glaser & Strauss, 1967). Primary-cycle coding involved going through the data set to describe what was happening while trying to avoid preconceptions as much as possible. Glaser (1978), for example, advocated for using gerunds to capture the actions or describe movement in the data, so that was one strategy we employed during coding. Since I was interested in learning more about specific terminology and language used within the stroke community, I also employed a technique called in vivo coding where the actual words of the participants are included in the initial coding procedure as much as possible (Strauss, 1987; Tracy, 2013). Primary-cycle coding also includes the constant comparative technique, which encourages researchers to keep the data at the center of the analysis by continually returning to the transcriptions, codes, and/or notes to make sure that concepts do not take on new,

unaccounted for definitions throughout the coding process, a phenomenon known as "definitional drift" (Gibbs, 2007, p. 98).

Since I had a team of coders, I addressed definitional drift in two ways. First, I constructed a detailed codebook, which is the final step in primary-cycle coding. I refined and organized the initial codes into a single Excel document that contained the codes, their definitions, and exemplars of each (Saldaña, 2015; Tracy, 2013). I tested the initial codebook by selecting a portion of the data set to code with my research team. At one of our weekly meetings, I introduced the codes, described their definitions, and gave examples so we could all approach the coding process with a common frame of reference. Then, we each independently coded the same interviews. We met the following week to compare our responses, talk about questions, and refine the codebook. The process of creating, coding, meeting, and refining took three iterations until we had a codebook that we felt reflected what we had all seen across the data set. Once we made our final changes to the codebook, we needed to make sure that the definitions were clear and that we were reliably utilizing the codes as a team. I employed a form of percent agreement to confirm our intercoder reliability by independently coding the same subset of interviews and comparing our codes. We used my coded interviews as a guide. Each time we encountered a section of coded text we marked our agreement if all of us coded it the same way. On those we did not agree on, we talked about why, came to a consensus, and examined the codebook to make sure each definition was clear. Using this process, we achieved 80 percent agreement across four coders (including myself). Next, we applied the codebook to the entire data set while continuing to meet weekly and discuss questions, tweak definitions, and add more exemplars. The pragmatic iterative approach states that this process is ongoing and a final codebook can still be amended should new data reveal something different (Tracy, 2013).

Secondary-cycle coding. The next stage of coding, according to Tracy (2013), is analysis and interpretation by building on the descriptive codes from primary-cycle coding. I utilized *secondary-cycle coding* to construct an overarching view of the data set as reflected in my model of relational changes after stroke (see Figure 4.1 in the next chapter). Secondary-cycle coding contains several elements that are similar to practices utilized in other sourcebooks on qualitative data analysis (e.g., Charmaz, 2014). First, I built on the codes that emerged during primary-cycle coding by reflecting on the codebook to ensure I was representing the main ideas across interviews (Tracy, 2013). This process is referred to in other texts as focused coding (Charmaz, 2014). Then, my research team and I worked to create a visual display of the relationship between various elements by constructing a model that represented what we saw happening across interviews, also known as axial coding (Charmaz, 2014; Tracy, 2013).

A crucial element of secondary-cycle coding is monitoring to make sure that the data are complete enough to address the research questions. Ongoing analysis of the transcribed interviews and weekly meetings as a research team ensured that I was immersed in the data throughout the process. Specifically, Glaser and Strauss (1967) discuss working to achieve theoretical saturation, or the point at which each interview seems to add little new information to the data set. Tracy (2013) addresses this issue by using Straus and Corbin's (1990) explanation of saturation as occurring when: (a) new data do not add any novel thematic contribution, (b) each thematic category is robust and distinct, and (c) the connections between categories are clear. There is also a balance between theoretical saturation and constructing a robust data set. I worked to strike that balance by continuing to conduct interviews beyond saturation to ensure that more voices and experiences were included in this project. In fact, taking the time to invest

in additional interviews allowed for a richer representation of the model by adding more perspectives to each element.

Steps to Protect Validity

Ethical qualitative research is transparent. The researcher should not, therefore, neglect thoughtful consideration of how to present the logical development of ideas within a study. Tracy (2010, 2013) elaborates on her position that qualitative researchers should intentionally consider the potential credibility and significance of their work. The pinnacle of that position is meaningful coherence, or research that (a) fulfills the goal and purpose of the research project, (b) utilizes the appropriate methods and theories that supplement the study, and (c) draws informative parallels and contradictions between the research project and existing literature. To achieve meaningful coherence, it is also important to track and reflect on developments that emerge across a study. I worked to maintain the validity of my findings by utilizing three of the most prominent and face valid techniques available to qualitative researchers: keeping notes throughout the process, using visual displays, and examining negative cases as necessary.

Memo writing. Each member of my research team and I wrote memos during the various stages of data analysis to track the development of codes, ideas, and possible connections throughout the project. We recorded the process of how codes emerged and followed ideas as they cycled in and out of the analysis; this is a crucial element within the pragmatic iterative approach (Tracy, 2013). Good record keeping also helped maintain my engagement within the data by offering an abstract perspective, since writing memos required the research team and me to step back and think about the project globally (Clarke, 2005). Additionally, my analytic memos provide a trail for others to follow as the story of these data emerged over time (Charmaz, 2014).

Visual data displays. Another method of reflecting on the project and attempting to draw informative parallels is to construct visual data displays (Tracy, 2013). For example, people often use matrices, tables, and flowcharts to reduce the overwhelming amount of textual data to a visual that shows how elements relate. This process gives the researcher freedom to wrestle with big ideas that may be emerging from the data set, to organize those thoughts, and to motivate conversation. My research team and I constructed visuals (i.e., we drew pictures that often-resembled flowcharts) of the transcribed data at three different timepoints. We did this to stimulate our thinking about the data set as a whole and play with ways we could represent the connections we saw. First, we drew what we thought we would see based solely on our experience conducting and transcribing the interviews. Next, we drew a visual of the data set after we finished with primary cycle coding. Finally, I constructed a model that grew out of the focused coding process (Figure 4.1). The exercise of drawing visuals in conjunction with writing memos helped the research team and me to distill the richness of the textual data by highlighting the main elements across interviews.

Negative case analysis. The cases that do not appear to fit my research questions or seem out of place in my theoretical model were considered as *negative cases* and they added value as a foil to my findings. For example, many of the couples shared similar experiences related to how their relationship changed after the stroke. Others, however, felt their relationship had not changed much. Upon further examination, my research team and I considered that individuals who felt their relationship had not changed may also be those who were more willing and able to adapt to change. I was then able to add more depth to my model by examining this negative case and articulating that as people respond to change, they do so by struggling to cope or adapting to change (often both simultaneously). Examining negative cases and including diverse

perspectives helped to amplify the claims that I make in this study while also demonstrating that there is still more work to be done on this topic. Negative cases do not always fit into the final model, but they show the complexity of the data set and add to the "fidelity and credibility" of the research project (Tracy, 2013, p. 197).

CHAPTER 4: RESULTS

Stroke is a complex experience that can dramatically alter people's way of life. Despite the relational complexities that emerge after stroke, the data in this study suggest that partners and caregivers share several key experiences. Participants described their relationship as undergoing significant change as they experienced shifts in how they viewed themselves, their partner, and their romantic relationship. Although the immediate changes were categorized as physical (e.g., limited mobility) and/or cognitive (e.g., limited short term memory), over time couples recognized that fluctuations in personality, temperament, and affection led to unforeseen relational consequences. Partners described a progression in which they worked to adapt their relationship to function in a post-stroke environment. The relational changes that emerged after the stroke created tension between partners and required spouses to alter their roles in the family and even develop new ways to communicate with one another. Throughout the post-stroke experience, survivors and caregiving partners struggled to manage the unknowns related to the stroke and to cope with changes to their relational dynamic. The data suggest that life post-stroke involved a difficult process of individual adaptation and relational reorientation.

Characteristics of the 24 couples represented in this study (i.e., 20 complete couples and four singletons) are important to note. First, the stroke survivors who disclosed their age ranged from 27 to 68 years old at the time of their stroke (M = 46) and 32 to 72 years old at the time of the interview (M = 53.11). According to the CDC, about 25% of the strokes reported each year in the U.S. occur in individuals under the age of 65 (Mozaffarian et al., 2015). Since the average age of the participants in this study was below the national average for first-time stroke survivors, the sample may not be representative of the whole population. Examining such a young sample responds to a call from scholars to focus on the unique experiences of families

who are, for example, raising children and balancing a career post-stroke (e.g., Anderson, Keating, & Wilson, 2017; Buschenfeld et al., 2009). Hamm (2018) noted that the occurrence of stroke in younger adults is on the rise. However, since little is known about the specific needs of this population, young people are struggling to cope and find community after their stroke. This study adds to the literature by highlighting the shared experiences of stroke survivors, many of whom are younger than the national average, and their caregiving partners.

A second distinctive feature of the sample is that several of the survivors and caregivers facilitate stroke support groups, host stroke related podcasts, or give lectures about life after stroke. The collection of such a group, including those who are social leaders in the stroke community, is a unique quality of this study. It also meant that some of the participants could respond to the prompts I offered during the interview in a thoughtful, well-reasoned way that proved difficult for others who may have never thought about some of questions I posed (e.g., "What were some of the big unknowns that you remember thinking about right after the stroke?"). I worked to include a diverse collection of voices in this chapter and every couple I interviewed is represented. I did, however, emphasize quotations from the individuals who could most clearly express the emotions and experiences that emerged across interviews.

In the following sections, I introduce *a model of relational changes after stroke within romantic dyads* that represents the progressive experiences of stroke survivors and caregiving partners (Figure 4.1). The chapter is divided into three sections that address different aspects of the model. In each section, I use quotations from participants (under pseudonyms) to explain the elements in the model and address my research questions. The sections vary in length due in part to the degree to which participants elaborated on the topic, but each research question was investigated using the same rigorous analysis procedures. The first section deals with Research

Question 1 and is the largest because it represents a majority of the model. The second section encompasses three research questions that focus on the experience of uncertainty associated with stroke. The final section addresses Research Question 5 and corresponds to one element in the model. In the sections that follow, I introduce each research question and then offer quotations from participants that address how the survivors and caregivers in this study encountered and conceptualized changes in their lives after stroke.

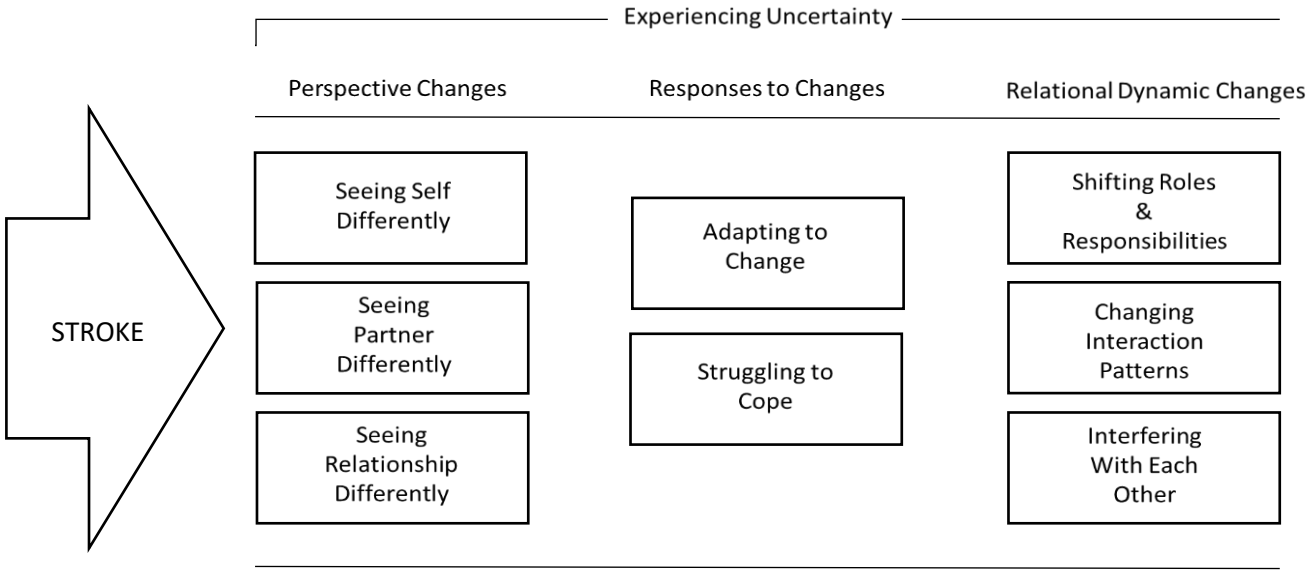


Figure 4.1. A model of relational changes after stroke within romantic dyads.

The Effects of Stroke on Romantic Relationships (RQ1)

The first research question asked what survivors and partners identified as the effects of stroke on their relationship. Participants reported that the stroke changed the way they thought about themselves and their relationship. Individuals generally managed to adapt to changes over time, but responding to shifts in personality or loss of mobility was a struggle initially. The stroke also influenced the dynamic between partners and meant that couples had to redistribute workloads, find new ways to communicate with each other, and/or negotiate instances of interference from each other. In the following sections, I address each element of the model to

highlight the common experiences of the caregiving partners and stroke survivors in this study (Figure 4.1). I begin with an overview of the *perspective changes* that couples encountered, how the shifts occurred immediately after the stroke, and how the changes continued to develop over time. Next, I elaborate on the *ways that couples responded* to various life changes that resulted from the stroke. Finally, I address the effects of stroke on the *relational dynamic* by focusing on shifts in roles, responsibilities, and interactions.

Perspective changes. Participants identified perspective changes as a major issue for both partners following a stroke. A change in perspective means that participants experienced a shift in the way they thought about themselves and their relationship. The change began soon after the stroke (e.g., "I am a stroke survivor"), but remained and continued to develop over time (e.g., "I am more of a parent than a partner to my spouse."). Ruby, whose husband Charles had a stroke, noted, "You're going along and then you know, the next morning everything's different. In an instant your life changes. And that's just how it happened. In an instant, everything was different." Ruby later described how their relationship changed because the way she thought about her husband changed: "I'm just, I'm treating him like a kid because as soon as he comes home he's physically challenged in everything." The changes continued to unfold after Charles had his stroke and the couple worked to, as Ruby said, "Straighten things out." Couples also discussed the process of change after the stroke as a positive experience. Salli, a stroke survivor, talked about her shift in perspective when she said:

> The stroke changed me, and it changed me I feel in a positive sense. It gave me a different perspective of what I was doing prior to my stroke. The kind of woman I was, the kind of life I was living. Which you don't see when you're in full stride, and you

don't see when you have all this noise around you and you're busy focusing on your career.

Salli articulated a recognizable change in the way she perceived her life circumstances after the stroke. Throughout the interviews, couples recounted their perspective shifts across three areas: (a) how they saw themselves differently, (b) how they saw their partners differently, and (c) how they saw the relationship differently. I address each area in the following paragraphs.

Seeing one's self differently. Participants commented that the stroke caused a perspective change in the way they saw themselves. Stroke survivors recognized that the stroke, and by extension their brain and body, was to blame for this shift and found that both frustrating and disconcerting. Survivors talked about how the stroke was responsible for changes to their *speaking ability*, *physical mobility*, *individual identity*, and *social relationships*. Partners focused on how the stroke led to the creation of an *identity as a caregiver* and they discussed how that altered their perspective of the relationship. The stroke introduced many changes that couples had to manage, but how people saw themselves was an important component of how they made sense of their life after the stroke.

Another aspect of how survivors saw themselves differently after the stroke was their ability to speak. Some participants remembered not being able to speak at all, while others had trouble with word recall; both are variants of aphasia. In fact, stroke survivors regularly commented on their speaking ability and the frustration it caused. For example, Ava mentioned, "There are words that I don't pronounce correctly, and I can't. I mean, I know that I'm not exactly pronouncing them well or like they should be, that gives me trouble." Others described that frustration by comparing their current speaking ability to the way they could talk before the stroke. Anna, a stroke survivor, stated:

> The speech really stressed me out because I am a fast talker. I can get my words out really quickly. My undergrad is in English, so you know, we like to use big words. And then to literally go from that to not talking very much because I had to form all the words in my head, I had to think about what I was going to say. And I knew that it wasn't going to come out very fast. I'm a huge conversationalist with people and hanging out with my friends, I was talking slower and I hated that because I want to get my ideas out really fast and I couldn't do that. There are still times that I will stutter, or I will lose a word. And, it's, I'm too young to do that. I've seen older people do that where you're having a conversation with your grandfather and they go, "Oh yeah that um, uh..." When I do that, it's like "No, I'm only 32."

Not being able to speak the same way, with the same speed, or with the same clarity as before frustrated Anna. This example illustrates how the stroke influenced individuals' perceptions of themselves. A fast-talking English major who talked more slowly and struggled to get her thoughts out after her stroke was a dramatic change to Anna's perception of herself because conversing was such an important part of her identity. Gloria summed up the pervasive feeling shared by other stroke survivors when she said, "I just wish I could talk." Losing the ability to speak was isolating for survivors because it limited their options during a conversation and influenced the way they viewed themselves during those interactions.

In addition to changes to their speaking ability, stroke survivors saw themselves differently due to their altered physical ability. This was a sudden change that participants felt took a considerable amount of time to manage. Betty had her stroke at age 42 and talked about her physical ability: "My weakness on the left side was dramatic. I used a wheelchair first and then a walker to get around. That kind of affected a lot of things." Others commented that they

could not engage in the same activities as they once did. Calvin, a former triathlete and stroke survivor, said:

> Triathlons? Yeah, I did a number of triathlons before I had the stroke. And the stroke has changed my lifestyle considerably. I don't exercise [like] I did [before the stroke]. And uh that for sure changed. If I could, if I was all relaxed, I would go exercise. I used exercise as a [way] to relax me, it would make me feel good about my life, but I don't do that now. I don't cycle the way I did. I don't swim as much as I did. So, I don't use exercise now to relax me [the way] I did before I had the stroke. I don't, I don't use exercise the way I used to, the way I should use it.

Due to his lifestyle changes after the stroke, Calvin was unable to get back in to the exercising rhythm that he once had and therefore struggled to see himself as he once did.

Embedded within Calvin's comment about his inability to exercise is his change in body image. Despite having the desire to be active, participants saw themselves as limited and that influenced the way they thought about themselves. Joan, a stroke survivor and former athlete, said, "I think because I'm not able to get out there and be as athletic as I want to be, definitely [my] body image has changed. I feel like, I don't know, I feel like, kind of a big slug sometimes." This shift in perspective was echoed by her partner, Bert, when he said, "So she was always super ripped, always. And now that she can't work out that much, she thinks she's fat as hell. She really isn't, and I cannot make her think otherwise." The change in physical ability led stroke survivors to juxtapose their activity level before the stroke and after the stroke and then tie those assessments to how they viewed themselves.

Due to changes in speaking and physical ability, participants described how their individual identity shifted after the stroke. Survivors in particular recognized that identity shifts

translated to changes within their family, their romantic relationship, and social circles. Betty, a stroke survivor, said:

> For a long time, even though I was still the mom, I'm still the mom and the wife, I felt like I was nothing but the patient because I had to rely so much on everyone else. I kind of felt like I lost my identity in the family model and then it didn't help that I could not go back to work, so I lost my work identity.

Betty mentioned that several of the key identities in her life (i.e., mother, wife, and employee) were altered, or disappeared, due to her stroke. Once those identities were changed, it was difficult to change them back to the way they were prior to the stroke. Tracy, another stroke survivor, commented about how the stroke permanently altered her identity:

> There's no such thing as you going back to who you were. Who you were no longer exists. You are this person now with a stroke, and you learn to deal with it, sure. And you work and try to get better but it doesn't matter how much better you get, you still are the stroke first.

Tracy recognized that the way she saw herself was forever altered by the stroke. Her comment exemplified the feeling across interviews that whatever happens after the stroke is forever influenced by that event, even if that influence is minor.

Identity changes also involved a shift in priorities. Survivors and partners alike used the stroke as a catalyst for reinventing themselves. For example, participants mentioned that the stroke offered an opportunity to alter their priorities and engage in a slower, more reflective lifestyle. Ava felt that her stroke helped her refocus: "I had a stroke and there are important things and there are important things that are not so important. I think I stopped and smelled the roses, or whatever you want to say." Participants also described an intentional and empowering

shift in the way they chose to see and interact with the world. Buckley, who had his stroke five years prior at age 35, said:

> There's less stress, things like that. But at first, [my wife] couldn't do her career and take care of me and the kids. Where does career fit into that? I told her I was a lawyer at a big firm before the stroke for 9 some years. I was up for partner the year I had my stroke. And I told her that maybe this was a blessing. Had I made partner, I would have been on a track at [the] firm for the rest of my life. I wasn't afraid of those things, but I think we were finding ourselves. Based on what happened to us at that time, Saffron [Buckley's wife] and I were both identifying ourselves by our careers. I don't think now either of us does that. So, I guess that's a big change…We look for other people and activities to define us. I think that's a perspective shift that a lot of people in their 30's especially don't understand or do.

The altered identities that Buckley described emerged soon after the stroke (i.e., "at first…"), but continued to take shape over time (i.e., "I don't think now either of us does that…"). In fact, Buckley notes that his perspective shift was something that also transformed his partner and their shared identity as a couple.

In addition to seeing themselves differently, stroke survivors witnessed a shift in the way other people interacted with them after the stroke. Survivors felt that when they interacted with friends and family they were mischaracterized as the stroke, or simply seen as a handicapped person. Tracy, who had her stroke 12 years prior at age 41, remarked:

> It's strange, it's like all of a sudden when I woke up from that surgery I was inside of something and it's like people couldn't see me anymore, or like I didn't exist. This person, I almost want to say this thing, after the surgeries, the strokes, this is what people

> see. And I'm still the same person, but I don't know if I'll ever be acknowledged like that again. Not even by my family. People talk, they patronize me, or they talk at me as if they have to tip toe around me. I'm still just me!

Tracy wanted to see herself as the same person she was before the stroke. Others, however, projected their ideas about who they thought she was after her stroke. Those projections influenced Tracy to think differently about herself, and in doing so she decided to leave her partner, because as she said, "I felt like a monster. I thought I looked like one too." How stroke survivors were seen by others impacted the way they thought about themselves.

Caregiving partners also elaborated on the altered perspective they had of themselves. This change involved more than taking up new responsibilities around the house; it was described by partners as a transformative shift in the way they saw themselves. In some cases, the stroke created or enhanced feelings of connection. Harold talked about how his wife's stroke created something inside of him that he had never seen before: "When the stroke happened, it hit me pretty hard because I cared about her… and so the caring stayed in there, something that I had not seen in myself for years, I mean forever for god's sake." Harold saw himself differently, in a positive way, as a result of his wife's stroke. Others struggled to find themselves again after the stroke. Iris reflected on caring for her husband after his stroke occurred four years ago when she said, "I was desperate. I was in a really bad place. I was crying all the time, I was drinking, I was angry. I didn't even know myself." Iris went on to elaborate on how she resisted the changes that she knew needed to occur in the relationship because she was struggling with the way she saw herself after her husband's stroke. Harold and Iris exemplify the complexity of how an altered view of one's self was represented in both constructive and challenging experiences in this study.

Seeing one's partner differently. Participants talked about how the stroke changed the way they viewed their partner. Some talked about *choosing* to see their partner differently, whereas others struggled with the fact that they were *forced* to see their partner differently. For instance, Sarah, a caregiving partner, described the challenges of having to see her partner in a new light: "There is [a] new normal and that's something that I struggled with. I wanted him to get back to the way he was before, and it took me a while to realize that this is who he is now." Sarah recognized and lamented the changes she saw in her partner after his stroke. In fact, participants knowingly compared their partner with who he or she was before the stroke. As survivors and caregivers reflected on the differences they saw in one another, they focused on two issues. First, participants recognized that their partner was *a different person* after the stroke. Second, they talked about how those differences *added stress* to their relationship. I address each of these points in the following paragraphs.

Participants struggled with the idea that the person they knew prior to the stroke was gone. Ruby talked about the changes she saw in her husband after his stroke:

> The first thing I noticed was a personality change. He came out of that stroke a totally different person. I mean, totally different person. Before the stroke, he was cocky, self-confident, self-assured. He had an air about him that was confident. And he was charming and intense, well he's still intense. Even his voice changed. I mean, he came out just a totally different personality. The person I married was gone. I mean just gone.

The changes that Ruby saw in her husband after his stroke were dramatic and long-lasting. She noted that nearly everything about him changed and how that made her reflect on who he was before the stroke. Gabriel, a caregiving partner, also mentioned the difficulty of seeing a partner who was different after his wife's stroke when he said, "[I had to] learn to love the new person."

Later in the interview he commented, “Everybody should know that it is hard to accept essentially a new person, someone who’s been in your life for 20-40-50 years and now they’re potentially [a] totally different person.” Other caregivers echoed Gabriel’s sentiment and talked about how it was difficult to manage personality changes in a long-term relationship because the established patterns of interaction and relational norms were disrupted.

Seeing one’s partner differently after the stroke was difficult and introduced stressors into the relationship. Partners experienced a tension between missing the person they knew before the stroke and accepting the person they saw after the stroke. The difference between those positions added stress to the relationship. For example, partners talked about how they occasionally saw their new caregiving needs (providing or receiving) as an added burden on the relationship. Cal remarked on his situation after his partner’s stroke by saying, “For a little while, I was, in my frustration, saying things like ‘well shit, now I’ve two kids to take care of.’” Cal’s partner, Hope, also remembered the conversation when they discussed that perspective shift:

> He said that he felt like he had two children because he’d have to come up and essentially clean up my mess. Um, and I remember him apologizing for saying that one. I’m not sure if he says it to other people, but I know he said it in front of me, and at that time, it didn’t really register. Like, it didn’t register that it was, um, uh…insulting.

