

What Happens to Marriage after Stroke?

By

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Abstract

Background: Family transitions such as the birth of children and retirement often necessitate a redefinition of the marriage relationship, as other roles are added or changed. Stroke is a common, and also a particularly difficult, transition for a married couple. In a third of marriages that have experienced stroke, both survivors and their spouses report they are dissatisfied with their lives. Marital relationships, however, seem to be a strength for many such couples.

Purpose: This dissertation responds to the need to understand how stroke survivors and spouses regard their marital relationships in the context of impairments from stroke and the survivors' need for care.

Methods: The dissertation consists of: (1) a systematic literature review that answers the research question "What is the current state of knowledge about what happens to a couple's marital relationship after one partner has suffered a stroke?" and (2) a grounded theory qualitative study of interviews with 18 couples that answers the questions "What happens to marriage in the context of care after stroke?" and "What are the key elements related to marriage stability or breakdown after stroke?"

Findings: Three research gaps were apparent in the literature review: how survivors and spouses characterize their post-stroke roles and marriages, the ways in which couples reorganize their marriages after stroke, and the impact of marriage, particularly a satisfying marriage, on the caregiver burden and the survivor's functional recovery after stroke. My empirical study revealed that at homecoming after stroke, the initial work involved role management for caregivers and care receivers. The work of realigning the husband and wife role-identities to fit the caregiving and care receiving contexts was a second post-stroke transition. To make this transition, couples had to rethink the meaning of their relationship in the new context of care and disability. Three distinct types of marriages evolved from these processes: the couple's

relationship was reconfirmed around the pre-stroke marriage relationship; the couple's relationship was recalibrated around care; the couple existed in a parallel relationship. I identified three themes related to the reconstruction or breakdown of the marital identity: feeling overwhelmed, resolving conflict, and perceiving value in the marriage.

Conclusion: Marriage relationships are not peripheral to survivors' and spouses' outcomes after stroke; rather, marriage is fundamental to the management of impairments and to the wellbeing of the couple.

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“Life’s strongest storylines are punctuated and enmeshed with other people.”

Richard L Settersten, 2015.

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Chapter 1 Introduction to the Research

Family transitions such as the birth of children and retirement often necessitate a redefinition of the marriage relationship, as other roles are added or changed (Beard, Knauss, & Moyer, 2009; Bhatti, Salek, & Finlay, 2011). There is considerable evidence that a couple's relationship is a critical context wherein partners make sense of their situation in light of such changes (Berg & Upchurch, 2007; Klein, Izquierdo, Bradbury, & Sloan, 2007). Close, satisfying relationships and collaboration are particularly important when couples are confronted with difficult transitions such as chronic illness or sudden-onset disability (Berg et al., 2008; Bookwala, 2005; Mancini & Bonanno, 2006). A recently published meta-analysis (126 empirical articles; 72,000 participants) demonstrated that in couples with a wide variety of ages and chronic conditions, higher marital quality was related to better health, lower risk of mortality, and lower cardiovascular reactivity during marital conflict (Robles, Slatcher, Trombello, & McGinn, 2014). The relationship between a higher quality, satisfying marriage and risk of premature mortality was shown to be strongest in mid and later life (Robles, 2014; Umberson & Montez, 2010; Umberson, Williams, Powers, Liu, & Needham, 2006), and was most evident when one or both partners were experiencing chronic disease (Robles et al., 2014).

In addition to supporting health outcomes, the marital relationship can enhance the quality of life. Couples managing chronic conditions who focus on their relationship rated their satisfaction with the marriage higher than those who concentrated exclusively on the illness (Falconier, Jackson, Hilpert, & Bodenmann, 2015; Traa, De Vries, Bodenmann, & Den Oudsten, 2015). However, at the time of the transition to chronic illnesses, satisfaction with the relationship declined (Karademas, 2014; Lyngstad & Jalovaara, 2010). It returned to pre-transition levels for most, but satisfaction continued to decline in some relationships, while in other relationships couples surpassed their pre-illness satisfaction levels. (Pretter, Raveis, Carrero, & Maurer, 2014; Schindler, Berg, Butler, Fortenberry, & Wiebe, 2010). Evidence that some couples do well when faced with difficult transitions begs the question of what differentiates those who thrive from those whose marital quality declines and for whom the likelihood of separation and divorce increases.