Over time, caregiving partners had to adapt to the added stress of interacting with a person who may have been drastically changed by the stroke. Ruby talked about the struggles with seeing her husband differently when she said, “I will never, I will not have a rational argument with him and I will not have a mature argument with him…because he is irrational. He rationalizes like a child.” The added strain of seeing one’s partner differently was compounded by the difficulty of

not always being able to discuss those changes or know that the conversation registered with the stroke survivor.

Seeing the relationship differently. In addition to seeing themselves and their partner differently, couples experienced a change in their relationship after the stroke (Figure 4.1). Across the interviews, participants commented that the stroke allowed for opportunities to reexamine their relationship, even though that was a difficult process. Betty said of her stroke, "I think the stroke changed our dynamic to make us stronger. And, um, I can say that even though it was not a good thing at the time, it's a good thing now." Additionally, Chris remembered that when his wife had a stroke it was a catalyst for their marriage: "[the stroke] gave us a chance to really find out how we mesh together as a couple." It was the stroke that helped this couple to see their relationship differently and help them realize that if they could negotiate that stressor they could do anything.

Caregiving partners also discussed the challenge of intentionally seeing the relationship differently to maintain hope and normalcy. Even while lamenting the fact that the relationship had changed and longing for the way things were before the stroke, partners said they addressed those changes only when the stroke survivor was ready. Jess talked about that approach:

> So, here's the thing about being a caregiver, I knew that old life was dead and gone, but I couldn't tell Earl that life was dead. If I killed his reason for getting up in the morning, if I killed all of his hope, now I've killed everything.

Jess went on to say that she made the choice to see the relationship differently with the hope of preserving the relationship:

> I wanted my husband back. I didn't want to become just caregiver/stroke survivor. I didn't want to be almost like mother/child. I still wanted to have my husband back. So,

> with everything that I did, and the way I spoke to him, so even though he was lost in la la land, I still had to speak to him like my husband and almost like pretend that he was okay because if I treated him like a patient, pretty soon that was where our relationship would go. I wanted my husband back, so I treated him like that even though I was bathing and dressing him and doing all this stuff. So, it was an absolute conscious effort to do that and not allow us to slip into a different type of relationship where we were never like a married couple again.

Intentionally reframing the relationship, as Jess did, was a helpful mechanism for adjusting to other life changes. In fact, managing the stress of relational changes through reframing was a common approach mentioned by participants across the interviews.

Couples also reframed their views on intimacy. As the relational dynamic changed, partners talked about struggling to have sex with one another and viewed that element of their relationship as strained. Cal talked about this change after his wife's stroke:

> It's affected our sexuality. It's to a point where, like it or not, I have to file a request for sex in the next two days. Spontaneous sex is a super rare occasion. This is something that she's going to therapy about and it's a major topic.

Ruby also remembered seeing the relationship differently after her husband had a stroke and recounted the changes to their intimate relationship when she said, "Your physical relationship changes. Um yeah, intimacy was non-existent, pretty much. It wasn't about love or relationship." Other participants talked about their intimate interactions changing after the stroke and the impact of that change on their relationship. Even as couples worked to adapt, they continued to struggle with the new relational dynamic that emerged after the stroke.

Responses to changes. As participants encountered changes to the way they saw themselves, their partner, and their relationship, they noted that their altered perspectives led them to take action (Figure 4.1). Survivors and caregivers mentioned the ramifications of their choices after the stroke and how they labored over what to do and how to respond to all the changes. During this part of the post-stroke experience, partners wrestled with next steps. They recognized that their perspective had changed, but they were now confronted with the question of what to do about those changes. The solution was intermingled with the ongoing struggle of dealing with all the things that were different because of the stroke. In the following sections, I address the complexity of how couples responded to changes after stroke.

Adapting to change. Participants gravitated toward an action-oriented, forward-thinking approach to life after stroke by constantly working to respond to their new circumstances. Stroke survivors still wanted to do many of the same things they did before the stroke, so the couple had to adapt. For example, Jenni's husband wanted to continue fishing after his stroke, so she wrote a short note on the back of his fishing license that read, "I have trouble speaking. Call my wife," just in case he was stopped by the game warden. For Jenni, seeing her partner differently and yet wanting to be a supportive spouse meant first accepting that her partner had changed and then adapting accordingly.

Acceptance was a milestone that participants regularly mentioned as an important first step in adapting to their life after stroke. Individuals acknowledged a perspective shift in themselves and their partner, but to *accept* those changes meant getting to a place where next steps were possible. Buckley talked about this when he said, "I was very frustrated at first. Now that I've accepted it, I'm less frustrated." He went on to say that the acceptance of his condition after the stroke allowed him to acknowledge his need for help: "When I can't do a certain task,

like folding laundry or turning pages of a book, or things like that, I ask for help to do those things. I would say that happens once every 3 or 4 days." Others talked about how the experience of initial frustration eventually led to action. Jess remembered how getting to a place of acceptance took her husband years after his stroke:

> It was awful, but once – it took a couple years – but finally he realized he couldn't do it anymore. That's when things kind of started to get better. He started being able to laugh again. I would say that was probably 3 or 4 years into the stroke.

Recognizing that everything had changed was an important first step. To move forward, however, stroke survivors and their caregiving partners had to talk about abandoning the old life and adapting to the new normal. Aaron described this process after his stroke when he said, "I can't change back. So, I've changed and I'm doing the best I can, and I keep working at it." Acceptance was not easy for the couples in this study, but it was the first step toward adapting to a new life.

After accepting the changes that followed the stroke, partners then began to make a plan of action. This step involved knowing one's limits, not to restrict activity, but to consciously create a strategy that acknowledged and pushed those limits. Joan commented on this process after her stroke: "It's been a struggle to kind of figure out what will work for me after [the] stroke because I think I handle things differently, situations differently. So, it's been a learning curve trying to figure out what will work." In this example, Joan talked about actively trying different things and strategizing about what would work best for her. She went on to say that she practiced conversations with her husband before she talked to her boss at work, for example. She also mentioned how she knew she needed rest before and after a big outing, so they planned time for that as well. Other stroke survivors commented on the need to rehearse their thoughts and/or

plan for events knowing they would need time to recover. These new approaches made spontaneity difficult for couples but planning made life more manageable.

The act of acceptance followed by planning for the future was part of the overall process of recovery, but progress took resolve and dedication. It was not enough to make a plan of action; the next step was to implement that plan and work toward a desired outcome. For example, Anna talked about the process of working on her social skills after the stroke:

> There were times where I'm like okay, I just really, really, really don't want to go out because it [takes] so much energy to talk and to get the ideas out. But then sometimes I knew it was a good thing because the more I worked at it, the better I would get. So, I mean it wasn't like you can stay home all the time. We need to get out.

In this comment, Anna recognizes that the stroke changed how she viewed herself socially. So, she accepted that change and responded by intentionally putting herself in situations to practice her social skills even though it was difficult for her. Likewise, Ava commented on her response to the changes after her stroke by saying, "I just keep moving because if I stop my recovery stops." Stroke survivors and their caregiving partners adapted to their altered circumstance through ongoing, action-oriented involvement.

Struggling to cope. Participants also discussed the psychological and/or physical strain after the stroke that limited their ability to manage various stroke-related changes. They knew they needed to act, but still struggled throughout the process. For example, Ruby reflected on her initial trials as a caregiver when she said, "Those first few years were just awful, just hard." The struggle to cope continued as survivors and caregivers wrestled with how they thought of themselves after the stroke. Joyce had her stroke four years prior and said, "I would cry because I thought I was stupid, and I thought I'd lost." Throughout the interviews, participants traced the

difficulties they had with managing *psychological* and *social* challenges to their perspective changes after the stroke.

Stroke survivors and their partners experienced periods of intense distress as they worked to manage life after stroke. Specifically, depression was a common issue that emerged as couples struggled to cope. Cal was confused when his wife started experiencing depressive symptoms years after the stroke: "It [the depression] was definitely significant and certainly during that time that, kind of came out of the blue. Um, I expected if she was gonna be depressed it'd be day one." Cal also admitted to having short periods of depression, but he said, "I can't be the one that's down now. I need to be on my feet." Cal prioritized his wife's health over his own. This was a choice that other caregiving partners talked about making as they struggled to manage life after stroke.

At times, the psychological challenges introduced by the stroke were so difficult that they led to post-traumatic stress disorder (PTSD). Jess described the family dynamic after her husband's stroke as tenuous and remarked that she was in the precarious position of being the linchpin holding everyone together. She commented that the stress of that position made her struggle even more:

> I was the only one sort of holding up this house of cards. If I went down, if I stopped being the strong one, the kids were gonna fall apart, Earl wasn't going to get any better. Everything, everything was going to crumble around us. It was crumbling already. But at least if I could try to be the strong one, I could make it maybe, maybe crumble a little slower. For the first few years, there was just no laughter. There was just none, it was too awful. I always say I'm the one with posttraumatic stress, not Earl. Earl was in la la land. He didn't really know and of course, I knew everything. And so, it was very hard on me.

Jess recounted a situation in which she was barely holding it all together and how that stress had a major influence on her life. Ruby also talked about this type of struggle after her husband's stroke: "There were so many dark nights where I would just sob. I would just be crying, he'd be sleeping, and I would just be sobbing" The experience of becoming a caregiving partner was a noticeable perspective shift but living with and owning that identity was also psychologically overwhelming.

In addition to experiencing psychological challenges, survivors and caregivers struggled with social interactions after the stroke. Participants talked about how the emphasis after the stroke was on the patient and recovery. That meant caregiving partners received little support from their spouse while trying to manage a myriad of changes. For example, Calvin remembered how Iris, his wife, was left without support while caring for him after his sudden stroke in a foreign country: "She had a lot of anxiety because there was no social structure in place to support her [and] to tell her that everything's gonna be okay. She had no resources except those that I had." Iris was focused on caring for her partner, but she had to do that without financial or social support. Stroke survivors and caregiving partners struggled to manage the combined stressors of the abruptness of stroke and their lack of resources to manage specific challenges.

Others recounted how their friendship networks changed and that influenced the social challenges they faced after the stroke. Bert noted that after his wife's stroke their friends disappeared: "You lost friends because they don't know what to say to you, or what to do, or how to approach it and then pretty soon they stop calling and – or stop thinking about calling and they just drift off." Bert went on to say that while he sympathized with his friends who left, that did not change the fact that their leaving made life after the stroke more difficult for him and his wife. Others reframed the changes to their social networks by seeing the positives. Betty said that

after her stroke the change within her friendship circle was difficult, but ultimately it was for the best: “For me it was a struggle, I really thought that my friend base kind of narrowed down dramatically to what I would call those real, true, heart friends.” Overall, a shifting social network added to the difficult transition for couples post-stroke because it introduced another layer of stress and restricted their opportunities to engage with others socially.

Relational dynamic changes. Participants talked about how perspective changes and their responses to those changes influenced their relational dynamic after the stroke. Survivors and caregivers commented on how their roles and responsibilities in the family shifted. Participants also mentioned how they had to work on different ways to communicate and address new topics related to life post-stroke. Additionally, an increased dependence on the caregiver generated feelings that both partners were interfering with each other’s independence. In the sections that follow, I explain the relational dynamic changes that emerged across interviews related to *shifting roles and responsibilities* as well as *changing interaction patterns* (Figure 4.1).

Shifting roles and responsibilities. The stroke led partners to adopt new roles and assume new responsibilities. Throughout the interviews, three main issues emerged related to the experience of changing roles and responsibilities. First, partners reported having to take on all the responsibilities of the house as well as do all the work to maintain the relationship, at least initially. Second, participants identified a clear shift from an interdependent partnership to one that was more one-sided. Third, caregiving partners talked about the stress of single-handedly managing all the finances. These three issues demonstrate the complexity of managing a relationship post-stroke.

For the participants in this study, shifting roles and responsibilities initially meant transferring all the roles and responsibilities to the caregiving partner. With this transition,

participants felt overwhelmed by the challenge of managing the house in addition to all the new caregiving tasks. For example, Iris talked about her experience with the mental, physical, and relational stress of taking on all the responsibilities for the household:

> Here I am with this man who can't talk about the relationship. Or doesn't see rationally and only sees...I felt like he's only looking at what I'm not doing. He doesn't even realize that I'm exhausted because I'm changing the bed sheets every day, and doing all his laundry, and taking him to doctor's appointments and managing the household in [CITY-US] and managing the condo in [FOREIGN COUNTRY], you know all those things. And he didn't care about any of that stuff.

The comments that Iris made are a complete illustration of my model of relational changes after stroke (Figure 4.1). The couple experienced perspective changes (i.e., caregiver and care-receiver), adapted to those changes (i.e., Iris did everything), and then they experienced a shift in their relational dynamic. Despite the difficulty of assuming new roles and responsibilities in their relationship, there was a common sentiment across the interviews with caregiving partners exemplified in Kathy's statement: "You do what you have to do." Caregivers recognized that they would need to take on more responsibility as their partner recovered. Rhonda talked about the change in responsibilities after her husband's stroke: "[We knew] that this would change our lives and I would have to be more in charge of some things that I hadn't been in charge of before." Partners also mentioned that they looked forward to the day when their spouse would regain the ability to contribute to the chores and help with other activities.

In addition to feeling the weight of all the responsibility for the family, caregiving partners experienced a relational dynamic shift when they felt forced into the role of a parent. June, a young caregiving partner, reflected on this issue by saying, "I mean, obviously our

relationship has changed. You know, it's bound to when you become more of like a mothering role than a spousal role in some ways." Partners described having to take on more of a parenting role with their husband or wife after the stroke. As a result, partners experienced blurred lines between their role as caregiver and role as spouse. Regina described the struggle of managing multiple roles: "It's a lot being the caretaker, [and] the lover, the uh…, you know what I mean?" The increase in dependence by one partner on the other was a change that stroke survivors commented on as well. Aaron noted that after his stroke he felt the roles changed: "All of a sudden you're like another baby." Neither spouse liked the change in roles from partner to parent. So, there was pushback from both sides as stroke survivors did not want to be parented and caregiving partners didn't want to parent their spouse.

The role of caregiver meant assuming responsibility for tasks that were difficult or new. One such responsibility was managing the family finances, including providing income and paying bills. Any length of time spent in the hospital by the participants in this study was expensive, and stroke survivors required rehabilitation programs once they were discharged. Further, financial issues were exacerbated when a two-income family dropped down to a single earner family. To alleviate the pressure, partners had to delegate responsibilities so they could return to work and earn money for the family. For example, Max chose to recruit the help of his son and father-in-law around the house after his wife's stroke so he could get a second job. He said, "I'll bring home more money, if you guys take care of [the house]." Betty talked about how the responsibility of managing the family accounts fell to her husband after her stroke: "Allen handled [the billing and getting the kids ready] and it's funny that he didn't know what bill had to be paid monthly, or how to balance the checkbook." Betty went on to talk about how the role changes were difficult:

> Our family [was] a shared partnership. We both worked outside of the home, we both contributed to the home and everything to make it function. And now there was this huge unknown because will I, can I go back to work, and what will that look like when that happens?

Couples who successfully navigated busy schedules before the stroke employed a division of labor in the home. That strategy, however, also contributed to the challenge of adapting to life after the stroke.

Changing interaction patterns. Partners shifted their roles and responsibilities in the relationship, but they also experienced a shift in the way they talked to one another and the topics they discussed after the stroke. Survivors commented on their aphasia and how their language appeared disjointed, confusing, or even inappropriate. Cal described the changes in his wife's ability to communicate by saying, "The pipe from the verbal part of her brain to her mouth has a problem." This disconnect between a person's brain and speech meant that couples had to develop new strategies for communicating with one another. Ruby said that after her husband's stroke she had to adapt the way she communicated: "Our conversations changed. The way I had to talk to him changed." Caregiving partners worked to be clear, slow down, and remain patient, but also became frustrated with misunderstandings. Stroke survivors commented that they too were aware of the changing interaction patterns and mentioned talking to their partner about how to manage those changes. Specifically, participants experienced changing interaction patterns due to the *longer processing time* needed by survivors and the *inappropriate communication* that is often associated with a brain injury.

Participants blamed the lack of dialogue in their relationship on how long it took to formulate their thoughts and articulate their words after the stroke. Survivors found this

particularly difficult because they knew what they wanted to say but could not find the words. Gloria remembered how hard it was to communicate after her stroke: “Well, it’s frustrating…when, in the back of my mind I know what I want to say, but it’s so far back and [I] can’t reach it.” The difficulty of not being able to express themselves was exacerbated when others would interrupt and try to help. Hope talked about the need to struggle through the stutters and pauses on her own after her stroke:

> If people put words in my mouth, then I can’t find the word that I was thinking of [and] now it’s even more difficult for me to find that word that I’m stuck on. The natural reaction for people is to try to think of that word and try to help me. But that actually makes that worse.

Hope went on to say that she and her husband talked about this issue and she told him what would be best for her: “He knows to give me my space in order to speak it out or talk it through.” The couple recognized that Hope needed more time to find her words, so they adapted their interaction patterns.

Caregivers also talked about their role in implementing new interaction strategies. Partners recognized the need to adjust and talked about how they could adapt their communication to be more effective. Regina knew that she needed to change the way she talked to her husband after his stroke:

> Maybe I’m talking too fast. I think that I forget that he has had the stroke so he’s not the same Edgar. I have to remember that when I’m talking he’s not gonna automatically finish my sentence, we might not be on the same page. It may take him a little bit longer to process the information, so I have to understand that.

Regina's comment demonstrates the need for caregiving partners to be cognizant of their own communication patterns. For example, caregivers had to become more attuned to nonverbal communication from their spouse. Jess noted that she had to watch for her husband to signal that he wanted her help during a conversation: "He just points to me and that's my cue to fill in." Others used touch or a look to indicate emotional connections that they could not fully articulate. Buckley struggled to communicate after his stroke and said, "Losing language sucks, but I communicated in other ways, which people said later made them think about how they communicate and what I did was more effective than words could ever do." Awareness, adaptation, and patience were mentioned by couples as the keys to successfully navigating their changing interaction patterns.

Participants noted a specific change in their interaction patterns as some of their conversations became inappropriate for certain audiences after the stroke. Profanity or coarse humor, which may not have been used before the stroke, emerged in conversations after the stroke. Jenni talked about how the change in her husband Calvin's language after his stroke was noticed by their friends:

> We went to church and we met another couple we know. The couple, the guy said to me, he says "Calvin's gonna really have to watch his language here because we're at church." I just, I bit my tongue. But in my heart, what I was saying is "I'm happy he can say a four-letter word, because at least he can say something." At that point in time, that was the only word he could say. That's okay.

Participants recognized that inappropriate language or joking was an element of their altered interaction patterns, but those issues seemed more difficult to explain to people outside the relationship who weren't managing the effects of the stroke on a daily basis.

The approach to addressing inappropriate language differed from couple to couple. For example, Blair talked about occasions when her husband would say inappropriate things in public or with friends after his stroke: “I don’t want to embarrass him. So, we just kind of roll with the flow or I’ll kind of nudge him like, um that probably wasn’t the right thing to say.” Jenni and Calvin’s interactions changed after the stroke as well, but she adapted and helped him understand the need to adapt as well. For example, she said that she talked to Calvin about the appropriate way to respond to the police if they ever asked for his identification: “You can’t start swearing at him. Because if you swear at him, he’s gonna have you on the ground and cuff you.” On the other hand, Chris, a caregiving partner, recognized that his dry, macabre sense of humor was not well received by his spouse after her stroke. He said, “I pretty well put my dry sense of humor to bed.” He elaborated by mentioning, “Before the stroke, she’d laugh, and then I had to put all that away. I had to watch any type of uh, levity, I had to watch what I was doing, what I was saying.” After her stroke Chris chose to alter his humor because he did not want to offend his wife. These examples illustrate the ways caregivers were mindful of interactions that may have been perceived as inappropriate or offensive.

Overall, survivors and caregivers experienced significant changes within their relationship that in turn influenced other areas of their lives. Specifically, participants chronicled the changes they noticed in themselves, their partner, and their romantic relationship. Those changes led couples to respond by making a plan and taking action, even as they struggled to cope with their lives after the stroke. As perspectives shifted and spouses responded to those changes, the relational dynamic was altered as well. Throughout this process, participants noted that change was a constant.

Uncertainty and Stroke

Uncertainty was portrayed as a constant by the participants in this study (Figure 4.2). From the moment the stroke occurred, questions about health, financial security, and the relationship began to emerge. To better understand the various aspects of uncertainty associated with stroke, I proposed three research questions that I will address in this section. First, I discuss how couples *appraised* the uncertainty they encountered after the stroke. Next, I present the various *sources of uncertainty* that partners articulated during our interview. Finally, I focus specifically on the experience of *relational uncertainty*.

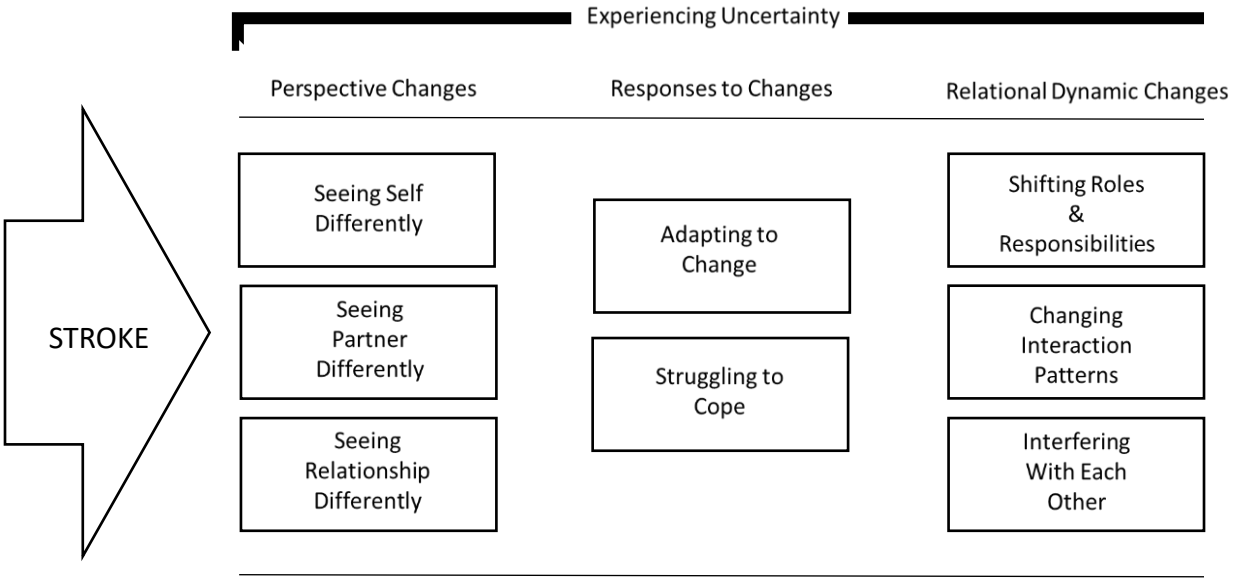


Figure 4.2. A model of relational changes after stroke within romantic dyads (emphasis on "Experiencing Uncertainty").

Uncertainty appraisals after stroke (RQ2). The second research question examined how stroke survivors and their partners appraised uncertainty after a stroke. Uncertainty, as articulated in Chapter 2, is an awareness that there is insufficient information to make sense of an experience, interaction, or relationship. The appraisal process is how people think about the uncertainties they experience. In this study, couples wrestled with questions about the physical,

cognitive, and relational aspects of stroke. They noted experiencing uncertainty from health-related sources, as well as from the changing nature of their relationship. Survivors and caregivers alike experienced the uncertainties they associated with the stroke as something that was *ever-present*, an *impetus for action*, and *changing over time*. I address each of these points in the following sections.

Uncertainty as ever-present. Participants experienced uncertainty as a constant factor in their lives. Some of the unknowns that originated at the stroke event (e.g., "Should we go to the hospital now?") morphed as time went on (e.g., "What if we had gone to the hospital earlier?"). That pattern led people to appraise uncertainty as ever-present (Figure 4.2). Participants talked about how the outcomes of the stroke continually generated questions related to various topics including the diagnosis, their relationship, and the future. Joan talked about how questions related to her stroke in 2004 were on her mind daily:

> I don't dwell on it but I'm gonna say it probably pops up every day because I'm affected by the stroke in one way or another, whether it's good or bad I'm reminded of it. So, I do think about it and think of how would things be different? Would I be in a totally different career? Where would I have gone? Where would things be different?

As Joan articulated, the stroke and the uncertainties that emerged from that event were regularly on her mind.

Survivors and caregivers considered the questions surrounding the stroke event to be a constant, even if they did not talk about those unknowns or dwell on them daily. In fact, even as survivors regained their mobility and cognitive function they reported that the stroke event was still a lens they used to view other areas of life. Anna, a stroke survivor, noted that, "[The stroke is] an ever-present thing…, but it doesn't impact daily life. It does impact the 'okay, what's our

future gonna look like? Are we gonna be able to go on trips together, are we gonna have a retirement?'" The questions generated by the stroke were considered to be an ever-present aspect of life even though they did not directly impact daily decision making.

Uncertainty as an impetus for action. Participants described feeling discouraged by the prolonged, chronic uncertainty that they associated with the stroke. The frustration of not having a diagnosis, struggling with speech, or changes in the relational dynamic led people to reconsider the ongoing uncertainties as a catalyst for action that motivated them to adapt. Anna felt that uncertainty was controlling her, and she finally had to take action to reconceptualize the unknown:

> I don't know what caused it. That is triple as frightening. So, I think people with undiagnosed issues who have strokes, I was scared for probably the first month. Every time I would get like a slight headache, and again I had a one year old who's screaming and crying, you know you weren't sleeping very well, so you might get a tension headache. And I knew the difference between a tension headache and the headache that I had when I had a stroke. But you still get super, super fearful. And you're like, "oh my god, am I gonna stroke out again? Am I gonna?" And it kind of controls your life for a little bit, and then eventually, you just have to let go. And be like, "if it's gonna happen, it's gonna happen." It's like "if I die and have a huge one today, then it's gonna happen. Just keep, keep living."