Stroke is a common, and also a particularly difficult, transition for individuals with this chronic condition and their families (Palmer & Glass, 2003). Each year in Canada, 50,000 people experience a stroke (Krueger et al., 2015). The lifetime risk of stroke is 1 in 5 for women, and 1

in 6 for men (Feigin et al., 2014; Go et al., 2013). Stroke is a condition of all ages, but the risk begins to rise sharply at 50 years of age, and the majority of strokes are in mid and later life (mean age 76) (Go et al., 2014). About three quarters of the people who survive strokes (85%) and return home (about 85% of survivors) to live with their spouse/partner (Hall et al., 2013; Palmer & Glass, 2003).

Stroke is not an easy transition for married couples (Carlsson, Forsberg-Warleby, Moller, & Blomstrand, 2007; Green & King, 2010; McCarthy, Lyons, & Powers, 2011). Both stroke survivors and their spouses report they are dissatisfied with their lives in a third of such marriages (Achten, Visser-Meily, Post, & Schepers, 2012; Carlsson et al., 2007; Eriksson, Tham, & Fugl-Meyer, 2005). Dissatisfaction with the marriage increases with time for spouses of a stroke survivor (King, Hartke, & Houle, 2010; Ostwald, Godwin, & Cron, 2009a; Visser-Meily et al., 2009). Depression rates are high for both stroke survivors and their spouses; about one third experience severe clinical depression (Hackett & Anderson, 2005; Hackett & Pickles, 2014, Kutlubaev & Hackett, 2014). Divorce rates are significantly higher for working aged men and women after a first stroke than for the age-matched population (Trygged, Hedlund, & Kåreholt, 2011). Women over 65 years of age are also at higher risk of divorce after a first stroke (Karraker & Latham, 2015).

Marital relationships, however, seem to be a strength for many couples. In two European studies, although relationship satisfaction was higher for stroke survivors (90%) than spouses (66%), both partners were satisfied with their relationship in about two thirds of couples who were recruited in acute care hospitals and followed for one (Achten et al., 2012) or three years (Carlsson et al., 2007).

Given the importance of marriage to life satisfaction and health, there have been calls for research to investigate how couples negotiate their relationships after stroke (Green & King, 2009; McCarthy et al., 2011; Robinson & Spalletta, 2010). Indeed, neurological and relationship scientists Clark-Polner and Clark (2014) suggested that to understand the behavior and the satisfaction with life of a person with a neurological condition (including stroke), it is crucial to understand his or her interactions with others. This dissertation responds to this need to understand how stroke survivors and spouses regard their marital relationships in the context of the impairments from stroke and the stroke survivors' need for care.

I asked the following research questions to explore the critical elements in how couples in long-term marriages construct their marital roles and relationships after the transition to stroke.

Research Questions

1. What is the current state of knowledge about what happens to a couple's marital relationship after one partner has suffered a stroke?
2. What happens to marriage in the context of care after stroke?
3. What are the key elements related to marriage stability or breakdown after stroke?

Chapter Introduction

In this introductory chapter, I describe my position in the research, including my reasons for conducting research on marriage relationships and stroke as a chronic illness. I also state the significance of the study, and outline the theoretical and methodological approaches to the three studies that comprise the main body of the dissertation. I conclude the chapter with an overview of the three papers included in this dissertation and a discussion of how they link to the overall research purpose.