Anna recognized that the uncertainty was ever-present and then only way she could manage the mounting unknowns was to take action and think about them differently.

Other participants also embraced the uncertainty they experienced after a stroke and used it as a justification to live in the moment. Cal and his wife were mired in uncertainty after her stroke, so they chose to take what action they could and focus on the present:

> For a little while a few years back, it was a little bit of, "I don't know how long she's gonna be around." So, it kind of brought in some, strictly speaking mild hedonism. Not in the fact that we were, running around naked on a beach or anything but like "let's enjoy life now" because she might be gone tomorrow.

Cal and his wife encountered an overwhelming amount of questions after her stroke, but they chose to reconsider that uncertainty as motivation for taking advantage of the time they did have together.

Uncertainty as appraised and reappraised. Participants identified an initial appraisal of uncertainty immediately following the stroke. They also talked about reappraising that uncertainty weeks, months, or years later. For example, survivors expressed feeling overwhelmed with questions as they laid in the hospital bed and interacted with the medical staff (e.g., "Will I ever be able to walk again?"). As time went on, individuals regained lost mobility, improved language, and enhanced cognitive functioning, and with those new developments they reassessed their original uncertainties (e.g., "Will I ever be able to run another marathon?"). Ruby talked about these changes as she cared for her husband after his stroke: "There was maybe three or four weeks where we didn't communicate, where I thought 'oh my gosh, are we ever gonna talk about something again? Are we ever gonna have a conversation?' Now I can't shut him up." Ruby reassessed her situation based on new information. In the interview, she went on to say that her partner's ability to speak is no longer an issue. Other participants also commented

that the way they initially thought about various uncertainties changed over time based on new information or an altered view of the unknowns.

Overall, participants felt that the ongoing experience of uncertainty was not sustainable. They viewed the unknowns associated with the stroke as a motivator to take action or reconsider how they enacted their relationship. Further, as new information came to light, or the prospect of new developments dwindled, people had the opportunity to rethink their initial uncertainties. As people adapted to various changes, settled into their new roles, and altered their interaction patterns, they could consider and reconsider how they thought about the ongoing uncertainties they associated with stroke.

Sources of uncertainty (RQ3). The third research question examined the sources of uncertainty that individuals reported experiencing after a stroke. Although participants in this study experienced uncertainty from multiple sources, the most salient across interviews were questions about *health* and *financial security*. I address each of these sources in the following sections.

The primary sources of uncertainty that participants encountered after the stroke were health-related. Survivors remembered being in the hospital after their stroke and questioning if they would ever walk again, be able to talk as they once did, or be healthy enough to return to work. Health-related uncertainties that emerged from physical/cognitive ability dominated the initial response to stroke. For example, when Dale had his stroke in 2016, he was told he may never walk again. After being in the hospital for a few weeks, he started attending outpatient physical therapy three times a week. He remembered how they tried to help him walk when he first arrived, but he was not successful. After a few more sessions, they tried again:

> The second time, pardon me, this is very emotional. The second time this, uh PT, she said, "We're gonna see if you can walk today." And I got up in the hallway, and I, you know, got out of the chair. And she hung on to the belt behind me, the gate belt, and I had the railing, and I started walking. That was when I knew I'd walk again, until then I didn't.

The uncertainty of whether the physical effects of stroke would remain or abate was a question that survivors and caregivers wrestled with in the immediate aftermath of the stroke. As time went on, however, participants began to consider other questions related to their health.

Age emerged as a health-related source of uncertainty that participants associated with stroke. The average age of the participants in this study at the time of their stroke was 46 years old. Participants felt that since they were so young they were not at risk of having a life-altering stroke. This health-related uncertainty led survivors and caregivers to question why the stroke occurred and what the long-term consequences would be from having a stroke at such a young age. Joan, who had her stroke in 2004 at age 27, considered these questions at the time of her stroke and then 13 years later:

> I'm so young and what am I supposed to do at this point? I still think as I'm getting older, I start to think, okay well I was able to recover from my stroke I think so well in the beginning because of my age, but now I'm kind of questioning well what's the long-term prognosis? Is my brain gonna age faster than it normally would? What's gonna happen? Should I be worried about things like dementia and other age-related diseases setting in, is it maybe [the] stroke catching up?

Joan had a stroke despite her age and good health, so those factors were the primary source of her uncertainties. Survivors were also aware that having a stroke so young contributed to various

other unknowns they experienced, including questions about the likelihood of another stroke in the future. Luke talked about the unknowns surrounding the future health of his wife, Anna, who had her stroke in 2014 at the age of 29, and how he might need to respond to those changes:

> There was a little bit of recognition that there may be more that I was going to have to do for caring for her. Which hasn't happened yet, but the recognition that it may happen in the future. You know and there was a little bit of fear that having had one, will she have more?

Luke was uncertain about the long-term consequences of Anna having a stroke so young. He and others were also thoughtful about how the roles in their family may be altered even more in the future as the couple continued to get older.

Age related questions about why the stroke occurred and the potential for future complications were reified when medical professionals seemed unwilling or unable to provide answers. Seth remembered asking the doctors and nurses repeatedly about what caused the stroke and if they could make his wife more comfortable while she was in the hospital. He recalls deferring to the medical experts, but not getting answers: "I know [the medical staff] have their hands tied, but at the same time you just know that there are things that can be done a little different to help the situation." Additionally, Anna talked about how the hospital staff was as perplexed as she was after her stroke: "[My stroke] was an unknown. And then they said, 'we couldn't find the clot, we don't know really what's going on, your blood pressure's never been high…'" Anna went on to say, "I remember at the first hospital, once I came to, they were all very nonchalant about it because they thought I was fine like they had never seen anybody my age with stroke symptoms." The health-related uncertainty that Seth, Anna, and others in this study experienced was exacerbated by the lack of information from the medical staff.

In addition to questions about health, participants wondered how to negotiate various household management issues that emerged after the stroke. Specifically, survivors and caregivers discussed how the future financial security of their family was a big question following the stroke. Couples who were two income families with mortgage payments, kids in school, and other financial responsibilities recognized the uncertainty of their financial future as one partner had to shoulder the entire financial burden after the stroke. Ava said that her stroke incited concern about the financial future of her family: "I worried about where, and of course it was much later, where's the money going to come from?" The lack of financial security was something that survivors, as well as caregiving partners, experienced as they struggled to go back to work and support their family. June remembered that after her husband's stroke she had no idea how they were going to maintain the lifestyle they had prior to his illness: "We had two brand new cars, so my concerns were financially how in the hell are we gonna do this? I was worried about financials, I was worried about my child's future--like what is it gonna be like?" Ava noted that financial uncertainties emerged "much later" and June talked about how this would likely be a long-term question in the family. The uncertainty related to financial security as well as health-related issues were presented by participants as ongoing issues that originated with the stroke.

Relational uncertainty (RQ4). The fourth research question examined the ways that stroke survivors and their partners experienced relational uncertainty after a stroke. Participants talked about how they faced questions regarding their commitment to their spouse, their partner's desire to remain in the relationship, and the unknown future of their marriage. The three sources of relational uncertainty (i.e., self, partner, relationship) began to emerge shortly after the stroke as partners began to realize that they had both changed (Figure 4.2), but those unknowns seemed

to linger as couples faced various stroke-related changes over time. In the following paragraphs, I discuss how couples experienced relational uncertainty after stroke. I separate the construct into its basic elements by addressing *self*, *partner*, and *relationship uncertainty* individually.

Self uncertainty. In this study I defined *self uncertainty* as the questions individuals have about their future participation and place in the relationship (Knobloch & Solomon, 1999; Solomon et al, 2016). Survivors and caregivers alike struggled within a marriage that had been altered by stroke. On the other hand, the sentiment of remaining committed to one's partner was pervasive, as Dwight regularly mentioned throughout my interview with him about his wife's stroke. He noted on several occasions that it was his faith and commitment to his wife that held their relationship together even though he struggled at times to make sense of life after stroke. Participants also wondered if they could remain in a relationship that was strikingly different than it was prior to the stroke. Questions about how individuals saw themselves within the relationship included an element of self-exploration. For example, Jess reflected on the difficulty of managing her perspective change after her husband's stroke when she said:

> In my case I mean, I really had to think okay, who am I really? You know, I claim to be a Christian and I made these vows when I got married. You know for better or for worse, rich or poor, all these things. And of course, you always think it's gonna only be the good ones. But it isn't. The pendulum swings [in both] directions. And everybody's going to experience these things. So, the question is, who am I, who do I profess to be, and can I actually carry that off? Can I be true to my words and my oath that I made all those years before?

Jess was struggling with how to conceptualize her commitment to her husband, Earl, who was a totally different person after his stroke. The focus, however, was not on Earl or even the

relationship, but on Jess trying to make sense of how the stroke changed her and how those changes would impact her wedding vows.

Others mentioned that their commitment involved not wanting to leave someone to go through life after stroke all alone. For example, Sarah worked to keep her family together after her husband's stroke and noted at several points during the interview that he did not deserve to be alone even though it was difficult to stay in that relationship:

> I think, it stems from this, not so much from a commitment of marriage, because I was certainly, I have been ready to get out of it for a long time. I don't know how long he is going to live, but he's a good guy, [he] doesn't deserve this.

Here, Sarah is not questioning her commitment as much as she was trying to understand how she saw herself in that relationship moving forward. She was a caregiver, but she wasn't sure if she was still a partner. The findings indicate that the questions participants had about their place in the relationship after stroke were related to the altered perspective they had of themselves as a partner.

Partner uncertainty. Survivors and caregivers in this study recognized that their partner was different after the stroke. That change in perception gave rise to questions about how committed one's partner may be to the relationship, known as *partner uncertainty* (Knobloch & Solomon, 1999; Solomon et al, 2016). After the stroke, participants remembered wondering what their partner thought about them and the relationship. For example, Hope and her husband, Cal, talked frequently about the changes in their marriage after her stroke. Those conversations created an opportunity for him to share his uncertainty and say that he suspected she didn't love him anymore. Hope replied, "Well, I kind of don't." The stroke had stripped the empathy section of Hope's brain and therefore she had difficulty feeling emotionally connected to others. Cal

knew that his wife had changed, but seeing those changes expressed by his spouse in such an intimate way was difficult. Buckley also wondered if his wife wanted to leave after his stroke. The therapist he was seeing at the time suggested he have a conversation with his wife about how she saw their future together. He remembered telling his wife, Saffron, that having a stroke was not in their plan: "I know you weren't asking to be a caregiver, but I understand if you want a divorce." Saffron replied that she took her vows seriously and was not planning to leave. Buckley talked about how afraid he was to have that conversation with his wife, but he said he needed to know how she felt.

Participants noted that although they questioned if their partner still wanted a relationship, they rarely discussed the topic. For example, Gloria, a stroke survivor, talked about how she was uncertain about whether or not her partner still loved her after the stroke: "It's been six years [since the stroke] and I know that I have to move on, I don't think he loves me. He's said it, but I don't think so." That position was countered by the uncertainty that her partner expressed regarding the same issue. Harold said, "Well I can only say that from my point of view I don't know why she sticks around. I've asked her: 'Why? If you don't want to talk to me why are you still here?' Doesn't answer. So, I don't know." These examples speak to how partner uncertainty further isolated individuals after the stroke.

Participants also recognized a change in themselves that led them to question if their partner would want to remain in the relationship. The struggles that accompanied Anna's life after stroke and the fact that she saw herself differently encouraged her to question why her husband, Luke, remained married to her: "He stood by [me through] it all and yeah there were times when I pinched myself, and there are times when I talk to him, I go 'Why haven't you married a skinnier, prettier person? Like what is wrong with you?'" Likewise, Steve was unsure

about how his wife, Sarah, felt about him after his stroke. He didn't want to bring up their future in conversation because he was unsure how she would respond: "I don't want to talk about it unless she wants to as well." Participants wondered if because they had changed after the stroke their relationship would change as well. They also questioned if their partner would even want to be in a relationship due to all the stroke-related changes. The uncertainty about a spouse's commitment seemed to be a difficult topic of conversation between partners in this study.

Relationship uncertainty. In addition to questions about their own and their partner's involvement in the relationship, uncertainties emerged around how the relationship would continue in the future. Couples living in a post-stroke relationship voiced questions about *how* the relationship would continue, but also wondered *if* the relationship could continue. For example, Iris said, "I had a lot of questions about the future and what we should do. I love him. That was never...I never questioned the fact that I loved him. It was just could I live with him?" Iris knew she still felt the same way about her husband after his stroke, but she struggled to make sense of how their relationship might be affected by the changes in their lives. Couples had to make sense of how they would respond to the changes in their relational dynamic due to the stroke, as exemplified by Aaron: "Next thing you know, because of everything that happened, my wife and I left that house and we bought a fifth wheel trailer because we didn't have a clue what life was gonna look like for us." Aaron and his wife, Blair, struggled with questions about what would come next for their family, and making a lifestyle change (buying the fifth wheel trailer) helped them move on together and focus on their relationship amidst the uncertainty.

Responses to relationship uncertainty were not always collaborative. Fluctuations in their post-stroke relationship led stroke survivors to consider preempting their partner's decision to leave by pushing their spouse away first. Survivors recognized that they had changed physically

and/or cognitively and those changes created what some considered to be an undesirable situation for their partner. For example, Betty said that after her stroke she pushed her husband away because she did not think he would want a relationship with her anymore:

> I felt like things had changed so dramatically that he needed an out. I felt like when we got married taking care of a 42-year-old woman with a stroke and having some of those disabilities was not what he signed up for. I mean when we got married that wasn't on my mind, that wasn't what he signed up for so, I initially was pushing him away very strongly and actually at one point I said to him: "This isn't what you signed up for, if you would like to go our separate ways I am okay with that." I really wasn't okay with it but it seemed like I needed to give him that opportunity to have an out.

Betty offered her husband "an out" because she thought he may not want to be in a relationship with her due to her stroke-related health issues.

The nature of the interview process allowed participants to tell the story of their relationship post-stroke and reveal the questions they had about how the stroke would influence their future as a couple. Cal encapsulated the experience of relational uncertainty when he talked about how perspective changes generated questions about the future with his wife, Hope, after her stroke:

> When you have somebody who has a very well-built personality that you grew to love and that relationship has then further shaped the personality and [then] all of a sudden you dig out a third of one side of their brain, who knows what came out? Now she is a different person overnight that's very similar to the person you married, but not the person you married. And you have to start from square one, that square single digit, and

> go “ok, I learned to love her once before. I can probably learn to love this person who’s very similar to her. And she can probably learn to love me.”

In this brief quote, Cal demonstrated the complexity of relational uncertainty. First, he reflected on the fact that the person who came home from the hospital was not his wife, but someone “similar to” his wife. That change led him to question how their relationship would continue when he said, “I can probably learn to love this person” (i.e., self uncertainty). He also questioned her future commitment when he said, “she can probably learn to love me” (i.e., partner uncertainty). Other survivors and caregiving partners interviewed questioned their own commitment, their partner’s dedication, and the nature of the relationship long after the stroke.

Overall, uncertainty associated with stroke was conceptualized by participants as an ongoing and complex experience. They felt uncertainty arise from health-related issues and wondered about the future financial security of their family. Finally, survivors and caregivers encountered questions about their ability to honor their marital vows, their partner’s desire to stay in the relationship, and what the relationship may look like in the future. From the moment the stroke occurred, couples were faced with a barrage of unknowns that persisted over time.

Interference from a Partner (RQ5)

The fifth research question focused on how individuals encountered interference from a partner after stroke. Interference from a partner is defined as one spouse inhibiting the everyday goals and routines of the other spouse (Solomon et al., 2016). The interview protocol included several prompts about issues related to interference from one’s partner (Appendix E), including the question, “Were there ways your partner made it harder for you to complete your everyday activities after the stroke?” Participants regularly addressed this prompt by saying that their partner did not interfere with their everyday activities. The nature of the semi-structured

interview format allowed me to ask for clarification, but that rarely led to much explanation. If participants did elaborate on instances of interference from their partner, they would generally mention hindrance as part of larger stories about life after stroke. Because participants seemed reluctant to overtly say that they were experiencing interference from their partner, my research team and I regularly discussed this research question, the definition of the code, and the exemplars in the codebook to make sure we were accurately depicting the reality of interference from a partner post-stroke. In fact, Tracy (2013) notes that talking to others is an important part of the iterative approach to data analysis. In the end, the coded data for this research question was not as large as the data for the other research questions, but partners did experience interference from one another after stroke. In the following paragraphs I highlight three aspects of interference from a partner. First, I present quotations from stroke survivors and caregivers illustrating how interference from a partner was *embedded in their story* about the stroke changing their relational dynamic. I then focus on the *lack of independence* and *career decisions* as two of the issues partners cited as causes of the interference they experienced from each other. Finally, I address the *relational ramifications* of interference from a partner post-stroke.

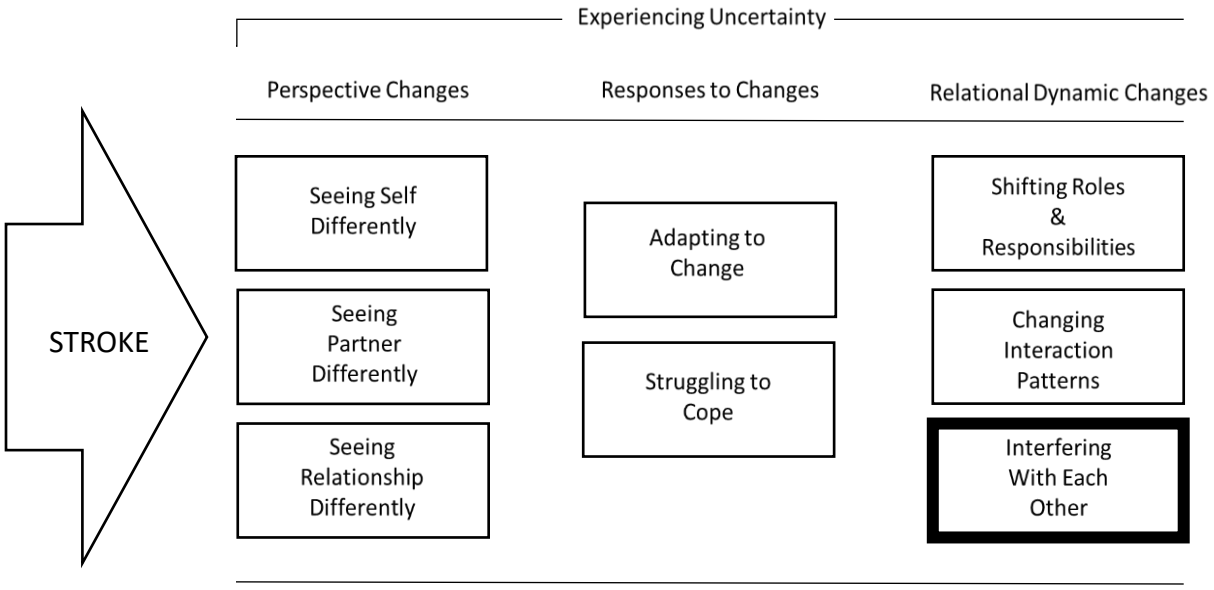


Figure 4.3. A model of relational changes after stroke within romantic dyads (emphasis on "Interfering with Each Other").

Across the interviews, participants intermingled the interference they experienced from their partner with how the stroke impacted their relational dynamic (Figure 4.3). As caregivers and survivors described life after stroke, they reported experiencing interference from their partner that included life-altering intrusions that had to be managed. June recounted how her whole life changed after Clark, her husband, had his stroke:

> He wouldn't allow us to leave him alone in the hospital, so we would do shifts where we would sleep there. So, the last couple weeks before he got discharged I slept on a cot every day. I don't think he needs someone to sit with him 24 hours like he used too, but I also find it inhumane to leave him alone longer than an hour because if he needs to go to the bathroom I don't think he should have to hold it just because he can't walk on his own. If he's hungry, I don't think he should have to sit there starving because no one's home.

In an instant, June became a full-time caregiver and her schedule revolved around making sure Clark was comfortable. Additionally, when she was away from the house for too long she felt that she was interfering with Clark's desire to not be left alone.

The data also show that the experience of life changing interference from a partner was not limited to the caregiver. Donna, a stroke survivor, mentioned that her ability to be spontaneous with her husband led to a feeling that they were both interfering with each other:

> If I know something's coming up, I rest the day before, I know I have to rest the day after. And I only do that particular thing, but I know it's coming up. Which means if he [Max] wants to do something that day whether it's go to a movie or do whatever, you know you sometimes can't do things because something else is interfering. My brain gets tired very easy, if that makes sense. I think he gets upset because I save my brain energy for one thing a week. I think it frustrates him that I have a lot of limitations.

June and Donna both shared how interference from a partner presented consequences for their spouse. The stroke changed their relational dynamic by shifting the way they had to plan their lives with their partner.

In line with thinking about interference from a partner as a dyadic issue, one of the ways partners encountered interference from one another was the perception that each person was infringing on the other's sense of independence. Stroke survivors felt homebound and separated from society. Calvin articulated this experience after his stroke by saying, "My wings were clipped. I can't go out anywhere." The reason that Calvin felt interference from his partner, Iris, was because he was not able to drive the family car and she was not always able to drive him when and where he desired. The struggle of losing one's freedom to be spontaneous meant that partners were more interdependent and had to coordinate their outings together. At the same

time, caregiving partners expressed the need for periods of separation for their own mental health, to recharge emotionally, or to manage the household. Regina remembered confronting her partner, Edgar, when he scoffed at her desire to get her hair and nails done after his stroke: "I have to tell him 'hey, hold it, brother. That's the only time I have is Saturday to make the appointment, because I'm working all through the week so, Edgar, you know, I have to have some time.'" Caregivers and survivors alike felt that their independence was stifled when their partner made plans that conflicted with their own agenda. Specifically, survivors felt that they were missing out or being left behind when their partner made plans without them, and caregivers felt that they needed to step away at times to run errands or manage stress. The data suggest that negotiating schedules to limit the feeling of burdensome dependence was a goal for both partners, but it was difficult to achieve within the context of a changing relationship.

A second source of interference from one's partner arose as caregivers sought to continue their careers after the stroke. Participants referenced the progress they wanted to make on their career goals and how the stroke altered those plans. When the stroke occurred, caregiving partners felt they had to give all their attention to the stroke survivor. That choice meant that their projected career timelines suffered. People talked about trying to go back to work, but managing a full-time job and the caregiving needs at home was difficult dilemma. Iris discussed balancing the responsibilities of her career and caring for her husband after his stroke:

> [After the stroke] I'm trying to work, I'm trying to have a normal life. I'm probably in denial. I'm trying to make it like everything's fine and nothing ever happened but – that's not gonna happen. It's not gonna be that way.

She went on to talk about how something had to change. Iris tried to manage her career and caregiving for a while, but she eventually recognized that working outside the home was not

going to be an option. The relational dynamic had changed. She said, "I went part-time for a while and then I just quit. He was upset and angry with me and felt like I didn't support him. But I knew that for my own well-being that I had to do that." Additionally, Buckley noted that after his stroke his wife's career was set back because she was taking care of him and not advancing at work: "She was a math teacher at the time, and she couldn't publish because she was so busy with me. She couldn't do her career and take care of me and the kids." In a post-stroke relationship, the demands of caretaking coupled with the desire to continue pursuing a career were overwhelming and usually required that partners choose one or the other.

Although less explicit than the causes of interference from a partner, participants did mention consequences of inhibiting one's goals or daily activities after a stroke. Caregivers and stroke survivors both felt that efforts to help throughout the recovery process were complicated. At times, the helpfulness of the caregiving partner actually impeded the recovery process of their spouse. For example, Betty struggled to get her words out after her stroke, but her husband, Allen, was always willing to help her. The help that Allen provided, however, was not always well received by Betty, a point they both mentioned in their individual interviews. Allen remembered wanting to help, and since they had been married for 20 years, he thought he could anticipate what Betty was trying to say:

> I know what she wants to say and that makes her very aggravated when she's speaking or… we're talking about something and I know exactly what – and I know the answer to the question or [can] finish her statement before she gets it completely out, that causes a lot of friction because she says "hey, you're cutting me off. Why are you cutting me off?" "I know what you're asking. I know what the answer is before you even finish." Then she gets upset [and] shuts down for two or three days and then we don't talk.

Allen interfered with Betty's goal of relaying her thoughts on her own and that choice introduced relational consequences. Likewise, Betty understood that Allen was trying to help her, but she knew that she needed to struggle through on her own so she could recover and not be dependent on Allen for speech:

> You just don't want to see your partner struggle and in trying to do [things] for them so they don't struggle and trying to make it easier for them sometimes it's a detriment because you know they are trying to get better too. I think sometimes for us, I know for me, that would be a very frustrating thing and it was very detrimental at some point and could often cause a number of arguments, or discussions, hot topics if you will, because I would tell him, don't finish my sentences. When I would finally get my words, I would say not to finish my sentences, or I could just give him a look that said, "Don't, you know not to finish my words." But it's done out of caring and I think caring and love, you just don't want to see your partner struggle, but it could be detrimental.

Betty and Allen had to negotiate the changing relational dynamic that emerged after the stroke, but the interference they experienced from each other was complex. Allen sought to facilitate Betty's recovery, but in doing so he introduced more frustration and stress into the situation. The recognition that helping may be hurting was a sentiment that emerged in other interviews as well. Jenni noted, "I pamper him too much. When I do that, I get angry at myself because I love him. That's why I do it. But I also am not helping him because he's not independent." Jenni acknowledges that her desire to help also restricts her husband's recovery from his stroke. The recognition that one's effort to help in the recovery process was actually interfering with a partner's ability to regain speech, for example, was a difficult realization and contributed to the complexity of how people conceptualized interference involving their partner.

Interference from a partner was a difficult topic of conversation for participants during the interviews, but the data suggest that it was an experience that couples regularly encountered. Embedded in their stories about the stroke and their recovery as a couple were instances in which partners felt that a lack of independence and their efforts to continue their career contributed to the interference they experienced in their relationship. Additionally, the notion that efforts to support one's partner could also be interfering with the recovery process made the relational dynamic post-stroke even more complex.

Conclusion

The participants in this study discussed several difficult relational changes that they associated with stroke. They talked about how they experienced perspective changes in themselves, their partner, and their relationship. Couples noted how they struggled to cope with those changes even as they worked to adapt to their new lives after the stroke. Partners commented on their new roles and responsibilities. Even the ways that partners communicated and the topics they talked about changed after the stroke. The immediacy and newness of the various changes introduced a myriad of unknowns including questions about health, finances, the future, and the relationship. Couples wondered if there would even be a relationship in the future or if it would ever be the same as it was before the stroke. The effects of stroke on relationships were summed up by the participants who said that a stroke changes everything all at once.

CHAPTER 5: DISCUSSION

Modern medicine often takes a pathological approach to the study of illness. Yet, interpersonal relationships as a part of research on illness related stressors have been studied across disciplines (e.g., Anderson et al., 2017; Banks & Pearson, 2004; Unson et al., 2015), mentioned in the Hippocratic Oath (Markel, 2004), and included in multiple theories (Brashers, 2001; Mishel, 1988), illustrating their importance. When an individual has a stroke, immediate medical attention is crucial (Kim et al., 2017), but after a hospital stay, treatment becomes less medical and more relational (White et al., 2014). Researchers have begun to look beyond the pathology of illness to the relational implications involved with the occurrence, treatment, and recovery from a major medical event. My study adds to that line of inquiry by focusing on the romantic dyad, drawing connections to theory, and offering practical implications for stroke survivors and caregivers.

In this project, I utilized sensitizing concepts from the uncertainty in illness theory (Mishel, 1988), the uncertainty management theory (Brashers, 2001), and relational turbulence theory (Solomon et al., 2016) to frame the research questions. I employed Tracy's (2013) pragmatic iterative approach toward data analysis to construct a model of relational changes after stroke within romantic dyads (Figure 4.1) and addressed five research questions: (RQ1) What do survivors and partners report as the effects of stroke, if any, on their relationship? (RQ2) How do survivors and partners appraise uncertainty after a stroke? (RQ3) What sources of uncertainty, if any, do individuals report experiencing after a stroke? (RQ4) In what ways, if at all, do couples experience relational uncertainty after stroke? (RQ5) In what ways, if any, do individuals experience interference from a partner after stroke? The previous chapter addressed each research question in turn, and I discussed how the model represented the experiences of the participants. In this chapter, I show how my findings extend previous research and existing

theory. The following sections situate this project within the broader literature on the effects of stroke, relational change, and uncertainty management. I then identify theoretical and practical implications, limitations, and opportunities for future research.

The Immediate and Lasting Effects of Stroke on Romantic Relationships (RQ1)

The first research question focused on the relational effects of stroke as identified by survivors and caregivers. Findings complement and extend research on how couples negotiate illness-related stressors by showing that partners experience three aspects of changes within their relationship: (a) perspective changes, (b) responses to change, and (c) relational dynamic changes. First, previous research has found that the impact of stroke on individuals can resonate throughout the relationship as partners see themselves and their future together in a new way (Buschenfeld et al., 2009). Additionally, post-stroke changes create an environment where couples must adapt, even as they struggle to cope with their new situation (McGurk et al., 2011; Saban & Hogan, 2012). Finally, as perspectives shift, and couples respond to life after stroke, their relational dynamic is altered as well (McCarthy & Bauer, 2015). Throughout this process, stroke survivors and caregiving partners experience uncertainty stemming from the stroke event and the changes they encounter after the stroke (Brann, Himes, Dillow, & Weber, 2010). The model emerging from the data (Figure 4.1) incorporates each of those elements and builds on previous research that links health-related stressors and relational change (e.g., Acitelli & Badr, 2005; Brashers et al., 2000; Mishel, 1984; Weber & Solomon, 2008). In the sections that follow, I draw connections between my results and the broader literature on relational changes associated with stroke. Specifically, I address how the relational effects of stroke are interconnected and manifested through perspective changes, responses to change, and relational dynamic changes.

Perspective changes. Scholars have long depicted "chronic illness as a biographical disruption" (Bury, 1982, p. 167) that can alter the way people perceive themselves (Pearlin, Menaghan, Lieberman, & Mullen, 1981; Pearlin, Mullan, Semple, & Skaff, 1990; Williams & Jones, 2017). Research has also shown that reconstruction and reformation of one's self-concept in the wake of a major illness is challenging (Radcliffe et al., 2013) and time consuming (Glintborg, 2015). Consistent with previous research that highlights the impact of stroke on one's self-concept (Buschenfeld et al., 2009; Murray & Harrison, 2004), survivors and caregivers in the current study indicated that the stroke altered the way they perceived themselves and that those changes were difficult to manage. For example, survivors juxtaposed their physical and cognitive abilities before and after the stroke. During the interviews, they shared how specific changes influenced the way they thought about themselves. Results also affirm Murray and Harrison's (2004) finding that when changes were assessed as permanent, survivors felt as though they lost part of themselves due to the stroke. Additionally, caregiving partners in my study talked about how they saw themselves differently in relation to the roles they chose or assumed after the stroke. They also mentioned that they struggled to maintain their identities as a spouse amid caregiving activities, which aligns with the findings by Bushenfeld et al. (2009). My results suggest that the stroke was a disruption to the way people saw themselves and that the resulting changes were immediate and impactful.

In addition to self-focused perspective changes, the data showed that participants acknowledged seeing their partner differently after the stroke. My results support previous research on the tension that arises as spouses were confronted with an altered view of their partner after stroke. Findings complement work by scholars who have utilized the relational dialectics theory to frame opposing forces, conflicting goals, and difficult decisions that emerge

after stroke (Brann et al., 2010; Pawlowski, 2006). Relational dialectics theory offers researchers a way to discuss and investigate opposing forces, conflicting goals, and difficult decisions within relationships. According to Baxter (1990), a *dialectic* is set of "paired opposites" (p. 70) that creates an ongoing, unresolvable tension. Dialectics exist at all levels of social interaction, but relational dialectics theory was created to explore how couples manage internal and external tensions in various types of relationships such as parent-child relationships (Braithwaite & Baxter, 2006), romantic relationships (Baxter & Widenmann, 1993; Montgomery, 1984), and close friendships (Bridge & Baxter, 1992). Within the current study, caregiving partners struggled with the tension of seeing their partner as changed by the stroke, while actively remaining hopeful for a full recovery, a tension that Brann et al. (2010) referred to as the *realism-idealism* dialectic. Caregivers also talked about how the stroke led them to see their partner as a burden at times and how they struggled to navigate the tension between their partner's increasing dependence and their own desire for independence. The tension between *dependence-independence* was expressed by survivors as well as caregivers and was exacerbated by a recognition that the other person had changed and needed more attention (i.e., survivors) or needed to provide more attention (i.e., caregivers). This tension created additional stress in the relationship and required couples to adapt their dynamic even as they struggled to cope with an altered perspective of one another.

The data suggest that the perspective shifts at the individual level contributed to relational change. The findings also affirm previous research on the power of a major illness to influence how individuals view and enact their role in the relationship (e.g., Bushenfeld et al., 2009; Thompson & Ryan, 2009). Specifically, partners mentioned that caring for their spouse and making unilateral decisions for the household shifted the power dynamic in their relationship in a

way that added stress to an already difficult situation. For example, caregivers assumed new intimate responsibilities when necessary that involved bathing, dressing, and feeding their partner. Stroke survivors also noticed the power shift and disliked being cared for even as they recognized their reliance on their partner. The results also add to work finding that how couples recalibrate their relationship after stroke is an important aspect of future marital success and post-stroke recovery (e.g., Anderson et al., 2017; Banks & Pearson, 2004). Changes in perspective prompted participants to adapt by rethinking their marriage or by separating. Seeing the relationship as unchanged was not an option for participants, especially in the short-term, but how they chose to see the relationship and its future was an ongoing assessment that evolved over time and reflected the developments and setbacks of life after stroke.

These findings on perspective changes enhance knowledge of intimate relationships after stroke by highlighting the interplay between seeing one's self differently and seeing one's partner differently, as well as how those shifts influence perceptions of the relationship as a whole. A growing trend in the literature on post-stroke couples is to include, or at least mention, the experiences of stroke survivors as well as caregiving partners when discussing the relational effects of stroke (see Anderson & Keating, 2017 for a systematic review). The perspective changes addressed in that corpus, however, are often bifurcated in their presentation and rarely reflect the communal experiences of both partners (Bran et al., 2010; Pawlowski, 2006). Yet, previous research has shown that survivors and caregiving partners often "undergo a parallel journey" as they navigate life after stroke together (Banks & Pearson, 2004, p. 414). Results from the current study add to the notion of a shared experience after stroke that influences individual and relational changes. Further, these data suggest that perspective shifts impact how couples adapt by altering their relationship after the stroke, as alluded to by Anderson et al.

(2017). The results are represented in a model that supports, unifies, and extends disparate research to show the common effects of stroke within relationships that caregivers and survivors both experience (Figure 4.1).

Responses to changes. Findings indicate that participants responded to their altered perspectives by taking action even as they struggled to cope with the many changes caused by stroke. This response is consistent with previous research on the complex situation that couples face as they work to adjust their behaviors, routines, and thinking post-stroke (O'Connell & Baker, 2004). Participants across studies have talked about their experiences of having to immediately pivot to balancing new responsibilities around the house, while at the same time adapting to a new relational dynamic with their partner (e.g., Branden, 2013; Hunt & Smith, 2004; O'Connell & Baker, 2004) Adjustments to these sudden changes can be difficult and may take people time to make sense of their new roles. My data suggest that the immediacy of stroke, coupled with individual and relational changes, may shape people's experiences after the stroke.

Findings support the theoretical framework provided by the relational turbulence model by illustrating the strain that married couples went through as they encountered a myriad of changes after stroke. Previous work utilizing the theory has revealed the difficulty of managing relationship issues in the midst of a chronic illness (e.g., Weber & Solomon, 2008). Specifically, the research suggests that as partners renegotiate their relationship in the wake of a stressful life change there are more opportunities for tumultuous experiences (Solomon & Knobloch, 2004). Scholars have also employed the relational turbulence model to better understand the connection between psychological predictors, including depression, and relational turbulence (Knobloch et. al., 2013). Although I was not able to assess time order in this study, the survivors and caregivers who I interviewed felt that new topics of conflict and episodes of depression could both be traced

back to the stroke. However, since Knobloch et al. (2013) used depression as a predictor of relational turbulence, future research is needed with stroke survivors and their partners to assess what, if any, impact psychological factors have on the experience of relational turbulence after stroke.

Relational dynamic changes. Results imply that as perspectives shift and partners respond to changes, new relational challenges emerge that need attention. Caregivers recounted their experience in the immediate aftermath of the stroke as intensely stressful since they were left to shoulder the burden of providing for their partner and maintaining the household. These findings align with Quinn et al.'s (2014) meta-synthesis of 12 papers on the experiences of spousal caregivers after a stroke. Their analysis revealed that the role of caregiver is often complex and requires that individuals split their attention between a number of competing objectives, a theme that emerged in the current study as well. Similar to the dialectic of *self-orientation-partner-orientation* outlined by Bran et al. (2010) regarding the experience of caregiving partners and the *independent-dependent* dialectic of stroke survivors offered by Pawlowski (2006), participants in the current study went through a process of being pulled between contributing their energy toward their spouse and the responsibilities of managing the household. Caregivers felt the weight of shouldering all the responsibility for their partner's recovery, the maintenance of the family, and the future of their marriage, even if it was just for the period immediately following the stroke. Additionally, the push and pull between competing goals has been shown to increase depression and decrease relational satisfaction in couples after a stroke (Blonder et al., 2007). Caregivers in the current study felt conflicted about where to put their energy and how that decision would impact their relationship.

In addition to the stress of taking on multiple responsibilities, participants worked to balance hope for the future and the reality of a brain injury amidst the chaos of their new roles in the family. The current study adds to previous findings by offering accounts of how the shift in roles and responsibilities that caregivers experienced after the stroke was overwhelming and consequential for both partners (Brandon, 2013; DeLaune & Brown, 2001; Hunt & Smith, 2004; Rigby, Gubitz, & Phillips, 2009). For example, participants noted that role changes increased the stress in an already stressful situation after the stroke because they had to navigate roles that they were not familiar with or comfortable enacting. My findings also affirm previous research that shows role changes in one partner impact how both partners experience depression (Cameron, Cheung, Streiner, Coyte, & Stewart, 2011; Epstein-Lubow et al., 2009), stress (Visser-Meily, Post, Schepers, & Lindeman, 2005), and uncertainty (Green & King, 2009). The notion that individual changes resonate throughout the relationship suggests that partner effects should be a consideration in research involving post-stroke couples. Not only does the model from the data chart the shared experiences of partners after stroke (Figure 4.1), but it can be used in future research to investigate the connection between categories at the individual and dyadic levels.

Results enhance previous research on the challenges and costs of role changes for both partners. Caregivers articulated the costs of focusing on their partner after the stroke and specifically noted that they had to adjust their career goals and sacrifice their independence, at least initially. Survivors lamented the loss of various roles in their marriage (e.g., sexual partner) and society (e.g., professional employee), while also struggling with their diminished autonomy. These findings support prior research that articulates the psychological and social strain that caregivers often experience as they take on new roles (DeLaune & Brown, 2001; Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2014), as well as the impact role changes

have on stroke survivors (Pawlowski, 2006). Previous research also notes that the strain of assuming new roles and responsibilities impacts both people (e.g., Banks & Pearson, 2004; Green & King, 2009). Findings extend the notion that role changes post-stroke are difficult by offering *perspective changes* as a potential precursor to the *relational dynamic changes* that couples experience (Figure 4.1). Participants continued to struggle with their new perspectives of themselves, their partner, and their relationship even as they worked to renegotiate how they enacted their marriage.

Stroke and ambiguous loss. As the relationship dynamic changed, participants also wrestled with a sense of unresolved grief that stemmed from their partner being physically present, but psychologically absent, a concept known as *ambiguous loss* (Boss, 2010). Specifically, participants found it difficult to cope with the loss of a partner who was still alive, but who was a different person than prior to the stroke. My findings suggest that caregiving partners struggled with the realization that the person they married may never be the same again. Sibyl, a caregiving partner, said during her interview, "The man I married is gone and I am having to grieve while he is still here." Sibyl also wrestled with the envy she felt for several people in her social circle who lost a spouse and how their ability to grieve afforded a sense of closure: "[they could] say goodbye and it's goodbye and there's an end. They can grieve and move on with their lives." The ongoing role of caring for one's partner seemed to complicate the experience of ambiguous loss for caregivers in this study. In the midst of helping their partner recover, caregivers were also reminded of what they had lost.

Amid all the changes that arose post-stroke, grieving the loss of a partner who was physically present, but psychologically absent appeared to exacerbate one's experience with relational uncertainty. For example, Sarah felt that the loss she experienced after her husband's

stroke was complicated: “I am dealing with my own sense of loss and my own frustrations, at him and at the system and at the situation… I just, I can’t do this anymore., [but] I’ve accepted that I have to do this.” These findings suggest that the frustration and uncertainty associated with ambiguous loss are tied to relational changes after stroke. Other participants also recounted how they mourned the loss of one type of relationship (e.g., egalitarian marriage) while enacting another type of relationship (e.g., unequal dependence). Past research has revealed that ambiguous loss is present within post-stroke couples when partners try to make sense of a relationship that may be drastically different than the one that existed prior to the stroke (Godwin et al., 2014). Further, the experience of ambiguous loss is isolating since caregiving partners must negotiate the changing relationship, care for their partner, and plan for the future all on their own (Kreutzer et al., 2016; Landau & Hissett, 2008). Narrative accounts in my data corroborate past findings and support the idea that dealing with the loss of a partner who is physically present, yet psychologically absent is a difficult and ongoing process. The results also point to a connection between ambiguous loss and how people conceptualize their relationship that has yet to be fully explored in the literature.

Uncertainty and Stroke

Uncertainty is central to the experience of illness. Participants in this study viewed uncertainty as an ongoing and multifaceted element of their lives post-stroke. Additionally, findings add to previous research on how people conceptualize and respond to uncertainty associated with illness. Prior studies have shown that uncertainty can be appraised in different ways (Brashers & Hogan, 2013; Mishel, 1988), emerge from multiple sources (Brashers et al., 2003; Martin, Stone, Scott, & Brashers, 2010), and impact relational dynamics (Nagy & Theiss, 2013). I divided my inquiry across three research questions to interrogate the experience of

uncertainty in more detail. First, I investigated how survivors and partners appraised the uncertainty they experienced after the stroke (RQ2). I found that as individuals in this study encountered uncertainties, they appraised those unknowns as an ever-present part of their life and also as something that encouraged them to take action. Next, I examined the sources of uncertainty that couples identified as related to their stroke (RQ3). The data revealed that individuals experienced uncertainty from multiple sources, but prioritized the unknowns related to health and financial issues. Finally, I sought to understand the experience of relational uncertainty after stroke (RQ4). I found that participants recognized changes in their partner due to the stroke and those changes contributed to a period of reflection on the relationship. In the following sections I address these research questions in more detail. Each section builds on previous research to show how the current study enhances the understanding of how people experience uncertainty associated with stroke.

Appraisals of uncertainty (RQ2). The second research question examined how stroke survivors and their caregiving partners appraised uncertainty. Findings support the uncertainty in illness theory (UIT) and the uncertainty management theory (UMT) that both speak to the appraisal of unknowns that people associate with illness. The appraisal process involves a cognitive assessment about the potential harms or benefits of uncertainties that lead to different actions (Mishel, 1988). Participants talked at length about the unknowns they associated with stroke and the steps they took to address those questions. Previous research has shown that as people encounter unknowns, they use the information they have available to appraise the uncertainty they associate with their changing relationship (Berger & Calabrese, 1975; Solomon et al., 2016), medical diagnosis (Brashers et al., 2003), or treatment regimen (Brashers et al., 1998). Specifically, UIT states that individuals gather information from their environment to

determine if the questions they have imply danger or hope (Mishel, 1988). Brashers (2001) later added that uncertainty can also be evaluated as inconsequential. Uncertainty appraised as dangerous, as an opportunity, or as unimportant leads people to pursue different goals. Across interviews, survivors and caregivers felt that their uncertainty was ever-present, changed over time, and led them to action. I address each of these points in the following paragraphs.

Findings support the reconceptualized theory of uncertainty in illness (RUIT) that views uncertainty as a defining and impactful characteristic of chronic illness (Mishel, 1990). Scholars have found that the duration of health-related uncertainty can contribute to the physical and emotional toll that people experience (Brashers et al., 1998; Mishel, 1984). To better understand how people manage chronic uncertainty over time, Mishel (1990) offered RUIT to extend UIT and show that people appraise ongoing uncertainty differently than the uncertainty associated with an acute medical procedure. Additionally, King and Mishel (1986) found that the longer people were exposed to chronic, illness-related uncertainty, the more likely they were to view that uncertainty as an opportunity for change. Findings in the current study suggest that stroke survivors and caregiving partners considered the unknowns they associated with stroke to be ongoing and ever-present. Although participants commented that they tried not think about the stroke every day or allow it to shape their lives, the uncertainties associated with the health ramifications of the stroke (e.g., the potential of having another stroke or having had a stroke at such a young age) were always present.

Findings align with the uncertainty management theory characterization of uncertainty appraisals as fluid. Previous studies have shown that a chronic state of uncertainty is not sustainable, leading survivors and caregivers to take action to adapt and reappraise their uncertainty (Brashers, 2001; Hilton, 1994; King & Mishel, 1986). Survivors and caregivers felt

that questions about the stroke, and the life changes it instigated, changed as they acclimated to their new roles and interacted with the stroke community. Participants recognized that many of the unknowns altered their vision of the future and might never disappear, but the way they responded to uncertainty did change over time. Brashers and Hogan (2013) noted that new information about treatments or a refined prognosis can lead people to reassess how they think about their uncertainty (e.g., "I do not know if I will ever have another stroke, but the new medicine I am on has a proven track record of helping others with my condition"). Mishel (1990) also suggested that as the experience of uncertainty lingers due to a chronic illness, it can lead to personal growth and encourage a person to reevaluate how he or she thinks about that uncertainty (King & Mishel, 1986). In my study, survivors and caregivers alike recounted similar experiences of having to change the way they thought about the stroke over time so they could cope. For example, "the new normal" was a phrase that couples used to describe their life after a stroke. This phrase was used to indicate that the couple had come to a place of choosing to reappraise their uncertainty and adapt to their new life post-stroke. The results of this study suggest that partners thought about the unknowns they associated with life after stroke as they adopted a new normal and altered their roles, responsibilities, communication, and relationship. These findings are consistent with previous research and theories on the appraisal of uncertainty associated with major illness as an ever-present, action-oriented process (Brashers et al., 2000; Mishel, 1990; Unson et al., 2015). The results also extend previous research by tying the cognitive process of appraisal/reappraisal (i.e., danger, opportunity, or inconsequential) to the various changes that occur within relationships post-stroke (e.g., role shifts and new responsibilities).

Previous research posits that uncertainty appraisals involve an evaluative process toward a specific goal (Mishel, 1988). For example, studies have shown that as people encounter ambiguous elements in their lives, they use relevant information to decide if that uncertainty is dangerous, beneficial, or trivial (e.g., Brashers, Hsieh, Neidig, & Reynolds, 2006). My findings confirm the notion that uncertainty appraisals include specific actionable outcomes. Participants expressed their experience of uncertainty as an impetus for reconsidering their self-concept, life goals, and relationship dynamic. For instance, survivors and caregivers appraised various uncertainties as *dangerous* and thus tried to learn everything they could about the stroke, treatment, and prognosis. With their newfound knowledge, they took action to address their uncertainties (e.g. "When I asked the doctor about my symptoms, she said they were likely nothing to worry about"). At other times, survivors and caregivers considered the uncertainty to be an *opportunity to foster hope* and chose not to learn about mortality rates or the likelihood of recurrence. The results suggest that different appraisals led to different behaviors and that goals could change over time.

Sources of uncertainty (RQ3). The third research question examined the sources of uncertainty that survivors and their partner experienced after a stroke. Brashers et al. (2003) offered medical, personal, and social issues as three causes of uncertainty associated with illness (see also Brashers & Hogan, 2013). Findings in the current study offer broad support for those sources, but through the semi-structured interview approach, I was able to encourage survivors and caregivers to clarify and elaborate on their experience. Across the interviews, individuals talked about wrestling with unknowns that could be categorized as medical, personal, and social sources of uncertainty, but it was health-related issues including not having a diagnosis and wondering how the stroke would affect their future health that dominated their experience.

Survivors and caregivers also coupled their health-related uncertainties with questions about their future financial security. These two sources of uncertainty were connected in the minds of the participants as the unknowns in one area impacted the other. These findings corroborate previous research on the existence of multiple, interdependent sources of uncertainty that exist across the illness trajectory (Brashers et al., 2003; Bylund et al., 2012). Further, Brashers (2001) noted that the relationship between sources of uncertainty is complex: "People experience multiple sources of uncertainty at once… manipulation of one type of uncertainty can impact (e.g., increase or decrease) uncertainties of other types" (p. 481). Participants in the current study talked about how the combined stress of multiple sources of uncertainty impacted their lives after the stroke. In the following paragraphs, I draw parallels between previous research and the current study related to the experience of uncertainty from various sources. First, I focus on the uncertainty caused by health-related questions surrounding the stroke. Next, I discuss the issues associated with financial security.

Findings show that health-related issues generated uncertainty for both survivors and caregiving partners. Prior research has also found that unknowns surrounding one's own health (Brann et al., 2010; Mishel, 1988) or the health of a family member (Bylund et al., 2012) are among the most salient issues in the wake of a major medical event. Survivors in the current study were unsure about what caused the stroke, if they would ever fully recover, and/or if they would have another stroke in the future. These types of questions have emerged in studies involving breast cancer survivors (Clayton, Dudley, & Musters, 2008), HIV/AIDS patients (Brashers et al., 2003), and stroke survivors (Brann et al., 2010). Caregivers in my study experienced health-related uncertainties stemming from questions about their partner's health as well, a finding that aligns with previous research (e.g., Brann et al., 2010; Pawlowski, 2006).

Caregiving partners also stated that their own health was now more important because of the uncertainty of their spouse's future prognosis. Partners felt the additional responsibility of caring for the family, the questions about their spouse's well-being, and their own health-related difficulties created a complicated mixture of post-stroke uncertainty.

Finances emerged as another source of uncertainty for the couples in this study. Questions about whether or not either partner would be able to return to work after the stroke created uncertainty about how the couple would, for example, pay for additional treatment while maintaining their current lifestyle. Although financial security is tied to the *personal uncertainty* outlined in UMT by Brashers et al. (2003), it also exemplifies the complex nature of uncertainty associated with illness (Brashers et al., 2006). Questions about the financial future of the family after stroke exist at the intersection of the medical, personal, and social sources of uncertainty. Unknowns involving finances led participants to question if they would be able to afford various treatments or have enough insurance to cover future medical issues. Financial uncertainty also contributed to altered roles in the family as survivors lost their identity in the workforce and caregiving partners assumed the majority of the income earning responsibility. Additionally, unknowns about the financial future introduced questions about how the couple would fit into their previous social circles without the same resources as they had prior to the stroke. The focus on finances as a source of uncertainty highlights the complexity of the lived experiences of survivors and caregivers as well as the difficulty of assigning various unknowns to one source.