My Position in this Research

I come to this research as the wife of a stroke survivor. My story, along with my recommendations to improve communication to spouses and families of stroke survivors, was published in the article, *The Language of Recovery* (Anderson & Marlett, 2004). It came as quite a shock to me in 1997 when my husband, John, had a stroke at age 46. When the neurologist first examined John three days after the stroke, I was even more devastated when he informed me that, with such a large stroke, John would not be considered for rehabilitation. I had assumed that everyone with a stroke would benefit from, and would receive, rehabilitation. My choices were to take John home without rehabilitation or begin arrangements for nursing home placement. John and I were lucky. We received unusual information about how to navigate our situation. The physiotherapist working with stroke patients called me at home to tell me she was going on maternity leave, and John would receive no further rehabilitation. However, she also informed me that there were private physiotherapists who would provide treatment at home and recommended that we take this route rather than look into his placement in a nursing home. She thought that John had the potential to make a significant recovery. With this advice in mind, I made the decision to bring John home. I hired the recommended physiotherapists and through their connections was able to find a speech language therapist who would provide therapy at

home. After a month of therapy and the therapists' advocacy, John was admitted to in-patient rehabilitation for three months. Although John still struggles with a weak right side (hemiplegia) and mild aphasia, he enjoys life.

The literature supports my contention (and experience) that now, as in 1997, once stroke survivors are sent home from a hospital or in-patient rehabilitation, families are left to cope with a wide range of physical, cognitive, and communicative disorders with little professional support (Bayley et al., 2012; Bhogal, Teasell, Foley, & Speechley, 2003; Teasell et al., 2012). Married couples face additional tasks such as: (1) adjusting their marriage to the physical, cognitive, communicative, and emotional sequelae of stroke; (2) integrating the stroke survivor's need for care into daily life and the marriage relationship; and (3) recalibrating marital processes in light of stroke impairments and caregiving (Green & King, 2007; McCarthy et al., 2011; Ostwald, 2008; Thompson, 2008). Despite the extensive literature on stroke caregiving and the impact of stroke on families, little is known about how couples negotiate these elements within their marital relationships or the types of interactions within marriages that might increase or decrease the likelihood of couples staying married and remaining satisfied with their relationships (McCarthy et al., 2011; Ostwald, 2008; Thompson, 2008). The limited research on stroke and marriage suggests that couples stay married, but have separate realities as caregivers and stroke survivors (Backstrom, Asplund, & Sundin, 2010; Banks & Pearson, 2004; Quinn, Murray, & Malone, 2014a). There is good evidence that living together but feeling lonely is likely not conducive to wellbeing (Gierveld, van Groenou, Hoogendoorn, & Smit, 2009; Warner & Kelley-Moore, 2012).

Although there has been little research regarding post-stroke relationships (McCarthy et al., 2011; Ostwald, 2008; Thompson, 2008), research on other chronic conditions has shown that perceptions of a satisfying marriage and a supportive spouse are associated with a wide range of superior outcomes, including: reductions in premature death, fewer symptoms and better symptom control, increased life satisfaction, emotional adjustment, reduced caregiver burden, and increased satisfaction with the marriage (Falconier et al., 2015; Park & Schumacher, 2014; Traa et al., 2015; Uchino, 2013). In fact, researchers reported that after cancer treatment, the ill spouse's mental health was significantly enhanced if the partner was perceived to be supportive, but declined if the support was perceived to be inadequate or misdirected (Berg et al., 2008; Kinsinger, Laurenceau, Carver, & Antoni, 2011; Rottmann et al., 2015). There is also evidence

that support from a spouse holds more significance than support from other relatives. In the course of cancer treatment, high levels of support from family or friends did not compensate for inadequate support from a spouse (Manne et al., 2004; Pistrang & Barker, 1995). Marital research involving other chronic conditions suggests that a relationship-based approach after stroke could improve survivors' and spouses' outcomes. But what specific features of relationships should be targeted? Should a couples-based approach consider the marital relationship, the caregiving relationship, or both?

It was not clear from the extant stroke research if there is a marital relationship after stroke. Most stroke researchers who have included married couples in their investigations have assumed that they are investigating a caregiving/care receiving relationship (McCarthy et al., 2011; Thompson, 2008). Based on this assumption, current intervention approaches involving the spouse or other family members have been based on the improvement of knowledge about stroke, on an increase in external social support, and on attempts to provide caregiver skills training (Bakas et al., 2014; Cheng, Chair & Chau, 2014; Lutz & Young, 2010). Reviews and meta-analyses confirm that caregiving interventions have been disappointing. Although stroke survivors and spouses have reported being generally happy with the increased knowledge and support provided by interveners, the interventions have little effect on outcomes such as functional recovery, mental health (depression), and perceptions of support (Ellis, Mant, Langhorne, Dennis, & Winner, 2010; Forster et al., 2012; Redfern, McKevitt, & Wolfe, 2006; Salter, Foley, & Teasell, 2010).

Researchers reviewing the literature also confirmed that caregiver interventions relieve burden and stress in the short term (three months), but in the long term (six months to one year) there are few significant differences between caregivers who received caregiver training and caregivers who did not (Bakas et al., 2014; Gaugler, 2010; Lutz & Young, 2010). Gaugler (2010) suggested that stroke caregivers seem to be resilient because they quickly learn caregiving skills. However, he noted that in the qualitative research, spouses of stroke survivors often viewed their marriage relationships as stressful, and relationship deprivation appeared to be prominent. Gaugler (2010) noted that further research was necessary to understand the relationship processes that might be implicated in caregiver stress and caregiver burden. I believe that an understanding of how couples regard their marital relationships, and information about what

factors they consider are important to adaptation, may offer different opportunities to intervene after stroke.

Why Study Marriages after Stroke?

The number of Canadians living with stroke is expected to increase to between 654,000 and 726,000 by 2038 (Krueger et al., 2015). There is a perfect storm of co-occurring elements contributing to the increasing prevalence of stroke survivors. First, as stroke is mainly a condition that afflicts older adults, the number of strokes is rising as baby boomers age. Second, stroke rates are rising in younger adults (Feigin et al., 2014). Third, new medical treatment has significantly increased survival rates for both younger and older adults (Krueger et al., 2015; Teasell et al., 2014). The need to react to this increased stroke prevalence was noted at the Canadian Cardiovascular Congress in 2010, when keynote speaker Dr. Robert Côté referred to the increasing occurrence of neurovascular disease—including stroke, dementia, and Parkinson—as the “tsunami of healthcare.” He called for a comprehensive multi- and interdisciplinary approach to research, practice, and policy to prevent and effectively treat chronic neurological conditions.

Most experts agree that preventing or completely reversing the effects of stroke is many years away despite the notable advances in emergency pharmaceutical (e.g., tPA, clot-busters), surgical (e.g., endovascular therapy to remove the artery blockage), and rehabilitation treatments (Krueger et al., 2015; Teasell, Hussein, McClure, & Meyer, 2014). In the meantime, researchers and practitioners recognize that more people will survive stroke and will be discharged from the hospital, many to live at home with their spouses.

Marriage can be viewed as the fundamental context for managing stroke and supporting the stroke survivor in the community. As the person closest to the stroke survivor, a spouse likely has the greatest influence on the survivor’s re-evaluation of self and the marital relationship. Evidence from two decades ago indicates that the type and quantity of support may influence a stroke survivor’s recovery (Baker, 1993; Glass & Maddox, 1992; Tsouna-Hadjis, Vemmos, Zakopoulos, & Stamatelopoulos, 2000). Stroke survivors who received high amounts of emotional support along with judicious instrumental support (i.e., only as required/desired by the survivor) experienced superior functional recovery, and the effects of such support on functional recovery were greatest in the most severe strokes (Glass & Maddox, 1992; Tsouna-Hadjis et al., 2000).