Relational uncertainty (RQ4). The fourth research question investigated the ways that couples experienced relational uncertainty after stroke. Findings support previous scholarship and contribute additional nuance to the experience of relational uncertainty by focusing on chronic illness and perspective changes. Relational uncertainty encompasses the questions

partners have about their changing relationship (Knobloch & Solomon, 1999). The sources of relational uncertainty (i.e., self uncertainty, partner uncertainty, and relationship uncertainty) are key components in the relational turbulence model and emerge during times of transition when partners renegotiate their relationship (e.g., Knobloch et al., 2016; Solomon & Knobloch, 2004; Steuber & Solomon, 2008). The data in this study suggest that caregivers experienced *partner uncertainty* after the stroke in conjunction with a shift in their perspective. An element of *seeing one's partner differently*, as represented in the model of relational changes after stroke (Figure 4.1), is questioning a partner's commitment to the relationship. Participants reflected on their experience with relational uncertainty when they wondered if the person who came home from the hospital would love them and want to remain in the relationship. Likewise, stroke survivors recounted their *self uncertainty* as they saw themselves differently and questioned their place in the relationship. Findings imply a link between perspective changes after stroke and the questions partners had about the future of their marriage and their involvement with their spouse.

Findings also align with previous research that shows couples are likely to encounter questions about their relationship after stroke (e.g., Anderson et al., 2017; Banks & Pearson, 2004). In fact, participants experienced such a radical shift in various aspects of their relationship, including how they enacted their individual roles and relational norms, that they reconceptualized life after stroke as being very different. The adjustment to that altered perspective involved addressing questions about their life before and after the stroke and where they saw their relationship within that altered framework.

Previous research has indicated that periods of relational transition are frequently difficult for couples (e.g., Knobloch et al., 2016; Nagy & Theiss, 2013). Studies have found that as relational uncertainty increases, stressors within the relationship increase as well (McLaren et al.,

2012; Theiss et al., 2009). My findings support the association between relational uncertainty and relational stress specifically and uncertainty and stress in general. Although both partners recognized perspective shifts after the stroke, the transition was difficult and generated questions about the future of their relationship.

Results broadly suggest that relationship experience may impact how couples negotiate uncertainty. Within the context of illness, *experience* has been linked to one's ability to contextualize and make sense of a situation. For instance, Mishel (1981) found that younger patients had higher stress levels, reported more uncertainty, and struggled to cope due to their lack of an "experiential frame of reference" (Mishel, 1984, p. 164). This may be the case for relational uncertainty as well. Couples who lack an experiential frame of reference when encountering questions about their relationship may be more likely to struggle with illness-related stressors that threaten their view of the relationship.

Overall, the findings in this study suggest a complex, multifaceted connection between uncertainty and stroke. Participants expressed how the stroke introduced uncertainty as a pervasive element in their lives that they suppressed or used as a catalyst for action. Survivors and caregivers alike felt that their uncertainties emanated from health-related issues and the well-being of their family. Specifically, participants wondered about their family's ability to earn or maintain the necessary financial resources. Within the relationship, partners encountered questions about each other's commitment and how their relationship would look in the future. Participants described the uncertainty they associated with stroke as ever-present, even as they worked to conceptualize their life post-stroke as the new normal.

Interference from a Partner (RQ5)

The fifth research question examined people's experience of interference from a partner after a stroke. Findings support the relational turbulence theory's explication of interference from a partner and the impact that it can have on relationships. *Interference from a partner* occurs when an individual intentionally or unintentionally disrupts a partner's goal achievement (Berscheid, 1983; Knobloch & Solomon, 2004). Within relational turbulence theory, interference from a partner is positively associated with the influence one partner has over the other (Solomon et al., 2016). In this study, caregiving partners experienced an increase in influence over their spouse as the relational dynamic shifted after the stroke. Previous research has shown that as influence increases, the opportunities to interfere with each other's routine increase as well (Solomon & Knobloch, 2001). Findings from the current study also confirm a connection between interdependence and experiences of interference. Specifically, caregivers encountered interference from their spouse when they tried to maintain a career outside the home after their partner's stroke. Caregiving responsibilities altered the power dynamic in a relationship since the stroke survivors had to relinquish independence and rely more on their caregiving partner. The imbalance influenced the independence of both partners. For example, caregivers were required to allocate more of their time and energy to family responsibilities and scale back or eliminate their career goals. The changes within the relational dynamic led to the mutual experience of interference from both partners.

Experiences with interference from a partner ranged from minor intrusions to larger, more consequential issues. My results support relational turbulence theory's characterization that interference from a partner impacts how people think and feel about their relationship (Solomon et al., 2016). Interference from a partner that emerged after the stroke involving altered sleep schedules or dietary restrictions, for example, were perceived as relatively minor and did not

require much adjustment or seem to negatively impact the relationship. In contrast, hinderances involving career goals, individual autonomy, and communication patterns were difficult for couples to manage and introduced conflict along with other relational issues. Continuing to investigate the way people experience interference from a partner may contribute to a better understanding of relational turbulence post-stroke.

Some participants found it difficult to acknowledge interference from a partner. Previous research has shown that individuals hinder each other's goals when facing a difficult medical diagnosis. Steuber and Solomon (2008), for example, used online forum and blog data to investigate the interference that couples experienced while coping with an infertility diagnosis. They found that partners had competing goals regarding family planning options and possible treatments. Individuals noted that they experienced interference from their partner when deciding how to manage the diagnosis. In an interview setting, however, asking about interference from a partner can be a challenge. Brown and Levinson's (1987) politeness theory offers an explanation about why questions related to interference from a partner may yield different results in an online forum when compared to an interview. A conversation about how a stroke survivor or caregiver makes life more challenging for their partner may be perceived as a face threatening act. This face threat may have made questions about interference from their partner uncomfortable for participants.

Survivors and caregivers initially commented that their partner did not interfere with their lives at all, which seems to align with the tenets of politeness theory advanced by Brown and Levinson (1987). As I continued the interview, however, survivors and caregivers brought up different situations or elaborated on ways that their partner did in fact interfere with their daily activities (e.g., getting chores done around the house) and/or larger life goals (e.g., adjusting or

abandoning one's career timeline). This finding is important to note for two reasons. First, interference from a partner has been shown to exist in the wake of a major medical event, so there was reason to believe that it would be present as a couple navigated life after a stroke. Results suggest that partners do interfere with one another after a stroke due to a decrease in independence experienced by both partners. Second, as a methodological issue, conversations about interference from a partner in an interview format can introduce face threats that may not exist to the same extent in an online forum or blog. The semi-structured format of my interviews gave me the opportunity to introduce the topic as one that I was interested in covering, but it allowed the participant to ease into the content as they relayed their experience of life after stroke. Even though interference from a partner seemed to exist post-stroke and participants embedded it in their stories, it appeared to be a difficult topic of conversation.

Theoretical Implications

Stroke introduces a time of change that impacts nearly every aspect of life in ways that have yet to be fully explored in research or explained with theory. Results support the current literature on health-related times of change and widen the scope of inquiry to include a focus on the dyadic experience of illness. The findings also add to established theories on uncertainty and suggest intersections between uncertainty management and relational change. I discuss the theoretical implications of my study in the following sections.

Uncertainty in illness theory (UIT). Findings support Mishel's (1988) model of perceived uncertainty in illness that reflects the complex cognitive processes individuals go through during a major medical event or acute illness (Mishel et al., 2009). UIT was constructed to investigate the quantitative relationships between various factors associated with illness-related uncertainty experienced by a patient (Mishel, 1981, 1984). The narrative accounts of

participants in my study offer broad support for uncertainty appraisal as a process that is influenced by many factors (Figure 2.1). For example, participants talked about how perspective changes, role shifts, and altered interaction patterns influenced their experience of uncertainty. These elements closely resemble the antecedents represented in Mishel's (1988) model (i.e., stimuli frame and structure providers) and further illustrate the complexity of uncertainty in illness.

The results of this study also resonate with Mishel's emphasis on uncertainty as a cognitive process. Mishel (1984) draws on Budner's (1962) conceptualization of uncertainty as a cognitive state generated when a person does not have the proper information to make sense of an event. For example, in the midst of a health-related event individuals encounter the *stimuli frame*, a collection of variables (i.e., symptom pattern, event familiarity, and event congruency) that influence initial assessments of a stimuli (e.g., "I have had this type of headache before"). The stimuli frame shares a negative association with the amount of uncertainty one experiences related to an event (e.g., "Because I have had this type of headache before I am not very worried about it"). Without a way to frame or characterize the stimuli (i.e., the stroke) as a nonthreatening event, individuals experience greater uncertainty. The narrative accounts of participants in this study show that the lack of knowledge about stroke in general, and their stroke in particular (e.g., causes, outcomes, future prognosis), did influence the way people experienced uncertainty. For instance, participants wondered why a young, healthy person would have a stroke since they thought of stroke as a condition that generally affects older adults. People's conceptualization of stroke as abnormal for someone their age or in their physical condition fits into the stimuli frame that Mishel (1988) outlines because age and health are factors that impacted the way they experienced the uncertainty.

The way people conceptualize uncertainty is also influenced by their ability to process information, or their *cognitive capacity* (Figure 2.1; Mishel, 1988). Mishel (1988) notes that mental resources are taxed due to illness and therefore people are not able to think about issues or questions as clearly. This is particularly applicable to stroke survivors since their cognitive capacity is often diminished due to the stroke, at least initially (Bowler, Hadar, & Wade, 1994; Ebrahim et al., 1985). Mishel (1988) also refers to Mandler (1979) to make the argument that stress causes the brain to triage cues from the environment and to only focus on the most salient. Although the focus of Mishel's (1988) perceived model of uncertainty in illness is exclusively on the patient, caregivers in this study talked about how they diverted mental resources to adapt to their new life after stroke (e.g., perspective changes, shifting roles, changing interaction patterns). This study supports findings by other researchers that have investigated the emotional, physical, and mental toll that caregiving can have on a person (e.g., O'Connell & Baker, 2004) and illustrates that the experience of uncertainty associated with illness is not isolated to the patient.

UIT does not currently represent the influence of one's partner or reflect the dyadic experience of illness. My data indicate that UIT could be developed to more accurately characterize the lived experiences of couples dealing with illness-related uncertainties. Uncertainty as a shared experience is something that resonates throughout the data set and in other studies (e.g., Anderson et al., 2017; White et al., 2014), and yet that aspect of the illness trajectory is not reflected in UIT or RUIT. Mishel (1988) does include social support as one of the structure providers that helps people make sense of illness-related uncertainties (Figure 2.1), but the theory does not go far enough to represent the impact of sharing the sense-making process with a partner and how that may influence the experience. Although Mishel's (1988)

model of perceived uncertainty in illness articulates the process patients go through as they make sense of a medical treatment or wrestle with a difficult diagnosis, it is lacking the inclusion of the caregiver's perspective and how that may impact the uncertainty appraisal process. The data in my study show that the perspective and influence of a caregiving partner is central to the experience of illness. The results of this study push back against the assumption within UIT that the uncertainty appraisal process is largely an individual endeavor. In fact, the data suggest that the appraisal process could be influenced by how partners interact with each other and respond to illness-related uncertainty as a couple.

My study contributes to the understanding of how people perceive uncertainty in illness by suggesting that there are at least two simultaneous and mutually influential appraisals that occur: one for the patient and one for the caregiving partner. The findings demonstrate that couples conceptualize the illness experience as individuals (e.g., "Am I ever going to walk again") and as a couple (e.g., "What will our relationship look like now?"). Mishel (1988) suggests a simplified view of the uncertainty appraisal process by mapping the trajectory of an individual's experience. That view, however, becomes more complicated when paired with the appraisal process of one's partner or family member(s). My results reveal that partners follow a similar path to each other as they manage life after a stroke. Therefore, the process outlined in UIT may be more accurately represented by showing how each person negotiates Mishel's (1988) model of perceived uncertainty in illness to show where the trajectories intersect, complement, or diverge from one another.

Uncertainty management theory (UMT). In addition to finding support for UIT, results bolster several tenets of UMT. At the center of UMT is the desire to broadly understand the influence of uncertainty on people's lives. Brashers (2001) suggested that theories of uncertainty

should acknowledge three issues related to how people experience uncertainty. All three issues are reflected in my study. First, uncertainty should be understood and investigated as a complex, multidimensional construct, according to Brashers and Babrow (1996). Participants in this study experienced uncertainty associated with a variety of topics including health-related issues, shifting roles in the family, and the future of their marriage. In fact, one reason survivors and caregivers may have felt that uncertainty was a constant is because the unknowns existed across multiple domains. Second, Brashers (2001) called for studies of how people manage uncertainty to investigate connections among various questions. Participants experienced uncertainty related to their future health and how that may impact their financial security, the type of connection that Brashers (2001) proposed regarding the coexistence of multiple sources of uncertainty. Additionally, questions about the prognosis of the stroke survivor generated uncertainty for both partners about the future of their relationship. Third, Brashers (2001) challenged scholars to consider the duration of the uncertainty and how that may impact the way people view specific unknowns. My data show that participants felt their uncertainty was ever-present and that it influenced many aspects of their lives even if they did not dwell on it daily. Finally, findings support the conclusion that Brashers (2001) drew from these three dimensions of uncertainty management: people must find ways to adapt to multidimensional, interconnected, and ongoing uncertainties. Participants talked about how they did that by altering their perspectives, adapting to change, adopting new roles, and taking on new responsibilities. UMT is a theory that recognizes the complexity of the uncertainty experience that is generated from multiple sources as exemplified by my results.

Findings also offer support for Brashers' (2001) conceptualization of uncertainty appraisals. UMT states that uncertainty is appraised to find meaning. To that end, uncertainty can

be thought of as harmful, helpful, or inconsequential and can involve varying emotions such as fear or hope. Additionally, new information can lead to an opportunity to reappraise one's uncertainty. Brashers and Hogan (2013) note that the process of appraisal is fluid, and as individuals are exposed to new information including new treatments, success stories, or updated mortality rates, they can change how they think about their uncertainty. Participants in my study wrestled with questions about life after stroke that emerged immediately as well as those unknowns that developed over time. As people learned more about how the stroke impacted their lives, they were able to reassess how they thought about their various uncertainties. Specifically, survivors and caregivers had the opportunity to regularly reassess their original questions about the prognosis since the full range of physical and mental effects of stroke may take time to manifest. Beyond changes to one's physical or cognitive ability, previous research has also found that perspective shifts and support from others allowed individuals struggling with illness-related unknowns to reappraise those uncertainties (Scott et al., 2011). Findings in this study affirm the notion that how people think about uncertainty associated with a chronic condition such as stroke is an ongoing process that can change over time.

Findings imply that UMT needs further development to more accurately represent the complex experience of uncertainty within romantic dyads. Previous research has found that individuals reported uncertainty associated with a health diagnosis (Brashers et al, 2016; Brashers et al., 2000), a treatment plan (Martin, Stone, Scott, & Brashers, 2010), and the future prognosis (Brashers et al., 1998). Findings in my study suggest that *individual* experiences of uncertainty may be more accurately represented as *shared* experiences of uncertainty. UMT is focused on the processes by which individuals make sense of their own uncertainties. However, by including partners in the study of the uncertainty management process, the scope widens and

scholars may gain a better understanding of how people collaboratively address various unknowns. Studies have shown that others can influence uncertainty appraisals (Scott et al., 2011) and co-own illness-related stressors (Acitelli & Badr, 2005), but UMT does not represent the relational processes that contribute to uncertainty management. In fact, UMT establishes uncertainty as an intrapersonal assessment (Brashers & Hogan, 2013). My study challenges that notion by highlighting the dyadic nature of uncertainty and the importance of one's romantic partner throughout the appraisal process in post-stroke relationships.

My results also broaden the study of uncertainty management by demonstrating the complexity of navigating various unknowns while suffering from cognitive impairment. Theories of uncertainty management have as core tenets that people have the agency and ability to address their levels of uncertainty (e.g., Afifi & Weiner, 2004; Berger & Calabrese, 1975; Brashers & Hogan, 2013; Mishel, 1988). The assumption that people can rationally approach and address their uncertainty through information management excludes those who are cognitively impaired. Participants in this study, for example, struggled to make sense of the stroke because they had trouble managing information, remembering events, or remaining focused. Others had to make a conscious allocation of their mental resources to perform daily functions, so there was little left over to address the various uncertainties that emerged after the stroke. The study of uncertainty management has neglected the reality that brain injury, cognitive impairment, and/or psychological disorders may hinder people from addressing their uncertainty. Future research should continue to consider *how* people negotiate uncertainty appraisals, but also begin to assess if people are *able* to go through that process.

Relational turbulence theory. Research Question 4 and Research Question 5 focused on constructs from relational turbulence theory. Findings add to the robust support that *relational uncertainty* and *interference from a partner* have already garnered from years of study (e.g., Harvey-Knowles & Faw, 2016; Knobloch & Solomon, 1999; Knobloch & Solomon, 2004; Nagy & Theiss, 2013). Previous research utilizing the relational turbulence model, precursor to relational turbulence theory, has examined how communication changes and life circumstances can affect how people think about their romantic relationship (Knobloch & Theiss, 2012; Solomon & Theiss, 2008; Theiss & Solomon, 2006; Weber & Solomon, 2008). Times of transition bring about a greater opportunity for stress in a relationship. In fact, increased stress or relational turmoil can arise through relational changes that originate from a choice such as moving from casual dating to more formal courtship (e.g., Knobloch, 2007), as well as transitions that are unplanned such as stroke (e.g., Thompson & Ryan, 2009; White et al., 2014). Both types of transitions represent an opportunity for partners to reexamine how they think about one another and how they see their future together. Participants in the current study experienced stroke as an abrupt, unplanned change to their relationship. Survivors and caregivers alike wrestled with how to think about their partner and relationship as a result of the stroke. The findings also suggest that when caregiving responsibilities were introduced into the relationship, both partners experienced interference from the other and a decrease in their independence. Overall, the results indicate that two of the key constructs in relational turbulence theory may resonate with couples negotiating life after stroke.

Findings also support the notion presented in relational turbulence theory that stressful episodes accumulate over time to create turbulence. Solomon et al. (2016) argue that it is not one change or one period of transition that introduces relational turbulence, but “the accumulation of

specific experiences that coalesce to form a global relationship judgment" (p. 518). This was reflected in the current study as couples negotiated life after stroke. Although the stroke event was, as participants noted, *the moment* that everything changed, survivors and caregivers recounted a myriad of changes that occurred in the aftermath of the stroke that led them to feel overwhelmed. It was not necessarily just the stroke itself, the physical deficits, the mental lapses, or the speaking issues; it was the combination of these effects during the transition that contributed to relational stress, a finding that aligns with relational turbulence theory.

Stroke appears to be a unique type of transition because, as with other traumatic brain injuries, the stroke survivor may be a very different person as a result. Participants noted that the stroke fundamentally changed them or their partner. Additionally, survivors and caregivers wrestled with accepting the new roles and interaction patterns within their relationship post-stroke, but as they accepted those changes, they also had to set aside the idea of who their partner was prior to the stroke. Findings show that the stroke often acted as a reset button for couples, allowing them to reprioritize their relationship or focus on things outside their relationship. Relational turbulence theory is based on a relationship between two people, but the question of what happens when one partner is radically different after a stroke is a new issue for the theory.

If relational turbulence theory is used to study times of change after stroke, the concept of interference from a partner may need to be reexamined. Solomon et al. (2016) defined interference from a partner as tied to the actions of an individual, whether intentional or accidental. Participants in this study were reluctant to assign instances of interference to their partner. However, they did talk about experiencing interference related to the stroke that *involved* their partner. For example, participants discussed how roles shifted and communication changed because of the stroke and that those changes interfered with their lives. Interference from a

partner in this context may have more to do with behavioral dynamics between partners rather than emanating from an individual. Future research should continue to examine this nuance by investigating how couples conceptualize, and manage, goal interference after a stroke.

Practical Implications

The practical implications of this study are pertinent to stroke survivors, family members, healthcare professionals, and the general public. Findings support previous work that showed stroke changes people and relationships (e.g., O'Connell & Baker, 2004; Tellier et al., 2011; Thompson & Ryan, 2009), but the results of this study extend a body of research that often lacks practical and prescriptive information about how to manage various relational changes associated with stroke. The findings suggest several pragmatic implications for couples, as well as medical staff who interact with stroke survivors and their families.

Participants commented that there was no way to prepare for life after a stroke. However, survivors and caregivers did say that they could have been better prepared for the stroke itself if they as a couple had known how to recognize the signs of stroke and knew what to do next. Research has shown that time is a crucial factor when dealing with brain-related injuries because the longer the brain goes without oxygen, the more severe and irreversible the damage (e.g., Flynn et al., 2014; Lees et al., 2010). The American Stroke Association notes that the U.S. Food and Drug Administration (FDA) has only approved one pharmaceutical treatment for ischemic stroke: tissue plasminogen activator, known as tPA (American Stroke Association, 2018b). The drug dissolves clots associated with an ischemic stroke and helps to restore blood flow to the brain. For the tPA to be effective, patients must receive the drug within three hours of the stroke, making early detection of the injury important. To increase awareness of stroke-related symptoms and decrease the time between the incident and treatment, a group of medical

professionals in the U.K. developed FAST (i.e., *Face Arm Speech Test*) in 1998 to help emergency personnel recognize the signs of stroke in the field (Harbison et al., 2003). Over the 20 years since its creation, FAST has developed into an international ad campaign (i.e., *Face, Arm, Speech, Time to call 911*) that has been adopted by prominent organizations including the American Stroke Association, the National Institute of Neurological Disorders and Stroke (NINDS), and the Mayo Clinic. Yet, not one participant in this study mentioned the acronym when talking about the moment the stroke occurred. In fact, there were instances when partners delayed going to the hospital because they did not know the signs of a stroke or assumed that stroke was an illness confined to older adults. In contrast to that belief, the CDC reports that one in four strokes in the U.S. each year (i.e., about 200,000 of the 800,000 strokes each year) occur in individuals under the age of 65 (Hall, Levant, & DeFrances, 2012). The reality is that the ad campaign, or information about how to recognize the signs of stroke, is not reaching or resonating with everyone. A key pragmatic implication for public health is that more education is needed about the early warning signs of stroke and its impact on all age groups and demographics.

Raising awareness about what to look for during a stroke is only part of the equation. Targeted messaging about the things people can do to prevent a stroke (e.g., quit smoking) may resonate with couples and generate conversations about lifestyle changes in the family. For example, several of the couples talked about their struggle to make healthy dietary choices before and after the stroke by recounting their experience with diabetes. Specifically, type 2 diabetes is a known risk factor for stroke (Peters, Huxley, & Woodward, 2014), but it is often preventable by maintaining a healthy lifestyle (Diabetes Prevention Program Research Group, 2015). Messaging that shows couples (and families) how to encourage one another to quit

smoking and pursue a low-sodium, low-fat diet to reduce the risk of stroke may generate conversation and raise awareness.

In addition to increasing awareness about how to recognize and respond to a stroke as it is happening, this study implies that there is often an underwhelming amount of support for individuals and families as they transition home after a stroke (Wittenberg-Lyles et al., 2014). Previous research has shown that support is a crucial element in the recovery process from a major illness or medical event (Brashers, Neidig, & Goldsmith, 2004; Egbert, Koch, Coeling, & Ayers, 2006). Yet, participants reported feeling isolated from their social networks and stigmatized by the stroke, at least initially. To address those feelings, some participants attend a support group for stroke survivors and caregivers. Participants felt that the sense of community with others who could empathize with their situation was a crucial element in helping them come to terms with their life after stroke. Although hundreds of stroke support groups exist nationwide, that information is not always shared with families as they leave the hospital and transition home. The lack of information about how to connect with others is one reason I sent a link to a support group finder website in my thank you email to participants after each interview (Appendix H). Additionally, participants noted that it can be difficult to find a group that fits an individual's needs. For example, some communities only have one support group and the members may all be older adults, so the challenges of a young family struggling with stroke may not resonate as much in a group without similar others. In contrast to localized gatherings, some groups across the U.S. have a large online presence or exist exclusively online. The Internet has minimized the need to be in a physical location for a support group and increased people's ability to find a group that aligns with their needs (Friedman, 2007). Regardless of whether the group meets in person or online, participants appreciated the support they received from the people

who could genuinely understand their situation. Given the importance of social support after stroke (e.g., Egbert et al., 2006; Hilari & Northcott, 2006; Wittenberg-Lyles et al., 2014), and the benefits that participants in this study reported by being a member of a stroke support group, medical groups should consider publicizing and facilitating such groups as a service to their patients and community.

Once a stroke survivor leaves the hospital, his or her care is often in the hands of a partner or family member who may or may not feel prepared for that responsibility. The gravity of the situation means that the transition from hospital to home care should be a collaborative effort between the medical staff and caregiving partner. The expertise and influence of the medical staff in general, and nurses in particular, place them in the unique position to help families adapt to changes from the stroke before they leave the hospital. The involvement of nurses in patient care and as information gatekeepers for other medical staff makes them strategically situated to assist both partners in understanding and adapting to new roles (DeLaune & Brown, 2001), assessing and preventing depression (McCarthy et al., 2011), and helping couples chart a path forward. For example, after stroke survivors are discharged from the hospital, they are often assigned to physical or occupational therapy. Nurses can help facilitate this transition by encouraging patients to include others in their recovery and to create connections that will help stroke survivors continue to progress (Wedgeworth, LaRocca, Chaplin, & Scogin, 2017). This type of care, often referred to as *patient-centered* care, is lauded as the gold standard in medicine. Patient-centered care is focused on setting patients up for success by empowering them to make decisions about their treatment and include their family members in the process (Epstein & Street, 2011; Han & Haley, 1999; Ontario Medical Association, 2010). Yet, the definition is fluid and can drift into *patient-only* care where partners

are left out of the process, or *illness-centered* care where decisions are made unilaterally by the medical team. In the current study, for example, caregiving partners mentioned that they had to continually ask to be involved in the rehabilitation process so they could maintain the regimen once the sessions ended. It is crucial that partners and family members are included in the decisions about treatment and in learning how to continue care once the patient leaves the hospital or rehabilitation facility.

Support from hospitals during the transition from formal care to in-home care is helpful, but employers have a role to play in the recovery and adaptation process as well. Research shows that the impact of a major medical event is not limited to the patient (e.g., Scarinci et al., 2009; World Health Organization, 2001). Findings in this study also revealed that participants struggled to adapt to life after stroke and the stress of that change was exacerbated when combined with uncertainty about financial security. Caregivers who are required to balance new roles and responsibilities while also maintaining their job outside the home may have more difficulty adjusting to a post-stroke lifestyle. The U.S. Department of Labor has a policy in place to address the added stress that accompanies health-related transitions. The Family Medical Leave Act (FMLA) was passed in 1993 and allows family members to take up to 12 weeks of unpaid leave without fear of losing their job so they can care for an immediate family member who has a serious illness (Department of Labor, 2018). This policy helps people know that their job will be waiting from them if they need to take time off to help a family member transition home after an illness, but it does not address the issue of financial security. Although companies may have paid medical leave for their employees, it is not a requirement under FMLA. Caregivers who know they have a job waiting for them may receive a bit of solace, but taking time off without pay is simply not an option for many families. The evidence that serious health

issues have a mental and physical impact on both partners is mounting, but more research is needed in this area (World Health Organization, 2001). The next step is to translate the findings of scholarly work into public policy to address the financial impact and lived experience of a major illness on families.

Limitations

Interviews and qualitative data collection methods carry limitations. Prior to the interview, participants may have never thought about the various stressors or potential relational changes that they attribute to stroke. An environment where people are talking about uncertainties for the first time may be traumatic and cause participants to pull back from the interview. In fact, during the interviews several participants said that they had never talked about or even thought about some of the topics we covered. Many of the participants, including those who had never shared their thoughts on the stroke before, said the interview was beneficial as a reflective tool that helped them realize how they felt about the stroke. However, to mitigate the stress of talking about this difficult topic, I worked to create a comfortable social space and remained sensitive to the conversational climate as I pushed for detail within a person's comfort level.

Exclusive use of an online consent form and incentive through an online retailer (i.e., Amazon) may have limited the prospective participant pool. The U.S. Census Bureau (2017) reported that in 2015 only 63% of households headed by an individual over the age of 65 had an internet connection. With that in mind, the number of individuals in this study over the age of 65 may have been influenced by my use of a digital recruitment and consent process. All participants had to complete a Qualtrics survey (i.e., an online survey building platform) stating their agreement to participate, and this process may have been a hindrance to some older adults

who did not have access to a computer or the internet. To address this issue, researchers should seek to collaborate with healthcare professionals and gain access to hospitals or care facilities where they can enroll participants in person.

Not all the interviews were conducted simultaneously. Although participants were given the option to have a private, individual interview at the same time as their partner (in person or by phone), many chose to schedule a different time than their spouse and therefore I was not able to ensure that the interview was private. Several participants even mentioned that they invited their partner or family member to be present during the interview. Participants who had a partner in the room or who could hear their responses may have felt restricted in what they could share. In certain situations, isolating each partner may be difficult and even undesirable for the participants, but future studies should still seek to provide a space for individuals to share their experiences openly and without the potential to invite scrutiny from one's partner.

Recall of past events may have introduced bias. In this study, I asked participants to discuss events, thoughts, and communication related to stroke. Memories of the stroke may have shaped people's interpretation of past circumstances, as well as how they viewed their present relationship. For example, Silverberg et al. (2016) found that after mild traumatic brain injury (MTBI), patients often suffered from "a systematic positive recall bias, referred to as the 'good-old-days bias' (GB)" (p. 388). In fact, participants with MTBI reported having fewer preexisting conditions prior to the injury than participants who did not suffer a brain injury. In other words, MTBI patients remembered being healthier than they actually were before the injury. Additionally, Baxter and Bullis (1986) acknowledged that asking participants to chart their relational development by looking back on specific turning points may introduce bias. The authors argued that people may be more likely to remember events that help them shape their

personal story about the relationship or focus on events that are still discussed in the relationship. The presence of retrospective recall bias is important to acknowledge because the central focus of this study was to better understand the experiences of couples after stroke. To counteract retrospective recall bias in the future, gathering longitudinal data from stroke survivors and partners starting before or immediately after the stroke may provide a more accurate account of how, if at all, communication between partners changes over time.

Limiting the participant pool to stroke survivors who could speak was also a limitation of this study. One of the common side effects of a stroke is aphasia, a communication disorder that affects roughly two million Americans (National Aphasia Association, 2017). Although there are various types of aphasia, it is typically associated with difficulty translating thoughts into language (Jordan & Kaiser, 2013). The severity of the disorder after a stroke ranges from no language ability at all to an occasional struggle to connect words to certain actions or objects (National Stroke Association, 2017). Stroke survivors with aphasia were not prohibited from participating in my study, but they needed to be able to verbally communicate their experience after the stroke. By limiting involvement in this way, I may have missed a component of the population who could have different experiences than what is represented in my data. I will need to collaborate with others including otolaryngologists and speech therapists in the future about how to best include individuals with severe aphasia.

A medical measurement of the severity of the stroke was not captured in these data. Participants self-reported the stroke type and severity, but I did not collect medical records to ascertain how they were assessed by the institution(s) where they received treatment. As I mentioned, participants had to be able to speak during our interview, but the impact on speech after a stroke is not as much an indicator of severity as it is of location of the stroke in the brain

(ASA, 2018). Future research should include the severity of the stroke using an established stroke scale since that information may impact people's perception of themselves, their partner, and their relationship after the stroke. For example, individuals who suffer a mild stroke and fully recover may report less uncertainty about the future and experience less relational change due to the event. In contrast, those who suffer a severe stroke may live in fear of having another or be more likely to think differently about themselves. Notably, the reverse could be true of either situation. By not gathering this piece of information from participants, I may have missed a distinguishing characteristic that leads to different experiences post-stroke. Additionally, knowing how the severity of stroke impacts couples could shape how practitioners prepare survivors and family members for life after stroke.

Another limitation involves the difficulty of isolating the effects of a stroke from other illnesses and aging more generally. Approximately 75% of stroke patients are over the age of 65, so it is possible that those individuals also have other ailments including diabetes, heart disease, dementia, or other illnesses that would be considered co-morbidities with stroke (Hall et al., 2012). Diabetes is an illness that introduces potentially life altering changes (UK Prospective Diabetes Study Group, 1998), but it also increases the risk of stroke, particularly in women (Peters et al., 2014). In fact, the presence of certain comorbidities, including type 2 diabetes and depressive symptoms, have recently been linked to an increase in stroke severity in women and reduced post-stroke cognitive functioning in older men (Swardfager & MacIntosh, 2016). Disentangling the health issues associated with depression, diabetes, and stroke is even more difficult when the illnesses occur at the same time. Further research in this area is important due to the potential impact on a person's health after a stroke when one or more comorbidities are present, especially in older individuals. To address these issues more comprehensively, a cohort

study or multi-group study with a control group may allow for a more focused approach. In this study, I asked participants to isolate, if possible, the effects of the stroke apart from other illnesses and aging more generally. The data I gathered may inform future studies that target more specific issues, illnesses, or effects associated with stroke.

Future Directions

Participants noted the impact of the stroke on their children and felt that the resources for families were deficient in this area. Within the literature on stroke, scholars have been investigating the effects on partners (e.g., Brann et al., 2010; Buschenfeld et al., 2009) and romantic relationships (e.g., Anderson et al., 2017; McCarthy & Lyons, 2015), but there is limited inquiry into how stroke impacts children in the family. Caregiving partners had to adapt to life after the stroke by adopting new roles and responsibilities, and young parents had to make those changes while raising their children with little help from their partner, at least initially. For example, survivors and caregivers who had children at home had to further divide their time between managing the effects of the stroke versus maintaining the family. Sarah, a caregiving partner said, “having a full-time job and having kids, you just run out of patience.” Participants recognized that their children were struggling with all the changes and knew that seeing a parent change abruptly was a difficult transition. In general, participants lamented not being able to offer their kids an outlet for stress beyond counseling, or provide more resources to help them understand the illness trajectory of stroke. Future research should investigate how the family dynamic is impacted by stroke, how children respond to stroke-related changes in their parents, and ways to talk with kids about stroke.

In addition to broadening the focus of care to the entire family, some insight into why relationships change after a stroke may be found by exploring the intricacies of the brain more

closely. Investigating where and how the brain stores information about interpersonal connections may help scholars better understand the aftermath of stroke in the family. Researchers have located areas of the brain that control movement, vision, speech, hearing, and memory, but the question that straddles cognitive neuroscience and social science is the location of interpersonal relationships in the brain. Scholars at the Beckman Institute at the University of Illinois, along with other universities, are beginning to expand the view of relational memory, which has traditionally been understood in terms of spatial linkages and temporal connections (Konkel & Cohen, 2009). The hippocampus, an area in the center of the brain that is responsible for memory, may also be at the center of understanding how the brain processes and stores information on interpersonal connections. The hippocampus has been linked to a person's ability to make character assessments and influence evaluative judgments of others (Croft et al., 2010; Rubin & Cohen, 2017). The combination of research from social science on the experience of turbulence during times of illness (e.g., Harvey-Knowles & Faw, 2016) and studies on the evolving definition of relational memory may help scholars draw a substantive connection to physical and relational outcomes of brain injury.

Findings in this study add to a growing body of research that suggests times of serious illness may have a negative effect on relational partners, but this area of inquiry has yet to be fully developed. In 2001 the World Health Organization (WHO) introduced the idea of third-party disability in the International Classification of Functioning, Disability and Health (ICF) as an area for future research. Third-party disability refers to the occurrence of an illness in one partner as a result of the medical condition of the other partner (World Health Organization, 2001). It was not until 2009 that researchers attempted to explore third-party disability by linking a hearing impairment in one person to impairments that emerged in a partner (Scarinci et al.,

2009). The researchers found that spouses struggled adjusting to their partner's hearing difficulties, but Scarinci et al. (2009) were unable to demonstrate that disability in one partner led to disability in the other. The link between aphasia and new or worsening health conditions in partners, however, seems more plausible (Grawburg et al., 2014). Partners were found to attribute medical conditions "including depression, anxiety, vertigo, ulcer, hypertension, and mental health changes" (Grawburg et al., 2014, p. 1187) to living with a partner diagnosed with aphasia. The medical community recognizes that illness impacts partners in profound ways, but it has only recently begun exploring the link between the health of one partner and the health of the other.

Time order is an issue throughout the literature on interpersonal communication during times of illness. Research suggests that relationships encounter periods of transition due to various catalysts and that those changes introduce an opportunity for relational turbulence (e.g., Knobloch & Theiss, 2012; Nagy & Theiss, 2013; Weber & Solomon, 2008). The research does not, however, include a discussion on the relationship prior to the period of transition. Extending the scope of data collection and analysis to include the state of the relationship before a transition would help researchers identify times of change as the cause of relational turbulence or as an amplifier of relational turbulence already in existence. An established baseline is needed to assess the true impact of an event, transition, or decision. Relational assessments prior to a stroke, for example, may help scholars to identify the effects of brain injuries on different types of relationships at various stages of development. Establishing the levels of relational turbulence prior to a period of transition may be difficult, however, and different methods to achieve this goal have both benefits and drawbacks. Scholars could use retrospective reports to have couples rate their relational turbulence, for instance, before the stroke or medical diagnosis. The desired

data may be captured in this way (e.g., Baxter & Erbert, 1999), but studies using retrospective reports often cite memory of the couple as a threat to reliability (Loveless, Powers, & Jordan, 2008). Another approach to gathering a view of the relationship prior to a stroke would be for researchers to collaborate on a project that combined multiple areas of inquiry. For example, one scholar may seek to understand how stroke impacts relationships and to establish a baseline from which to measure relational change, and another scholar may want to understand how type 2 diabetes and smoking (two comorbidities associated with stroke) influence relationships over time. The data could be gathered through surveys or interviews that occur on a scheduled time frame, and at each data gathering session the partners are asked about relational variables, smoking behavior, diabetes treatment, and if a major medical event (e.g., stroke) has occurred since the last survey. Following people who present the greatest likelihood to have a stroke will allow scholars to establish a baseline of relational turbulence and create a clear timeline of relational change due to major medical events. The process will also permit researchers to learn more about the effectiveness of health campaigns and the use of specific messages to increase stroke prevention.

Conclusion

I have offered a model of relational changes after stroke within romantic dyads (Figure 4.1) based on the 44 individual interviews I conducted for this project. I presented qualitative evidence of how the experience of stroke influenced the way partners thought about themselves, each other, and their relationship. The results suggest that stroke changed people's relationships and that those changes were difficult and long-lasting. Survivors and caregivers shared that in the midst of overwhelming changes after the stroke, they had lingering questions about their future health and how that may impact the financial security of their family. The relational experience

after stroke is complex and this study contributes to a body of research focused on understanding that complexity. The results from this study are a starting place for a larger effort to investigate the role of relationships and interpersonal communication across the stroke trajectory.

REFERENCES

Abendschein, B. (2018). *Stroke survivor and caregiver expressions of uncertainty.* Manuscript in preparation.

Abendschein, B., & Trees. A. (2018). *Relational turbulence in the family: A study of the changing dynamic between emerging adults and their parents.* Manuscript in preparation.

Acitelli, L. K. (1988). When spouses talk to each other about their relationship. *Journal of Social & Personal Relationships, 5*, 185-199. doi:10.1177/026540758800500204

Acitelli, L. K., & Badr, H. J. (2005). My illness or our illness? Attending to the relationship when one partner is ill. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples coping with stress: Emerging perspectives on dyadic coping* (pp. 121-136). Washington D.C.: American Psychological Association. doi:10.1037/11031-006

Afifi, W. A., & Weiner, J. L. (2004). Toward a theory of motivated information management. *Communication Theory, 14*, 167-190. doi:10.1111/j.1468-2885.2004.tb00310.x

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine, 41*, 303-315. doi:10.1016/0277-9536(94)00384-6

American Stroke Association (2018a). *About stroke.* Retrieved from http://www.strokeassociation.org/

American Stroke Association (2018b). *Stroke treatment.* Retrieved from http://www.strokeassociation.org/

Anderson, S., & Keating, N. (2017). Marriage after the transition to stroke: A systematic review. *Ageing and Society*, 1-39. doi:10.1017/S0144686X17000526

Anderson, S., Keating, N., & Wilson, D. (2017). Reconciling marriage and care after stroke. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement, 36,* 386-401. doi:10.1017/S0714980817000241

Babrow, A. S., Kasch, C. R., & Ford, L. A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. *Health Communication, 10,* 1-23. doi:10.1207/s15327027hc1001_1

Badr, H., & Acitelli, L. K. (2005). Dyadic adjustment in chronic illness: Does relationship talk matter? *Journal of Family Psychology, 19*, 465-469. doi:10.1037/0893-3200.19.3.465

Banks, P., & Pearson, C. (2004). Parallel lives: Younger stroke survivors and their partners coping with crisis. *Sexual and Relationship Therapy, 19*, 413-429. doi:10.1080/14681990412331298009

Baxter, L. A. (1990). Dialectical contradictions in relationship development. *Journal of Social & Personal Relationships, 7*, 69-88. doi:10.1177/0265407590071004

Baxter, L. A., & Bullis, C. (1986). Turning points in developing romantic relationships. *Human Communication Research, 12*, 469-493. doi:10.1111/j.1468-2958.1986.tb00088.x

Baxter, L. A., & Erbert, L. A. (1999). Perceptions of dialectical contradictions in turning points of development in heterosexual romantic relationships. *Journal of Social & Personal Relationships, 16*, 547-569. doi:10.1177/0265407599165001

Baxter, L. A., & Widenmann, S. (1993). Revealing and not revealing the status of romantic relationships to social networks. *Journal of Social and Personal Relationships, 10*, 321-337. doi:10.1177/0265407593103002

Berger, C. R., & Bradac, J. J. (1982). *Language and social knowledge: Uncertainty in interpersonal relations*. London, UK: Arnold.

Berger, C. R., & Calabrese, R. J. (1975). Some explorations in initial interaction and beyond: Toward a theory of interpersonal communication. *Human Communication Research, 1*, 99-112. doi:10.1111/j.1468-2958.1975.tb00258.x

Berscheid, E. (1983). Emotion. In H. H. Kelley, E. Berscheid, A. Christensen, J. H. Harvey, T. L. Huston, G. Levinger, E. McClintock, L. A. Peplau, & D. R. Peterson (Eds.), *Close relationships* (pp. 110–168). New York, NY: Freeman.

Bevan, J. L., Stetzenbach, K. A., Batson, E., & Bullo, K. (2006). Factors associated with general partner and relational uncertainty within early adulthood sibling relationships. *Communication Quarterly, 54*, 367-381. doi:10.1080/01463370600878479

Blonder, L. X., Langer, S. L., Pettigrew, L. C., & Garrity, T. F. (2007). The effects of stroke disability on spousal caregivers. *NeuroRehabilitation, 22*, 85-92.

Bowler, J. V., Hadar, U., & Wade, J. P. (1994). Cognition in stroke. *Acta Neurologica Scandinavica, 90*, 424-429. doi:10.1111/j.1600-0404.1994.tb02752.x

Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family, 66*, 551-566. doi:10.1111/j.0022-2445.2004.00037.x

Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology, 59*, 137-145. doi:10.1007/s11089-009-0264-0

Braithwaite, D., & Baxter, L. (2006). "You're my parent but you're not": Dialectical tensions in stepchildren's perceptions about communicating with the nonresidential parent. *Journal of Applied Communication Research, 34*, 30-48. doi:10.1080/00909880500420200

Brann, M., Himes, K. L., Dillow, M. R., & Weber, K. (2010). Dialectical tensions in stroke survivor relationships. *Health Communication, 25*, 323-332. doi:10.1080/10410231003773342

Brandon, I. L. (2013). Easing the burden on family caregivers. *Nursing Management, 44*, 20-28. doi:10.1097/01.NUMA.0000437769.63768.ca

Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication, 51*, 477-497. doi:10.1111/j.1460-2466.2001.tb02892.x

Brashers, D. E., & Babrow, A. (1996). Theorizing communication and health. *Communication Studies, 47*, 243–251. doi:10.1080/10510979609368479

Brashers, D. E., Basinger, E. D., Rintamaki, L. S., Caughlin, J. P., & Para, M. (2016). Taking control: The efficacy and durability of a peer-led uncertainty management intervention for people recently diagnosed with HIV. *Health Communication, 32*, 1-11. doi:10.1080/10410236.2015.1089469

Brashers, D. E., & Hogan, T. P. (2013). The appraisal and management of uncertainty: Implications for information-retrieval systems. *Information Processing & Management, 49*, 1241-1249. doi:10.1016/j.ipm.2013.06.002

Brashers, D. E., Hsieh, E., Neidig, J. L., & Reynolds, N. R. (2006). Managing uncertainty about illness: Health care providers as credible authorities. In R. M. Dailey and B. A. Le Poire (Eds.), *Applied interpersonal communication matters* (pp. 219-240). New York, NY: Peter Lang Publishing, Inc.

Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*, 305-331. doi: 10.1207/S15327027HC1603_3

Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communications Monographs, 67*, 63-84. doi:10.1080/03637750009376495

Brashers, D. E., Neidig, J. L., Reynolds, N. R., & Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory. *JANAC: Journal of the Association of Nurses in AIDS Care, 9*, 66-77. doi:10.1016/S1055-3290(98)80078-2

Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., . . . Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing, 24*, 497-522. doi:10.1080/01612840305292

Bridge, K., & Baxter, L. A. (1992). Blended relationships: Friends as work associates. *Western Journal of Communication, 56*, 200-225. doi:10.1080/10570319209374414

Brown, P., & Levinson, S. C. (1987). *Politeness: Some universals in language usage*. Cambridge, UK: Cambridge University Press.

Budner, S. (1962). Intolerance of ambiguity as a personality variable. *Journal of Personality, 30*, 29-50. doi:10.1111/1467-6494.ep8933446

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*, 167-182. doi:10.1111/1467-9566.ep11339939

Buschenfeld, K., Morris, R., & Lockwood, S. (2009). The experience of partners of young stroke survivors. *Disability and Rehabilitation, 31*, 1643-1651. doi:10.1080/09638280902736338

Bylund, C. L., Fisher, C. L., Brashers, D. E., Edgerson, S., Glogowski, E. A., Boyar, S. R., …Kissane, D. (2012). Sources of uncertainty about daughters' breast cancer risk that emerge during genetic counseling consultations. *Journal of Genetic Counseling, 2,* 292-304. doi:10.1007/s10897-011-9400-y

Cahill, J., LoBiondo-Wood, G., Bergstrom, N., & Armstrong, T. (2012). Brain tumor symptoms as antecedents to uncertainty: An integrative review. *Journal of Nursing Scholarship, 44,* 145–155. doi:10.1111/j.1547-5069.2012.01445.x

Cameron, J. I., Cheung, A. M., Streiner, D. L., Coyte, P. C., & Stewart, D. E. (2011). Stroke survivor depressive symptoms are associated with family caregiver depression during the first 2 years poststroke. *Stroke, 42,* 302-306. doi:10.1161/STROKEAHA.110.597963

Carlsson, E., Hartelius, L., & Saldert, C. (2014). Communicative strategies used by spouses of individuals with communication disorders related to stroke-induced aphasia and parkinson's disease. *International Journal of Language & Communication Disorders, 49,* 722-735. doi:10.1111/1460-6984.12106

Charmaz, K. (2014). *Constructing grounded theory: A practical guide through qualitative research*. Thousand Oaks, CA: Sage.

Clark, S. L., & Stephens, M. A. (1996). Stroke patients' well-being as a function of caregiving spouses' helpful and unhelpful actions. *Personal Relationships, 3,* 171-184. doi:10.1111/j.1475-6811.1996.tb00110.x

Clarke, A. E. (2005). *Situational analysis: Grounded theory after the postmodern turn.* Thousand Oaks, CA: Sage.

Clayton, M. F., Dudley, W. N., & Musters, A. (2008). Communication with breast cancer survivors. *Health Communication, 23,* 207-221. doi:10.1080/10410230701808376

Cohen, E. L., Scott, A. M., Record, R., Shaunfield, S., Jones, M. G., & Collins, T. (2016). Using communication to manage uncertainty about cervical cancer screening guideline adherence among Appalachian women. *Journal of Applied Communication Research, 44*, 22-39. doi:10.1080/00909882.2015.1116703

Croft, K.E., Duff, M.C., Kovach, C.K., Anderson, S.W., Adolphs, R., & Tranel, D. (2010). Detestable or marvelous? Neuroanatomical correlates of character judgments. *Neuropsychologia, 48*, 1789–1801. doi:0.1016/j.neuropsychologia.2010.03.001

Croteau, C., & Le Dorze, G. (2001). Spouses' perceptions of persons with aphasia. *Aphasiology, 15*, 811-825. doi:10.1080/02687040143000221

DeLaune, M., & Brown, S. C. (2001). Spousal responses to role changes following a stroke. *MEDSURG Nursing, 10*, 79-88.

Department of Labor (2018). *Family and medical leave act*. Retrieved from: https://www.dol.gov/whd/fmla/

Diabetes Prevention Program Research Group (2015). Long-term effects of lifestyle intervention or metformin on diabetes development and microvascular complications over 15-year follow-up: The Diabetes Prevention Program Outcomes Study. *The Lancet Diabetes & Endocrinology,* 3, 866–875. doi:10.1016/S2213-8587(15)00291-0

Dillard, J. P., & Carson, C. L. (2005). Uncertainty management following a positive newborn screening for cystic fibrosis. *Journal of Health Communication, 10*, 57-76. doi:10.1080/10810730590904580

Donovan-Kicken, E., & Bute, J. J. (2008). Uncertainty of social network members in, the case of communication-debilitating illness or injury. *Qualitative Health Research, 18*, 5-18. doi:0.1177/1049732307309005

Ebrahim, S., Nouri, F., & Barer, D. (1985). Cognitive impairment after stroke. *Age and Ageing, 14*, 345-350. doi:10.1093/ageing/14.6.345

Egbert, N., Koch, L., Coeling, H., & Ayers, D. (2006). The role of social support in the family and community integration of right-hemisphere stroke survivors. *Health Communication, 20*, 45-55. doi:10.1207/s15327027hc2001_5

Ellis, N. K., & Ledbetter, A. M. (2015). Why might distance make the heart grow fonder?: A relational turbulence model investigation of the maintenance of long distance and geographically close romantic relationships. *Communication Quarterly, 63*, 568-585. doi:10.1080/01463373.2015.1078390

Epstein R. M., & Street, R. L. (2011). The Values and Value of Patient-Centered Care. *The Annals of Family Medicine, 9*, 100-103. doi:10.1370/afm.1239

Epstein-Lubow, G. P., Beevers, C. G., Bishop, D. S., & Miller, I. W. (2009). Family functioning is associated with depressive symptoms in caregivers of acute stroke survivors. *Archives of Physical Medicine and Rehabilitation, 90*, 947-955. doi:10.1016/j.apmr.2008.12.014

Erkinjuntti, T., Østbye, T., Steenhuis, R., & Hachinski, V. (1997). The effect of different diagnostic criteria on the prevalence of dementia. *New England Journal of Medicine, 337*, 1667-1674. doi:10.1056/NEJM199712043372306

Fann, J. R., Uomoto, J. M., & Katon, W. J. (2000). Sertraline in the treatment of major depression following mild traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences, 12*, 226-232. doi:10.1176/jnp.12.2.226

Fisher, C. L. (2010). Coping with breast cancer across adulthood: Emotional support communication in the mother-daughter bond. *Journal of Applied Communication Research, 38*, 386-411. doi:10.1080/00909882.2010.513996

Flynn, D., Ford, G. A., Rodgers, H., Price, C., Steen, N., & Thomson, R. G. (2014). A time series evaluation of the FAST National Stroke Awareness Campaign in England. *PloS one, 9*, e104289. doi:10.1371/journal.pone.0104289

Foerch, C., Misselwitz, B., Sitzer, M., Berger, K., Steinmetz, H., & Neumann-Haefelin, T. (2005). Difference in recognition of right and left hemispheric stroke. *The Lancet, 336*, 392-393. doi:10.1016/S0140-6736(05)67024-9

Forsberg-Wärleby, G., Möller, A., & Blomstrand, C. (2002). Spouses of first-ever stroke victims: Sense of coherence in the first phase after stroke. *Journal of Rehabilitation Medicine, 34*, 128-133. doi:10.1080/165019702753714156

Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology, 28*, 1281-1300. doi:10.1080/02687038.2014.928664

Fridriksson, J., Fillmore, P., Guo, D., & Rorden, C. (2015). Chronic Broca's aphasia is caused by damage to Broca's and Wernicke's areas. *Cerebral Cortex, 25*, 4689-4696. doi:10.1093/cercor/bhu152

Friedman, T. L. (2007). *The world is flat: A brief history of the twenty-first century*. New York, NY: Picador.