The marriage relationship may be a source of stress for a spouse burdened with new roles and care tasks and for a stroke survivor coping with impairments. Irritability (e.g., short temper, withdrawing from situations, frustration, rolling eyes, talking down to) has been reported by both stroke survivors and their spouses (Banks & Pearson, 2004; Quinn et al., 2014a). Spousal interactions that might have been perceived as supportive pre-stroke can seem paternalistic, over-supportive, or inadequate post-stroke (Backstrom et al., 2010; Buschenfeld, Morris, & Lockwood, 2009). Miscommunication and differing expectations contribute to irritations and conflicts (Gillespie, Murphy, & Place, 2010; McCarthy & Lyons, 2015). It can be assumed that the marital relationship is strained as stroke survivors and spouses attempt to cope with the changes in equity and to integrate the role changes necessitated by impairments and caregiving (McPherson, Wilson, Chyurlia, & Leclerc, 2010; McPherson, Wilson, Chyurlia, & Leclerc, 2011). A few studies have shown that conflictual marriage and divorce can increase the risk of stroke (Engstrom et al., 2004; Maselko, Bates, Avendaño, & Glymour, 2009; Tanne, Goldbourt, & Medalie, 2004), yet how marital relationships function after stroke has been overlooked.

Theoretical Approach

In this project, life course and symbolic interaction theories were used to frame an exploration of the meaning couples assign to marriage, and how couples make sense of their roles and relationships after the transition to stroke. Theory informed the design of the interview guide and sensitized me to survivors' and spouses' interactions. Life course theory was useful for thinking about how people's lives were shaped over time, whereas symbolic interaction was valuable for considering the meaning of roles and relationships.

Life Course Theory

Three key principles from life course theory were relevant to this research: interdependence, transitions, and change over time (Elder Jr., 1985; Settersten, 2015). Interdependence is the assumption that individual lives are linked to others, so draws attention to how individual development is shaped in interaction with significant others (Settersten, 2015). Husbands and wives have to constantly negotiate individual autonomy and interdependence (Settersten, 2015), as well as the benefits and the costs of resolving inevitable differences in each partner's expectations and needs (Impett, Gable, & Peplau, 2005; Joel, Gordon, Impett, MacDonald, & Keltner, 2013). Thus I was thinking about how a marital partner could support

but also constrain his or her spouse's agency when I was framing participant interviews and when study participants were describing their marriages.

The life course concept of transitions brought a focus to changes that result from the stroke transition. Transitions are conceptualized as changes in state and status that are more or less abrupt (Elder & Giele, 2009; Elder Jr., 1985). Stroke survivors experience physical, cognitive, and communication impairments that make it difficult for them to assume their pre-stroke roles and social positions. The linked lives assumption is that in a transition such as stroke, the stroke survivor's marital role changes and that change will alter the spouse's reciprocal role (Elder & Giele, 2009; Elder Jr., 1985). In thinking about a couple's linked lives, I wanted to know how each member responded to the changes in his or her roles, but I also wanted to avoid making a direct pre-stroke/post-stroke comparison. Thus I framed the interview topics to get couples to talk about other transitions in their marriage (happy, difficult) beginning with how they met, how they transitioned to marriage, and then how they handled other transitions. I then moved on to their current marriage and roles. Transitions were the punctuation points in couples' narratives about their marriage, demarking many role changes.

The life course assumption of change over time highlights that, while transitions such as stroke occur at a particular moment in time, incorporating the impact of such a transition may be a long-term process—moving along a trajectory (Macmillan, 2004; Mitchell, 2006). Participants testified that particular transitions continued to reverberate through their marriage whereas other transitions were mere turning points. In my analysis, I used transitions as a sensitizing concept to understand if couples' experiences in previous transitions, such as a prior marriage, or moving with the military, shaped their experiences in this new illness transition.