Gibbs, G. (2007). *Analyzing qualitative data*. London, UK: Sage.

Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.

Glintborg, C. (2015). Disabled & not normal: Identity construction after an acquired brain injury. *Narrative Inquiry, 25*(1), 1-21. doi:10.1075/ni.25.1.01gli

Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., ... & Turner, M. B. (2014). Heart disease and stroke statistics—2014 update a report from the American Heart Association. *Circulation, 129*, e28-e292. doi:10.1161/01.cir.0000441139.02102.80

Godwin, E., Chappell, B., & Kreutzer, J. (2014). Relationships after TBI: A grounded research study. *Brain Injury, 28,* 398-413. doi:10.3109/02699052.2014.880514

Godwin, K. M., Swank, P. R., Vaeth, P., & Ostwald, S. K. (2013). The longitudinal and dyadic effects of mutuality on perceived stress for stroke survivors and their spousal caregivers. *Aging & Mental Health, 17,* 423-431. doi:10.1080/13607863.2012.756457

Goldsmith, D. J. (Ed.) (2015). *Uncertainty and communication in couples coping with serious illness*. New York, NY: Routledge.

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2014). Describing the impact of aphasia on close family members using the ICF framework. *Disability & Rehabilitation, 36*, 1184-1195. doi:10.3109/09638288.2013.834984

Green, T. L., & King, K. M. (2009). Experiences of male patients and wife-caregivers in the first year post-discharge following minor stroke: A descriptive qualitative study. *International Journal of Nursing Studies, 46,* 1194-1200. doi:10.1016/j.ijnurstu.2009.02.008

Gustafson, L. (1996). What is dementia? *Acta Neurologica Scandinavica, 94*, 22-24. doi:10.1111/j.1600-0404.1996.tb00367.x

Hall, M. J., Levant, S., & DeFrances, C. J. (2012, October). *Hospitalization for congestive heart failure: United States, 2000–2010*. (NCHS Data Brief, 108). Reterived from https://www.researchgate.net/profile/Carol_DeFrances/publication/232718240_Hospitalization_for_Congestive_Heart_Failure_United_States_2000-2010/links/0f317535869223eaea000000.pdf

Hamm, T. L. (2018). Abstract 10: Strategies to support young stroke survivors. *Stroke, 49*, A10.

Han, B., & Haley, W. E. (1999). Family caregiving for patients with stroke. *Stroke, 30*, 1478-1485. doi:10.1161/01.STR.30.7.1478

Harbison, J., Hossain, O., Jenkinson, D., Davis, J., Louw, S. J., & Ford, G. A. (2003). Diagnostic accuracy of stroke referrals from primary care, emergency room physicians, and ambulance staff using the face arm speech test. *Stroke*, *34*, 71-76. doi:10.1161/01.STR.0000044170.46643.5E

Harvey-Knowles, J., & Faw, M. H. (2016). A relational turbulence model perspective on communication in intimate relationships post-HPV testing. *Health Communication, 31*, 688-694. doi:10.1080/10410236.2014.990080

Hesketh, A., Long, A., & Bowen, A. (2011). Agreement on outcome: Speaker, carer, and therapist perspectives on functional communication after stroke. *Aphasiology, 25*, 291-308. doi:10.1080/02687038.2010.507818

Hilari, K., & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology, 20*, 17-36. doi:10.1080/02687030500279982

Hilton, B. A. (1994). The uncertainty stress scale: Its development and psychometric properties. *Canadian Journal of Nursing Research Archive, 26*(3), 15-30. Retrieved from http://cjnr.archive.mcgill.ca/article/view/1237/1237

Hong, S. J., & You, K. H. (2016). The effects of experienced uncertainty and patients' assessments of cancer-related information-seeking experiences on fatalistic beliefs and trust in physicians. *Health Communication,* 31, 1495-1505. doi:10.1080/10410236.2015.1089399

Hunt, D., & Smith, J. A. (2004). The personal experience of carers of stroke survivors: An interpretative phenomenological analysis. *Disability & Rehabilitation, 26*, 1000-1011. doi:10.1080/09638280410001702423

Jordan, L., & Kaiser, W. (2013). *Aphasia: A social approach*. San Diego, CA: Singular Publishing Group Inc.

Jorge, R. E., Robinson, R. G., Starkstein, S. E., & Arndt, S. V. (1993). Depression and anxiety following traumatic brain injury. *The Journal of Neuropsychiatry and Clinical Neurosciences, 5*, 369-374. doi:10.1176/jnp.5.4.369

Kelly-Hayes, M., Robertson, J. T., Broderick, J. P., Duncan, P. W., Hershey, L. A., Roth, E. J., . . . Trombly, C. A. (1998). The American Heart Association stroke outcome classification. *Stroke, 29*, 1274-1280. doi:10.1161/01.STR.29.6.1274

Khan, A., Kalaria, R. N., Corbett, A., & Ballard, C. (2016). Update on vascular dementia. *Journal of Geriatric Psychiatry and Neurology, 29*, 281-301. doi:10.1177/0891988716654987

Kim, J., Fonarow, G. C., Smith, E. E., Reeves, M. J., Navalkele, D. D., Grotta, J. C., … Saver, J. L. (2017). Treatment with tPA in the "golden hour" and the shape of the 4.5 hour time-benefit curve in the national US get with the guidelines stroke population. *Circulation, 135*(1), 128-139. doi:10.1161/CIRCULATIONAHA.116.023336

Kimura, M., Robinson, R. G., & Kosier, J. T. (2000). Treatment of cognitive impairment after poststroke depression a double-blind treatment trial. *Stroke, 31,* 1482-1486. doi:10.1161/01.STR.31.7.1482

King. B., & Mishel, M. (1986, April). *Uncertainty appraisal and management in chronic illness*. Paper presented at the Communicating Nursing Research Conference, Western Society for Research in Nursing, Portland, OR.

Kinney, J. M., Parris Stephens, M. A., Franks, M. M., & Norris, V. K. (1995). Stresses and satisfactions of family caregivers to older stroke patients. *Journal of Applied Gerontology, 14,* 3-21. doi:10.1177/073346489501400101

Knobloch, L. K. (2007). Perceptions of turmoil within courtship: Associations with intimacy, relational uncertainty, and interference from partners. *Journal of Social & Personal Relationships, 24,* 363-384. doi:10.1177/0265407507077227

Knobloch, L. K. (2008). The content of relational uncertainty within marriage. *Journal of Social & Personal Relationships, 25,* 467-495. doi:10.1177/0265407508090869

Knobloch, L. K., & Delaney, A. L. (2012). Themes of relational uncertainty and interference from partners in depression. *Health Communication, 27,* 750-765. doi:10.1080/10410236.2011.639293

Knobloch, L. K., Ebata, A. T., McGlaughlin, P. C., & Ogolsky, B. (2013). Depressive symptoms, relational turbulence, and the reintegration difficulty of military couples following wartime deployment. *Health Communication, 28,* 754-766. doi:10.1080/10410236.2013.800440

Knobloch, L. K., McAninch, K. G., Abendschein, B., Ebata, A. T., & McGlaughlin, P. C. (2016). Relational turbulence among military couples after reunion following deployment. *Personal Relationships, 23,* 742-758. doi:10.1111/pere.12148

Knobloch, L. K., & Solomon, D. H. (1999). Measuring the sources and content of relational uncertainty. *Communication Studies, 50,* 261-278. doi:10.1080/10510979909388499

Knobloch, L. K., & Solomon, D. H. (2002). Information seeking beyond initial interaction: Negotiating relational uncertainty within close relationships. *Human Communication Research, 28,* 243-257. doi:10.1111/j.1468-2958.2002.tb00806.x

Knobloch, L. K., & Solomon, D. H. (2004). Interference and facilitation from partners in the development of interdependence within romantic relationships. *Personal Relationships, 11*, 115-130. doi:10.1111/j.1475-6811.2004.00074.x

Knobloch, L. K., & Theiss, J. A. (2011). Relational uncertainty and relationship talk within courtship: A longitudinal actor-partner interdependence model. *Communication Monographs, 78,* 3-26. doi:10.1080/03637751.2010.542471

Knobloch, L. K., & Theiss, J. A. (2012). Experiences of u.S. Military couples during the post-deployment transition: Applying the relational turbulence model. *Journal of Social & Personal Relationships, 29,* 423-450. doi:10.1177/0265407511431186

Konkel, A., & Cohen, N. J. (2009). Relational memory and the hippocampus: Representations and methods. *Frontiers in Neuroscience, 3,* 166-174. doi:10.3389/neuro.01.023.2009

Kreutzer, J. S., Mills, A., & Marwitz, J. H. (2016). Ambiguous and emotional recovery after traumatic brain injury. *Journal of Family Theory & Review, 8,* 386-397. doi:10.1111/jftr.12150

Kundrat, A. L., & Nussbaum, J. F. (2003). The impact of invisible illness on identity and contextual age across the life span. *Health Communication, 15*, 331-347. doi:10.1207/S15327027HC1503_5

Landau, J., & Hissett, J. (2008). Mild traumatic brain injury: Impact on identity and ambiguous loss in the family. *Families, Systems & Health: The Journal of Collaborative Family HealthCare, 26*, 69-85. doi:10.1037/1091-7527.26.1.69

Lazarus, R. S. (1974). Psychological stress and coping in adaptation and illness. *The International Journal of Psychiatry in Medicine, 5*, 321-333. doi:10.2190/T43T-84P3-QDUR-7RTP

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer Publishing Company.

Lees, K. R., Bluhmki, E., Kummer, R., Brott, T.G., Toni, D., Grotta, J. C., … Hacke, W. (2010). Time to treatment with intravenous alteplase and outcome in stroke: An updated pooled analysis of ECASS, ATLANTIS, NINDS and EPITHET trials. *The Lancet, 375*, 1695–1703. doi:10.1016/S0140-6736(10)60491-6

Loveless, M., Powers, W. G., & Jordan, W. (2008). Dating partner communication apprehension, self disclosure, and the first big fight. *Human Communication, 11*, 231-239.

Lurbe-Puerto, K., Leandro, M. E., & Baumann, M. (2012). Experiences of caregiving, satisfaction of life, and social repercussions among family caregivers, two years post-stroke. *Social Work in Health Care, 51*, 725-742. doi:10.1080/00981389.2012.692351

Mandler, G. (1979). Thought processes, consciousness, and stress. In V. Hamilton & D. M. Warburton (Eds.), *Human stress and cognition: An information processing approach* (pp. 197-201). New York, NY: John Wiley and Sons.

Markel, H. (2004). “I swear by Apollo”—on taking the Hippocratic oath. *New England Journal of Medicine, 350,* 2026-2029. doi:10.1056/NEJMp048092

Martin, S. C., Stone, A. M., Scott, A. M., & Brashers, D. E. (2010). Medical, personal, and social forms of uncertainty across the transplantation trajectory. *Qualitative Health Research, 20*, 182-196. doi:10.1177/1049732309356284

Mayo Clinic (2018). *Stroke: Overview*. Retrieved from http://www.mayoclinic.org/diseases-conditions/stroke/home/ovc-20117264

McCarthy, M. J., & Bauer, E. (2015). In sickness and in health: Couples coping with stroke across the life span. *Health & Social Work, 40*, e92-e100. doi:10.1093/hsw/hlv043

McCarthy, M. J., & Lyons, K. S. (2015). Incongruence between stroke survivor and spouse perceptions of survivor functioning and effects on spouse mental health: A mixed-methods pilot study. *Aging & Mental Health, 19*, 46-54. doi:10.1080/13607863.2014.913551

McCarthy, M. J., Lyons, K. S., & Powers, L. E. (2012). Relational factors associated with depressive symptoms among stroke survivor-spouse dyads. *Journal of Family Social Work, 15*, 303-320. doi:10.1080/10522158.2012.696230

McCarthy, M. J., Powers, L. E., & Lyons, K. S. (2011). Poststroke depression: Social workers' role in addressing an underrecognized psychological problem for couples who have experienced stroke. *Health & Social Work, 36*, 134-143. doi:10.1093/hsw/36.2.139

McGurk, R., & Kneebone, I. I. (2013). The problems faced by informal carers to people with aphasia after stroke: A literature review. *Aphasiology, 27*, 765-783. doi:10.1080/02687038.2013.772292

McGurk, R., Kneebone, I. I., & Pit ten Cate, I. M. (2011). “Sometimes we get it wrong but we keep on trying”: A cross-sectional study of coping with communication problems by informal carers of stroke survivors with aphasia. *Aphasiology, 25,* 1507-1522. doi:10.1080/02687038.2011.599528

McLaren, R. M., Solomon, D. H., & Priem, J. S. (2012). The effect of relationship characteristics and relational communication on experiences of hurt from romantic partners. *Journal of Communication, 62,* 950-971. doi:10.1111/j.1460-2466.2012.01678.x

Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research, 30*, 258-263. doi:10.1097/00006199-198109000-00002

Mishel, M. H. (1984). Perceived uncertainty and stress in illness. *Research in Nursing & Health, 7,* 163-171. doi:10.1002/nur.4770070304

Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship, 20,* 225-232. doi:10.1111/j.1547-5069.1988.tb00082.x

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship, 22*, 256-262. doi:10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H., & Braden, C. J. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research, 37,* 98-103. doi:10.1097/00006199-198803000-00009

Mishel, M. H., Germino, B. B., Lin, L., Pruthi, R. S., Wallen, E. M., Crandell, J., & Blyler, D. (2009). Managing uncertainty about treatment decision making in early stage prostate cancer: A randomized clinical trial. *Patient Education & Counseling, 77*, 349-359. doi:10.1016/j.pec.2009.09.009

Montgomery, B. M. (1984). Communication in intimate relationships: A research challenge. *Communication Quarterly, 32*, 318-325. doi:10.1080/01463378409369569

Mozaffarian Benjamin, E., Go, A., Arnett, D. K., Blaha, M. J., Cushman, M., ... & Turner, M. B. (2015). Heart disease and stroke statistics-2016 update: A report from the American Heart Association. *Circulation, 132,* e1-e162. doi:10.1161/CIR.0000000000000350

Murray, C. D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretative phenomenological analysis. *Disability and Rehabilitation, 26,* 808-816. doi:10.1080/09638280410001696746

Nagy, M. E., & Theiss, J. A. (2013). Applying the relational turbulence model to the empty-nest transition: Sources of relationship change, relational uncertainty, and interference from partners. *Journal of Family Communication, 13,* 280-300. doi:10.1080/15267431.2013.823430

Narushima, K., Chan, K. L., Kosier, J. T., & Robinson, R. G. (2003). Does cognitive recovery after treatment of poststroke depression last? A 2-year follow-up of cognitive function associated with poststroke depression. *American Journal of Psychiatry, 160,* 1157-1162. doi:10.1176/appi.ajp.160.6.1157

National Aphasia Association (2017). *What is aphasia*. Retrieved from http://www.aphasia.org

NINDS: National Institute of Neurological Disorders and Stroke (2018). *NINDS stroke information page.* Retrieved from http://www.ninds.nih.gov/disorders/stroke/stroke.htm

National Stroke Association (2017). *Stroke Facts*. Retrieved from http://www.stroke.org

O'Connell, B., & Baker, L. (2004). Managing as carers of stroke survivors: Strategies from the field. *International Journal of Nursing Practice, 10,* 121-126. doi:10.1111/j.1440-172X.2004.00469.x

Ontario Medical Association. (2010, June). *OMA policy on patient-centered care* (Issue Brief). Ontario, Canada: Hanna, A.

Papathanasiou, I., Coppens, P., & Potagas, C. (2016). *Aphasia and related neurogenic communication disorders.* Burlington, MA: Jones & Bartlett Publishers.

Pawlowski, D. R. (1998). Dialectical tensions in marital partners' accounts of their relationships. *Communication Quarterly, 46,* 396-416. doi:10.1080/01463379809370111

Pawlowski, D. R. (2006) Dialectical tensions in families experiencing acute health issues: Stroke survivors' perceptions. In L. Turner & R. West (Eds.), *The family communication sourcebook* (pp. 469-489). Thousand Oaks, CA: Sage Publications.

Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social behavior*, 337-356. doi:10.2307/2136676

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583-594. doi:10.1093/geront/30.5.583

Peters, S. A., Huxley, R. R., & Woodward, M. (2014). Diabetes as a risk factor for stroke in women compared with men: A systematic review and meta-analysis of 64 cohorts, including 775 385 individuals and 12 539 strokes. *The Lancet, 383,* 1973-1980. doi:10.1016/S0140-6736(14)60040-4

Quinn, K., Murray, C., & Malone, C. (2014). Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: A meta-synthesis of qualitative research. *Disability & Rehabilitation, 36,* 185-198. doi:http://dx.doi.org/10.3109/09638288.2013.783630

Radcliffe, E., Lowton, K., & Morgan, M. (2013). Co-construction of chronic illness narratives by older stroke survivors and their spouses. *Sociology of Health & Illness, 35,* 993-1007. doi:10.1111/1467-9566.12012

Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke, 4,* 285-292. doi:10.1111/j.1747-4949.2009.00289.x

Román, G. C., Erkinjuntti, T., Wallin, A., Pantoni, L., & Chui, H. C. (2002). Subcortical ischaemic vascular dementia. *The Lancet Neurology, 1,* 426-436. doi:http://dx.doi.org/10.1016/S1474-4422(02)00190-4

Ross, K. B., & Wertz, R. T. (2002). Relationships between language-based disability and quality of life in chronically aphasic adults. *Aphasiology, 16,* 791-800. doi:10.1080/02687030244000130

Rubin R.D., Cohen N.J. (2017). Memory, relational representations, and the long reach of the hippocampus. In D. Hannula & M. Duff (Eds.), *The Hippocampus from Cells to Systems* (pp. 337-366). Cham, Switzerland: Springer. doi:10.1007/978-3-319-50406-3_11

Ryan, C. & Lewis, J. M. (2017, September). Computer and internet use in the United States: 2015. *American Community Survey Reports, ACS-37.* Retrieved from www.census.gov

Saban, K. L., & Hogan, N. S. (2012). Female caregivers of stroke survivors: Coping and adapting to a life that once was. *Journal of Neuroscience Nursing, 44,* 2-14. doi:10.1097/JNN.0b013e31823ae4f9

Saldaña, J. (2015). *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage.

Scarinci, N., Worrall, L., & Hickson, L. (2009). The ICF and third-party disability: Its application to spouses of older people with hearing impairment. *Disability and Rehabilitation, 25,* 2088-2100. doi:10.3109/09638280902927028

Scott, A. M., Martin, S. C., Stone, A. M., & Brashers, D. E. (2011). Managing multiple goals in supportive interactions: Using a normative theoretical approach to explain social support as uncertainty management for organ transplant patients. *Health Communication, 26*, 393-403. doi:10.1080/10410236.2011.552479

Shoamanesh, A., Preis, S. R., Beiser, A. S., Kase, C. S., Wolf, P. A., Vasan, R. S., . . . Romero, J. R. (2016). Circulating biomarkers and incident ischemic stroke in the Framingham offspring study. *Neurology, 87*, 1206-1211. doi:10.1212/WNL.0000000000003115

Silverberg, N. D., Iverson, G. L., Brubacher, J. R., Holland, E., Casagrande Hoshino, L., Aquino, A., & Lange, R. T. (2016). The nature and clinical significance of preinjury recall bias following mild traumatic brain injury. *Journal of Head Trauma Rehabilitation, 31*, 388-396. doi:10.1097/HTR.0000000000000198

Solomon, D., & Knobloch, L. K. (2001). Relationship uncertainty, partner interference, and intimacy within dating relationships. *Journal of Social & Personal Relationships, 18*, 804. doi:10.1177/0265407501186004

Solomon, D. H., & Knobloch, L. K. (2004). A model of relational turbulence: The role of intimacy, relational uncertainty, and interference from partners in appraisals of irritations. *Journal of Social & Personal Relationships, 21*, 795-796. doi:0.1177/0265407504047838

Solomon, D. H., Knobloch, L. K., Theiss, J. A., & McLaren, R. M. (2016). Relational turbulence theory: Explaining variation in subjective experiences and communication within romantic relationships. *Human Communication Research, 42*, 507-532. doi:10.1111/hcre.12091

Solomon, D. H., & Theiss, J. A. (2008). A longitudinal test of the relational turbulence model of romantic relationship development. *Personal Relationships, 15,* 339-357. doi:10.1111/j.1475-6811.2008.00202.x

Sullivan, N., Walenski, M., Love, T., & Shapiro, L. P. (2017). The comprehension of sentences with unaccusative verbs in aphasia: A test of the intervener hypothesis. *Aphasiology, 31,* 67-81. doi:http://dx.doi.org/10.1080/02687038.2016.1154499

Stewart, M., Davidson, K., Meade, D., Hirth, A., & Makrides, L. (2000). Myocardial infarction: Survivors' and spouses' stress, coping, and support. *Journal of Advanced Nursing, 31,* 1351-1360. doi:10.1046/j.1365-2648.2000.01454.x

Steuber, K. R., Priem, J. S., Scharp, K. M., & Thomas, L. (2014). The content of relational uncertainty in non-engaged cohabiting relationships. *Journal of Applied Communication Research, 42,* 107-123. doi:10.1080/00909882.2013.874569

Steuber, K. R., & Solomon, D. H. (2008). Relational uncertainty, partner interference, and infertility: A qualitative study of discourse within online forums. *Journal of Social and Personal Relationships, 25,* 831-855. doi: 10.1177/0265407508096698

Strauss, A. L. (1987). *Qualitative analsysis for social scientists*. New York, NY: Cambridge University Press.

Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: Sage Publications, Inc.

Swardfager, W., & MacIntosh, B. J. (2016). Depression, type 2 diabetes, and poststroke cognitive impairment. *Neurorehabilitation and Neural Repair,* 31, 48-55. doi:10.1177/1545968316656054

Tatemichi, T., Desmond, D., Stern, Y., Paik, M., Sano, M., & Bagiella, E. (1994). Cognitive impairment after stroke: Frequency, patterns, and relationship to functional abilities. *Journal of Neurology, Neurosurgery & Psychiatry, 57*, 202-207. doi:10.1136/jnnp.57.2.202

Tellier, M., Rochette, A., & Lefebvre, H. (2011). Impact of mild stroke on the quality of life of spouses. *International Journal of Rehabilitation Research, 34*, 209-214. doi:10.1097/MRR.0b013e328343d540

Tham, W., Auchus, A. P., Thong, M., Goh, M.-L., Chang, H.-M., Wong, M.-C., & Chen, C. P.-H. (2002). Progression of cognitive impairment after stroke: One year results from a longitudinal study of singaporean stroke patients. *Journal of the Neurological Sciences, 203*, 49-52. doi:10.1016/S0022-510X(02)00260-5

Theiss, J. A., & Knobloch, L. K. (2014). Relational turbulence and the post-deployment transition: Self, partner, and relationship focused turbulence. *Communication Research, 41*, 27-51. doi:10.1177/0093650211429285

Theiss, J. A., Knobloch, L. K., Checton, M. G., & Magsamen-Conrad, K. (2009). Relationship characteristics associated with the experience of hurt in romantic relationships: A test of the relational turbulence model. *Human Communication Research, 35*, 588-615. doi:10.1111/j.1468-2958.2009.01364.x

Theiss, J. A., & Solomon, D. H. (2006). A relational turbulence model of communication about irritations in romantic relationships. *Communication Research, 33*, 391-418. doi:10.1177/0093650206291482

Thompson, H. S., & Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of Clinical Nursing, 18*, 1803-1811. doi:10.1111/j.1365-2702.2008.02694.x

Tracy, S. J. (2010). Qualitative quality: Eight "big tent" criteria for excellent qualitative research. *Qualitative Inquiry, 16*, 837-851. doi:10.1177/1077800410383121

Tracy, S. J. (2013). *Qualitative research methods*. Chichester, UK: Wiley-Blackwell.

UK Prospective Diabetes Study Group (1998). Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. *BMJ: British Medical Journal, 7160,* 703-713. Retrieved from http://www.jstor.org/stable/25180360

Unson, C., Flynn, D., Glendon, M. A., Haymes, E., & Sancho, D. (2015). Dementia and caregiver stress: An application of the reconceptualized uncertainty in illness theory. *Issues in Mental Health Nursing, 36*, 439-446. doi:10.3109/01612840.2014.993052

Venetis, M. K., Magsamen-Conrad, K., Checton, M. G., & Greene, K. (2014). Cancer communication and partner burden: An exploratory study. *Journal of Communication, 64*, 82-102. doi:10.1111/jcom.12069

Visser-Meily, A., Post, M., Schepers, V., & Lindeman, E. (2005). Spouses' quality of life 1 year after stroke: Prediction at the start of clinical rehabilitation. *Cerebrovascular Diseases, 20*, 443-448. doi:10.1159/000088983

Weber, K. M., & Solomon, D. H. (2008). Locating relationship and communication issues among stressors associated with breast cancer. *Health Communication, 23*, 548-559. doi:10.1080/10410230802465233

Wedgeworth, M., LaRocca, M. A., Chaplin, W. F., & Scogin, F. (2017). The role of interpersonal sensitivity, social support, and quality of life in rural older adults. *Geriatric Nursing, 38,* 22-26. doi:10.1016/j.gerinurse.2016.07.001

Weiss, R. S. (1994). *Learning from strangers: The art and method of qualitative interview studies*. New York, NY: The Free Press.