Symbolic Interaction Theory

Symbolic interaction theory assumes that role-identities are made in interactions with others (Charon, 2010; Stryker, 2008). Role-identity is the identity associated with a specific role or social position (Charon, 2010; Stets, 1997). Role-identities are influenced by the cultural context in which they exist and are developed through taking the perspectives of others (Charon, 2010). The symbolic interaction assumption of role making, how a person plays the role and adapts the role to his or her social context (Charon, 2010; Stryker, 2008), was particularly relevant to my study. Social structures provide a general outline for roles, but people have significant leeway in how they shape their roles to meet their goals (Charon, 2010; Stets &

Burke, 2014). The principle of the looking glass self is important in role making. Individuals reflect on how they play their roles, consider how others regard their performance, and may revise their performance accordingly. Role-taking, that is, being able to understand another's perspective—his or her expectations and feelings about a situation—is particularly useful for husbands and wives (Charon, 2010; Stryker, 2008). Sensitive role takers are able to anticipate and understand their partners' behaviors.

Couples' role making processes become more challenging in transitions when roles are radically changed, lost, or added, as is the case after the transition of one partner to stroke (Charon, 2010; Serpe & Stryker, 2011; Tajfel, 1979). Disability can add new roles—disabled person, spouse of a disabled person—to existing roles of husband and wife (Alexander, Hwang, & Sipski, 2002; Edwards & Chapman, 2004). A person disabled by stroke may have few individual resources with which to position or re-position a role-identity threatened by another's positioning (Cohen-Mansfield, 2011; Dewing, 2008). Bendz (2000), for example, found it was difficult for stroke survivors in a hospital to position themselves as anything but a person with impairments.

Symbolic interactionists assume that a spouse's endorsement will increase his or her partner's trust and the salience of the relationship (Cast & Cantwell, 2007; Rusbult, Kumashiro, Kubacka, & Finkel, 2009), and that self-esteem will suffer if a spouse is critical or rejecting (Baldwin, 2006; Rusbult et al., 2009). In the analysis I looked at how couples talked about emotions and what triggered the emotions. I also paid attention to critical comments and signs that a spouse believed that his or her partner had been insensitive in pointing out his or her personal shortcomings (Amato, 2015; Gottman, 2011; Murray & Holmes, 2011).

Research Design

I used two methodological approaches to answer my research questions. I began with a systematic review and then completed an empirical study. As the research question should drive the methodology choice (Charmaz, 2006; Cresswell, 2014; Glaser & Strauss, 1967; Maxwell, 2012), the literature review informed my research questions for the study. As my goal was to understand complex phenomena and participants' experiences or interpretations, qualitative methodologies were appropriate. Marriages, stroke, disability, and older adults are all diverse. In this section on research design; I discuss my rationale for choosing a systematic literature review and constructivist grounded theory methodologies. The literature review methods are described

in chapter 2. The constant comparison grounded theory methods are described in chapter 3 and chapter 4, so are not discussed in this section.

Literature Review

Researchers conduct critical and in-depth evaluation of previous research to establish the reasons for selecting a particular research question. Current evidence-based practice positions systematic reviews as the best sources of evidence because they analyze and summarize individual research reports on the topic of interest (Aveyard, 2014; Grant & Booth, 2009). Like other research methodologies, literature reviews have a range of methodologies to suit the research question. In their typology, Grant and Booth (2009) identified 14 types of reviews and recently MacLure et al. (2016) added 14 additional types. The range of methodologies, all with different purposes and methods, raised the question of which type was appropriate to answer my first research question. My decision on the type of review most suitable for my purposes began with two literature searches, one to isolate the types of reviews that fit my research questions and the second to find out what was known about stroke and marriage and where there might be research gaps.

Determining the review methodology. I began by considering whether to do a scoping review or a systematic review. Scoping reviews are used to map the existing literature when the reviewer is unsure about the parameters of the literature. The research question can evolve as the researcher becomes familiar with the literature (Fitzgerald et al., 2015). In a systematic review, the research question and the inclusion and exclusion criteria for the literature are defined from the outset. I completed a systematic literature review because I had a specific research question and had already scoped the stroke and caregiving literature for marital research.