White, C. L., Barrientos, R., & Dunn, K. (2014). Dimensions of uncertainty after stroke: Perspectives of the stroke survivor and family caregiver. *Journal of Neuroscience Nursing, 46,* 233-240 238p. doi:10.1097/JNN.0000000000000066

Williams, G. H., & Jones, I. R. (2017). Making sense: Further studies of living with chronic illness. *Sociology of Health & Illness, 39,* 653-658. doi:10.1111/1467-9566.12608

Winkler, M., Bedford, V., Northcott, S., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect the carer and their relationship with the person with aphasia? *Aphasiology, 28,* 1301-1319. doi:10.1080/02687038.2014.928665

Wittenberg-Lyles, E., Washington, K., Demiris, G., Oliver, D. P., & Shaunfield, S. (2014). Understanding social support burden among family caregivers. *Health Communication, 29,* 901-910. doi:10.1080/10410236.2013.815111

Wolfe, C. D. (2000). The impact of stroke. *British medical bulletin, 56,* 275-286.

World Health Organization (2001). *International classification of functioning, disability and health, ICF*. Geneva: World Health Organization.

Wortman, C. B., & Dunkel Schetter, C. (1979). Interpersonal relationships and cancer: A theoretical analysis. *Journal of Social Issues, 35,* 120-155. doi:10.1111/j.1540-4560.1979.tb00792.x

APPENDIX A: CONSENT FORM

Hard Copy Consent Form



SOCIAL BEHAVIORAL RESEARCH CONSENT FORM

Research Information and Consent for Participation in Social Behavioral Research

Communication and Stroke: A Pragmatic Iterative Approach

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Dr. Leanne Knobloch, Professor
Department and Institution: Department of Communication, University of Illinois
Address and Contact Information:
3001 Lincoln Hall, 702 S. Wright St., Urbana, IL 61801
Phone: 217-333-8913
Email: knobl@illinois.edu

Why am I being asked?

You are being asked to be a subject in a research study about relational partners' communication after a stroke.

You have been asked to participate in the research because you have had a stroke or are the partner of someone who has had a stroke.

Your participation in this research is voluntary. **If you decide to participate, you are free to withdraw at any time.**

Approximately 60 participants may be involved in this research at the University of Illinois at Urbana-Champaign.

What is the purpose of this research?

The objective of this study is to learn more about relational partners' communication after a stroke.

What procedures are involved?

This research will be performed in person at the University of Illinois at Urbana-Champaign or locations in the community (e.g., coffee shops and local libraries), as well as through technology (e.g., Skype and phone calls).

You will be asked to participate in an interview about your experience with stroke in your relationship with your partner.

The interview may take about 60 – 90 minutes.

What are the potential risks and discomforts?

The risks you will encounter by participating in this research are comparable to those you would experience in everyday life. Since you will be discussing possibly difficult topics, however, you may experience distress or discomfort. **You may end your participation at any time, and you may skip any question you do not feel comfortable answering**. Although your interaction will be audio recorded, you may rescind your consent at any time, and your audio file will be deleted and not used for further research.

Are there benefits to taking part in the research?

Participation might allow you to explore difficult topics in your relationship that you associate with stroke. You will also receive a $20 Amazon e-gift card for your time and participation. Furthermore, participation in this study might benefit others by providing information about how stroke affects relationships.

What other options are there?

You have the option to not participate in this study.

Will my study-related information be kept confidential?

Faculty, staff, students, and others with permission or authority to see your study information will maintain its confidentiality to the extent permitted and required by laws and university policies. The names or personal identifiers of participants will not be published or presented.

What are the costs for participating in this research?

There are **no costs** to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will receive a $20 Amazon e-gift card for your time and participation. If you do not finish the study, you will still receive the e-gift card. You will receive your payment within approximately 7 days of your visit through the email account you provided.

Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

The researchers also have the right to stop your participation in this study without your consent if:

→ They believe it is in your best interest; OR

→ You are unable to successfully understand the items in the consent discussion.

In the event you withdraw or are asked to leave the study, you will still be compensated as described above.

Who should I contact if I have questions?

Contact the researchers Dr. Leanne Knobloch at knobl@illinois.edu OR Bryan Abendschein at abendsc2@illinoi.edu:

- if you have any questions about this study or your part in it, or
- if you have questions, concerns, or complaints about the research.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu

Remember:

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

By signing below, I assert that I meet the following requirements:

- I am 18 years of age or older;
- I have read and understand the above consent document;
- I voluntarily agree to participate in the study; and
- I am willing to be audio-recorded.

_____ _____

Signature Date

_____

Printed Name

_____ _____

Signature of Person Obtaining Consent Date (must be same as subject's)

_____

Printed Name of Person Obtaining Consent

Online Consent (Qualtrics survey)

Please submit your first and last name:
First Name (1)
Last Name (2)

SOCIAL BEHAVIORAL RESEARCH CONSENT FORM

Research Information and Consent for Participation in Social Behavioral Research

Communication and Stroke: A Pragmatic Iterative Approach

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Dr. Leanne Knobloch, Professor
Department and Institution: Department of Communication, University of Illinois
Address and Contact Information:
3001 Lincoln Hall, 702 S. Wright St., Urbana, IL 61801
Phone: 217-333-8913
Email: knobl@illinois.edu

Why am I being asked?

You are being asked to be a subject in a research study about relational partners' communication after a stroke.
You have been asked to participate in the research because you have had a stroke or are the partner of someone who has had a stroke.

Your participation in this research is voluntary. **If you decide to participate, you are free to withdraw at any time.**

Approximately 60 participants may be involved in this research at the University of Illinois at Urbana-Champaign.

What is the purpose of this research?

The objective of this study is to learn more about relational partners' communication after a stroke.

What procedures are involved?

This research will be performed in person at the University of Illinois at Urbana-Champaign or locations in the community (e.g., coffee shops and local libraries), as well as through technology (e.g., Skype and phone calls).

You will be asked to participate in an interview about your experience with stroke in your relationship with your partner.

The interview may take about 60 – 90 minutes.

What are the potential risks and discomforts?

The risks you will encounter by participating in this research are comparable to those you would experience in everyday life. Since you will be discussing possibly difficult topics, however, you may experience distress or discomfort. **You may end your participation at any time, and you may skip any question you do not feel comfortable answering**. Although your interaction will be audio recorded, you may rescind your consent at any time, and your audio file will be deleted and not used for further research.

Are there benefits to taking part in the research?

Participation might allow you to explore difficult topics in your relationship that you associate with stroke. You will also receive a $20 Amazon e-gift card for your time and participation. Furthermore, participation in this study might benefit others by providing information about how stroke affects relationships.

What other options are there?

You have the option to not participate in this study.

Will my study-related information be kept confidential?

Faculty, staff, students, and others with permission or authority to see your study information will maintain its confidentiality to the extent permitted and required by laws and university policies. The names or personal identifiers of participants will not be published or presented.

What are the costs for participating in this research?

There are **no costs** to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will receive a $20 Amazon e-gift card for your time and participation. If you do not finish the study, you will still receive the e-gift card. You will receive your payment within approximately 7 days of your visit through the email account you provided.

Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

The researchers also have the right to stop your participation in this study without your consent if:

→ They believe it is in your best interest; OR

→ You are unable to successfully understand the items in the consent discussion.

In the event you withdraw or are asked to leave the study, you will still be compensated as described above.

Who should I contact if I have questions?

Contact the researchers Dr. Leanne Knobloch at knobl@illinois.edu OR Bryan Abendschein at abendsc2@illinoi.edu:

- if you have any questions about this study or your part in it, or
- if you have questions, concerns, or complaints about the research.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu

Remember:

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

By signing below, I assert that I meet the following requirements:

- I am 18 years of age or older;
- I have read and understand the above consent document;
- I voluntarily agree to participate in the study; and
- I am willing to be audio-recorded.

❍ Yes, I want to participate (1)

❍ No, I do not want to participate (2)

APPENDIX B: INFORMED CONSENT DISCUSSION GUIDE

The consent discussion will focus on three main points:

1. How much does it cost to be a part of this study?
    a. *Answer: Nothing*
    b. *Participant response: Correct / Incorrect*

2. Is participation voluntary?
    a. *Answer: Yes*
    b. *Participant response: Correct / Incorrect*

3. Are you allowed to stop the interview at any time?
    a. *Answer: Yes*
    b. *Participant response: Correct / Incorrect*

Although quiz style assessments have an established history of use in psychological studies to test understanding of informed consent (see Dunn & Jeste, 2001), there is no agreed upon standard for how to assess a person's understanding of the consent document. The selection of the questions in this "consent discussion" are meant to address the most crucial elements related to the participant's involvement (i.e., no cost to participate, participation is voluntary, and he or she can stop the interview at any time). To participate, a person must understand these three elements as scored by the researcher. A participant will be ineligible if he or she incorrectly does not understand the areas covered in this discussion.

APPENDIX C: EMAILS TO GROUP ADMINISTRATORS

Initial Email

Hello,

Thank you for all you do to help stroke survivors and caregivers connect to share their stories. My name is Bryan Abendschein, and I am a graduate student at the University of Illinois at Urbana-Champaign where I study communication among couples. I am currently conducting a study about the experiences of stroke survivors and their spouses / romantic partners, and I wondered if you would help me share this information with others.

The study involves an interview about how people communicate after stroke. Interviews can be done in person, over the phone, or through Skype (for more information please see the attached flyer or visit the website for the study).

To get the message out to potential participants, I would appreciate your help. I have attached a flyer with information about the study and how to contact me. May I have your permission to share the flyer with [NAME OF FORUM or GROUP]? Alternatively, you are welcome to post the flyer or circulate it in other ways (e.g., send it to listservs or post it to Facebook pages).

The findings from this study will help physicians and researchers better understand people's relationship experiences after stroke. If you are willing to share information about the study, please reply to this email to let me know.

Do not hesitate to reach out to me with questions. If sharing this information [ON YOUR PAGE / IN YOUR GROUP] is not an option, please let me know and I will not email you again.

I also welcome any ideas you have on how to advertise this study.

Thank you for your time.

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois, Urbana-Champaign
abendsc2@illinois.edu

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

Follow-up Email

Hello,

Thank you for all you do to help stroke survivors and caregivers connect to share their stories. My name is Bryan Abendschein, and I am a graduate student at the University of Illinois at Urbana-Champaign where I study communication among couples. I am writing to follow up on an email I sent you about helping me get the word out about my study.

The study involves an interview of stroke survivors and spouses / romantic partners about how they communicate after a stroke (for more information please see the attached flyer or visit the website for the study). May I have your permission to share the flyer with [NAME OF FORUM or GROUP]? Alternatively, you are welcome to post the flyer or circulate it in other ways (e.g., send it to listservs or post it to Facebook pages).

The findings from this study will help physicians and researchers better understand people's relationship experiences after stroke. If you are willing to share information about the study [ON YOUR PAGE / IN YOUR GROUP], please reply to this email to let me know.

If sharing this information on your page is not an option, please let me know and I will not email you again.

This research is very important to me, so I welcome any ideas you have on how to advertise this study.

Thank you for your time.

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois, Urbana-Champaign
abendsc2@illinois.edu

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

APPENDIX D: STUDY FLYERS

Flyer to accompany emails

Have you or your spouse / romantic partner suffered a stroke?

If so, researchers from the University of Illinois are interested in hearing your story.
We are conducting interviews with couples to better understand what life is like after stroke.

Each participant will receive a $20 Amazon e-gift card.

You are eligible if you:
~Are a stroke survivor -OR- the spouse / romantic partner of a stroke survivor~
~Are willing to participate in interviews separately that may last 60 – 90 minutes~
~Are willing to have the interview audio recorded~

To learn more or to volunteer:
Email Bryan Abendschein: abendsc2@illinois.edu
-OR-

Visit the website for the study:

communicationandstroke.weebly.com

Questions?
Contact:
Bryan Abendschein, M.A.
Doctoral Candidate
University of Illinois at Urbana-Champaign
abendsc2@illinois.edu

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

Facebook Message

Have you or your spouse / romantic partner suffered a stroke?

If so, researchers from the University of Illinois are interested in hearing your story.
We are conducting interviews with stroke survivors as well as partners of stroke survivors to better understand how people communicate after stroke.

Receive a $20 Amazon e-gift card in exchange for participation.

You are eligible if you:

~ Are a stroke survivor -OR- the partner of a stroke survivor
~ Are willing to participate in an interview that may last 60 – 90 minutes
~ Are willing to be interviewed and have the interview audio recorded

To learn more or inquire about participation:
Email Bryan Abendschein: abendsc2@illinois.edu

Visit our website: communicationandstroke.weebly.com

APPENDIX E: INTERVIEW PROTOCOL

Combined: stroke survivor/partner

Welcome. Thank you very much for agreeing to participate in this study. The purpose of this project is to gather information that will be beneficial for couples who experience stroke. I am interested in your communication after stroke.

My research team and I will be the only ones who hear what you say. Protecting your privacy is very important to us. Are you okay with me audio recording the interview? If you feel uncomfortable answering a question, let me know and we will move on. If you wish to end the interview at any time, you are welcome to do so. Do you have any questions before we begin recording?

(*Begin recording*)

Questions about demographics and the relationship
I'll begin with some basic questions about you and your partner.

- (*Relationship*)
    a. Can you tell me, briefly, the story of your relationship?
        i. (*Potential guiding questions*)
            1. Are you married?
            2. How long have you been together?
            3. Do you have any children?

Questions about stroke (incident)
I would now like to talk about your experience with stroke.

- How many strokes have you/your partner had?
- What was your/your partner's age at the time of the stroke(s)?
    - How old are you both now?
- What type(s) of stroke(s) was/were it/they? (Ischemic, Hemorrhagic, TIA)
- Do you know where in the brain the stroke took place (e.g., left or right side of the brain)?
    - What hand is your dominant hand (what hand do you write with)?
- What type of medical treatment did you/your partner receive?
- Did you (your partner) have to stay in the hospital?
    - *If so*, for how long?
- What symptoms followed the stoke(s)?
    - *If necessary*: Physical, cognitive
- Did your lifestyle change because of the stroke?

Questions about uncertainty
I would like to focus briefly on the questions you may have related to the stroke.

- When the stroke(s) occurred, can you remember the things that seemed like big unknowns or things you had questions about?
    - *If necessary*: This could relate to the stroke, family, friends, health, etc.
    - How did you address those questions?
    - Were you successful in addressing those questions?

- Do you remember if your (your partner's) body image changed after the stroke? Meaning, did you (or your partner) think differently about your body because of the stroke?
    - *If so,* can you describe that change?

- Are there new questions, or questions that remain that are directly related to the stroke(s)?
    - Have you taken steps to address those questions?
    - If so, what steps have you taken?

- Did you experience any stressors from the stroke right after it happened?
    - Do you have new stressors that you associate with stroke?
    - Have you addressed any of those stressors?
        - *If so*, how?

- Did you discuss any of those stressors with your partner?
    - *If so*, how did he/she respond?
        - *If necessary*: What did your partner say/do?
    - *If not*, whom did you talk to about the stressors?
        - Did you join or your partner join a support group?
    - What sort of support did you receive from:
        - Your friends
        - Family
        - Medical professionals
        - Strangers

Questions about the relationship

Next, I would like to ask you about your relationship with your partner.

- Can you tell me a little bit about your relationship with your partner before the stroke?
    - What sort of things did you two like to do for fun?
    - What plans did you have for your future?
        - Did those things change because of the stroke?
        - *If so*, how?
    - Did your / your partner's behavior change because of the stroke?
    - *If necessary*: Can you think of any positive changes that occurred in your relationship because of stroke?
    - *If necessary*: Can you think of any negative changes that occurred in your relationship because of stroke?

- How, if at all, did your relationship with your partner change after the stroke?

    - What was your role in the relationship after the stroke?
    - What was your partner's role in the relationship after the stroke?
    - What sort of caregiving responsibilities were required from you/your partner after the stroke?

- How did you feel about your relationship with your partner after the stroke?
    - Did you want to continue in the relationship?
    - Were there specific questions you had about your involvement in the relationship?

- How do you think he/she felt about you after the stroke?
    - Do you think he/she was committed to the relationship?
    - Were there specific questions you had about your partner's involvement in the relationship?

- Are there things you do or say to each other now that are different from before the stroke?
    - Do you act differently towards each other?
    - *If so,* how?

- After the stroke, do you think you and your partner felt the same way about the relationship?
    - Do you think they had the same vision for the future of the relationship as you did?
        - *Has that changed?*

- Were there ways your partner made it harder for you to complete your everyday activities after the stroke?
        - *If so,* how did your partner get in your way?
        - *If so,* what kinds of everyday activities were disrupted?
    - *Possible follow-up*: How did you feel about your partner getting in your way?

- Were there ways your partner helped you achieve everyday goals after the stroke?
    - *If so,* how did your partner help?
    - *If so,* what kinds of everyday activities did he/she help you accomplish?

Questions about communication competence

I would now like to ask a few questions about communication.

- Do you think you are an effective communicator?
    - Why or why not?

- Do you think your partner is an effective communicator?
    - Why or why not?

- How did your interaction with each other change, if at all, after the stroke(s)?
    - *If so,* how did the interactions change?

    - Were you/your partner diagnosed with aphasia because of stroke?
        - *If so,* what type of aphasia?
        - *If so,* do you think aphasia affected your interactions with each other?
            - *If so,* how, if at all, did you address those changes in your interactions?

- Do you remember any times since the stroke(s) that you were frustrated by the way you and your partner were communicating?
        - *If so,* why do you think you were frustrated?
    - Were there any times that you felt your/your partner's speech was out of place or inappropriate?
        - *If so,* can you give me an example?

Questions about stroke (effects)

a. What, if any, emotional impact did the stroke have on your life, relationship, social network?
    i. How did your friends and family respond to the stroke?
b. Did any of your close relationships change due to the stroke?
    i. *If so,* how?
b. Are there physical or cognitive issues in your life you attribute to the stroke and not to the normal aging process or other illnesses?
    a. *If so,* please explain?

Concluding questions

I just have a few final questions.

- What advice would you give to others who are in a similar situation?
    - How should people deal with the questions they have after stroke?
    - How should people respond to the stressors of stroke?
    - How can people keep their relationship together after a stroke?

- What advice would you give to those who have not yet faced anything like this in their lives?
    - Is there any way to prepare for something like this?

- Is there anything else you would like to add or tell me about your experience?

APPENDIX F: EMAILS TO POTENTIAL PARTICIPANTS

Initial Email

Dear (NAME),

Thank you for your interest in sharing your story about stroke. My name is Bryan Abendschein and I am a graduate student at the University of Illinois at Urbana-Champaign. I am working on my dissertation study about how couples communicate after stroke.

To participate, you and your spouse / romantic partner will be interviewed separately in a session that may last from 60 – 90 minutes. I will be audio recording and transcribing the interviews. Everything we say in the interview, however, will be confidential and no recordings or transcribed files will be associated with your name.

You and your spouse / romantic partner are eligible to participate if you are both over the age of 18 and one of you is a stroke survivor.

If you and your spouse / romantic partner choose to participate we can arrange a time for each interview to take place in person, over the phone, or through Skype. Each participant will also receive a $20 Amazon e-gift card.

To sign up, or learn more send an email to Bryan Abendschein at abendsc2@illinois.edu with your partner's email address so I can contact him/her to set up an interview as well.

I look forward to hearing from you.

My best,

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois
abendsc2@illinios.edu
communicationandstroke.weebly.com

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

Recruitment Email to Partners

Dear (NAME),

My name is Bryan Abendschein and I am conducting a study at the University of Illinois at Urbana-Champaign where I am a graduate student. I am working on my dissertation study about how couples communicate after stroke. I recently heard from your spouse / romantic partner that you both may be interested in participating.

To participate, you and your spouse / romantic partner will be interviewed separately in a session that may last from 60 – 90 minutes. To participate you should both be over the age of 18 and one of you must be a stroke survivor.

If you choose to participate we can arrange a time to meet in person, over the phone, or through Skype. Each participant will also receive a $20 Amazon e-gift card.

To sign up, reply to this email and we will begin the process of arranging a time for the interviews. For more information, please visit the website for the study.

I am also interested in hearing from you about ways you think I can get the word out to people who may want to participate. Thank you!

Please also let me know if you are not interested and I will take you off my contact list.

I look forward to hearing from you.

My best,

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois
abendsc2@illinios.edu
communicationandstroke.weebly.com

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

Follow-up Email

Dear (NAME),

Recently I sent you an email describing the study I am conducting at University of Illinois at Urbana-Champaign where I am a graduate student. I am working on my dissertation study about how couples communicate after stroke. I wondered if you might still be interested in participating.

To participate, you and your spouse / romantic partner will be interviewed separately in a session that may last from 60 – 90 minutes. To participate you should both be over the age of 18 and one of you must be a stroke survivor.

If you choose to participate we can arrange a time to meet in person, over the phone, or through Skype. Each participant will also receive a $20 Amazon e-gift card.

To sign up, reply to this email [with your spouse's / romantic partner's name and email address] and we will begin the process of arranging a time for the interviews. For more information, please visit the website for the study.

I am also interested in hearing from you about ways you think I can get the word out to people who may want to participate. Thank you!

Please also let me know if you are not interested and I will take you off my contact list.

I look forward to hearing from you.

My best,

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois
abendsc2@illinios.edu
communicationandstroke.weebly.com

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

APPENDIX G: REMINDER EMAILS

Reminder for Interviews Through Technology

Dear (NAME),

Thank you for your willingness to participate in my study. Our interview is scheduled for [TIME] on [DATE] on [SKYPE / TELEPHONE]. I will call you at the time of the interview.

Our interview may last from 60 – 90 minutes. I will be transcribing the interviews, so I will need to audio record them. Everything we say in the interview, however, will be confidential and no recordings or transcribed files will be associated with your name.

I am also including a link to an important document for you to read before our interview. Please follow the link, review the document, and indicate if you agree to participate. [LINK TO QUALTRICS – INFORMED CONSENT].

Please let me know what questions you have about the process. Also, as a thank you for participating, I will send you an $20 Amazon e-gift card after the interview. Please follow the link that I send you and provide the necessary information. However, the University of Illinois at Urbana Champaign is only able to process payments to U.S. citizens, permanent residents, and resident aliens.

I look forward to our interview on (DATE) at (TIME).

My best,

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois
abendsc2@illinios.edu
communicationandstroke.weebly.com

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

Reminder for Interviews In-Person

Dear (NAME),

Thank you for your willingness to participate in my study. Our interview is scheduled for [TIME] on [DATE] at [LOCATION].

Our interview may last from 60 – 90 minutes. I will be transcribing the interviews, so I will need to audio record them. Everything we say in the interview, however, will be confidential and no recordings or transcribed files will be associated with your name.

I am also including a link to an important document for you to read before our interview. Please follow the link, review the document, and indicate if you agree to participate. [LINK TO QUALTRICS – INFORMED CONSENT].

Please let me know what questions you have about the process. Also, as a thank you for participating, I will send you an $20 Amazon e-gift card after the interview. Please follow the link that I send you and provide the necessary information. However, the University of Illinois at Urbana Champaign is only able to process payments to U.S. citizens, permanent residents, and resident aliens.

I look forward to our interview on (DATE) at (TIME).

My best,

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois
abendsc2@illinios.edu
communicationandstroke.weebly.com

STUDY DETAILS: Data collection procedures were approved by the Institutional Review Board of the University of Illinois (protocol #XXXXX)

APPENDIX H: THANK YOU EMAIL

Dear (NAME),

Thank you for taking the time to talk with me and participate in my study. Your contribution is very important and will potentially help other couples navigating life after a stroke.

As a thank you, I will be emailing you a $20 Amazon e-gift card. To start that process, please click on the link below and answer the questions. Your responses will be kept confidential. As a reminder, the University of Illinois at Urbana Champaign is only able to process payments to U.S. citizens, permanent residents, or resident aliens.

[LINK TO QUALTRICS SURVEY - PAYMENT INFORMATION]

If you experienced emotional distress during our interview, I encourage you to contact a trained professional for help. Find a certified counselor in your area: Here.

You may also find it helpful to connect with others dealing with life after stroke. You can do that through the American Stroke Association.

If you have any questions, please let me know.

My best,

Bryan Abendschein, M.A.
Doctoral Candidate
Department of Communication
University of Illinois
abendsc2@illinios.edu

APPENDIX I: PAYMENT INFORMATION (QUALTRICS SURVEY)

Communication and Stroke: A Pragmatic Iterative Approach

Payment Information

Thank you for taking the time to talk with me today. Your participation in this research is important and may help other couples who are working to navigate their relationship after a stroke.

As a thank you, I will be sending you a $20 Amazon e-gift card. Please complete the following information so the University of Illinois at Urbana-Champaign can process the payment. Your responses will remain confidential and will not be linked to the answers you provided during your interview.

What is your full name (First and Last)?

What is your email address?

What is your street address (Street, City, State, Zip)

I am a U.S. citizen, permanent resident, or resident alien

- ❍ Yes (1)
- ❍ No (2)

APPENDIX J: DESCRIPTION OF STUDY SAMPLE

Table J.1

Description of Study Sample by Age and Year of Stroke

Participant	Year of stroke	Age at stroke	Year of interview
Steve	2010	53	2017
Joan	2004	27	2017
Betty	2007	42	2017
Anna	2014	29	2017
Salli	2004	43	2017
Buckley	2013	35	2017
Dale	2016	68	2017
Ava	2012	52	2017
Aaron	2010	-	2017
Earl	2008	51	2017
Donna	2016	41	2017
Gloria	2011	65	2017
Hope	2012	33	2017
Joyce	2012	-	2017
Clark	2008	27	2018
Calvin	2014	68	2018
Charles	1997	43	2018
Selina	-	-	2018
Duncan	2016	-	2018
Edgar	2016	52	2018
Tracy	2006	41	2018
Francis	2014	32	2018