Gaps identified in the systematic review. My review revealed three main research gaps: (i) how stroke survivors and spouses characterize their post-stroke roles and marriages, (ii) the ways by which couples reorganize their marriages after one of the pair has a stroke, and (iii) the impacts of marriage, particularly satisfying marriages, on outcomes such as caregiver burden and a stroke survivor's functional recovery. My primary interest was in marital functioning once the stroke survivor made the transition to home. The literature provided scant insight into the nature of post-stroke marriages, including how couples might reframe the functioning and meaning of

their marriage after stroke. Consequently, for my empirical study I focused on understanding stroke survivors' and spouses' perspectives of the development of their relational roles and marriage after the stroke transition.

Grounded Theory

An appropriate approach to understanding marriage development after stroke was grounded theory, which was developed to understand how the people being studied construct their realities (Glaser and Strauss, 1967). Since 1967, a number of grounded theory variants have been developed, including classic or Glaserian (Glaser, & Strauss, 1967; Glaser, 1978), Straussian (Strauss & Corbin, 1990; Strauss, 1998), constructivist (Bryant, 2003; Charmaz, 2008), situational (Clarke, 2005, 2014), and feminist (Wuest, 1995). I chose to use constructivist grounded theory because I believe that research is an interpretive portrayal of reality (Charmaz, 2006; Charmaz, 2009; Suddaby, 2006).

To maintain the trustworthiness and credibility of qualitative research, the methods used should adhere to the selected methodology (Cresswell, 2014; LaRossa, 2005; Suddaby, 2006). Three principles distinguish grounded theory from other qualitative methodologies: the conclusions must be grounded in the data; theoretical sampling is performed, that is, participants who are likely to throw light on the research questions are selected; and constant comparison of emerging data drives the evolution of answers to the research question. In what follows, I outline how the constructivist grounded theory methodology informed my methods and how I maintained methodological rigor.

Grounded in the data. The main principle in grounded theory is that the findings are grounded in the data. That is, data are not forced into categories that have been deductively derived from a pre-existing theory or research hypothesis, rather the concepts are found in the data (Glaser, 1978). Some researchers have assumed that grounded in the data means forgoing a literature review and theoretical framework (Suddaby, 2006). Others argue that the researcher requires knowledge of the subject in order to understand the concepts in the data (Larossa, 2005; Suddaby, 2006). In fact, Glaser and Strauss (1967) recommended using the literature or “existing” theory to “provide a stimulus to a ‘good’ idea” and “give direction in the development of relevant categories and properties” in analysis (p. 79). The constructivist approach includes a review of the literature to determine what is known in the area of interest, then the literature, the

researcher's experience, and extant theory are used as "sensitizing concepts" (Charmaz, 2006, p. 17). Concepts that are not grounded in the data are dropped when they are not confirmed in the analysis (Charmaz, 2006).

Following Charmaz's (2008) constructivist approach, I assumed that knowledge is constructed by researcher and participants. I expected that my experience of being married to a stroke survivor would influence the ideas to which I was sensitive in interviews and analyses. Stroke survivors and spouses would also interact differently in interviews with the wife of a stroke survivor, the wife of a healthy individual, an unmarried person, or an older or younger person. I used a reflexive interview guide and journal to understand how my knowledge of the literature, the theoretical framework of the study, and my experience with stroke were influencing data collection and analysis (Roulston, 2010; Roulston, deMarrais, & Lewis, 2003). After the first two interviews, I recognized that I needed to wait longer for participants to respond. I also noticed that survivors and spouses often said "you know" when referring to aspects of marriage or stroke.

In subsequent interviews, I used "you know" as an opportunity to ask participants to tell me how that worked in their experience, because the purpose of the research was to have their experience on record. As a constructivist, I wanted to elicit participants' assumptions, the tacit rules in their relationships, and the implicit meanings within couples' interactions within the situations and events that they chose to share.

Theoretical sampling. The second fundamental principle in constructivist grounded theory methodology is that decisions about what data to collect are based on emerging ideas about the phenomenon being investigated (Charmaz, 2006; Glaser, 1978; Strauss, 1998). The first few participants are recruited because they seem to represent the phenomenon of interest. As patterns begin to appear, the aim is to sample theoretically, which means seeking participants who are most likely to increase understanding of the emerging codes and categories. According to Charmaz (2006), the idea is to increasingly focus your analysis by recruiting participants or going back to previous participants to confirm, contradict, or elaborate on the constructs of the preliminary codes/categories. The key point is to fully develop the properties of categories (saturate) until no new properties develop.

Sampling in my study was theoretical (Charmaz, 2006; Glaser & Strauss, 1967). Informants were recruited with the goal of understanding the development of the post-stroke

marriage relationship (Charmaz, 2006). I began by identifying and accessing couples who could provide a thick description, a detailed account of their perceptions of their roles and relationships; I then recruited couples to elaborate specifically on categories that were emerging in my analysis (Charmaz, 2006; Morse, 2015a). For example, regardless of the severity of the stroke, participants all referred to caregiving after stroke. Some said the marriage relationship re-emerged, but others talked about reorganizing their marriage around care or continuing to work toward the relationship they had before the stroke. I specifically searched for couples who had separated or divorced a few years after the stroke survivor was sent home, to broaden my comprehension of factors that caused them to separate and to figure out why some couples continued to work at their relationships while others separated.

Constant comparison. The third principle of grounded theory is that constant comparison of data shapes the development of descriptive categories and emerging theoretical connections between the categories (Charmaz, 2006; Suddaby, 2006). Constant comparison methods are used in all the grounded theory variants, as well as in many other qualitative methodologies (e.g., interpretive description) (Fram, 2013; Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2015; Thorne et al., 2014). Despite the wide use, variations between Glaser's (2013) and Strauss's (1998) descriptions of their constant comparison methods exposed differences in grounded theorists' uses of constant comparison methods. Different ontological and epistemological beliefs underpinned the way constant comparison methods were interpreted. Strauss and Corbin (1990) introduced the reflectivity and relationality that researchers reflect to participants in a research study. In so doing, they acknowledged the symbolic interactionist and constructivist perspectives that researchers and participants share as they create data. Glaser (1978) took, and continues to adhere to (Glaser, 2013), a positivist viewpoint that the researcher is objective. In his view, the grounded theory researcher takes into account all the data, produces the abstractions (not descriptions), and determines the theory (Glaser, 1978; Glaser, 2013).

I assumed that the research process was socially constructed (Charmaz 2006). I acknowledge that I made interpretive and conceptual decisions from the inception of the research to the write-up. The interactions I had with participants were an essential part of collecting and analyzing the data. In using the constant comparison analysis in constructivist grounded theory, I found two of Charmaz's techniques particularly useful. First, following Charmaz's (1995) suggestion that she "generates data by investigating aspects of life that the research participant

takes for granted” (p. 36), I specifically sought and looked for meaning in participants’ descriptions of the elements that they commonly credited with marriage success (e.g., communication and commitment).

Second, I used Charmaz’s (1991) concept of identifying moments as a sensitizing technique in my analysis. In her study of chronic illness, Charmaz coded the time when someone conferred a negative illness or disability identity on the person with chronic illness as an identifying moment. In her theoretical coding, she elevated identifying moments to an explanatory theme for her overarching storyline of “Suffering as a Moral Status” (Charmaz, 2006, p. 73). In my analysis, I looked for points where participants noted a change in behavior or an incident that changed a participant’s self-view, a partner’s identity, or the meaning of the marriage. Following participants’ descriptions of their relationships after such identifying moments enabled me to expand on the elements associated with each relationship category as well as the factors associated with marital stability or breakdown.

Strategies for maintaining methodological rigor. Rigor refers to the goal of assuring validity, reliability, and generalizability of the research (Charmaz, 2006; Morse, 2015b). In qualitative research, validity denotes how well the findings represent the phenomena under study. To ensure validity in qualitative research it is critical that: (1) each participant’s meaning is accurately understood, analyzed, and reported, and (2) negative cases are included in the analysis (Charmaz, 2006; Morse, 2015b).

To ensure that I was capturing participants’ meanings accurately in the interviews I used three strategies. First, when participants talked broadly about a concept like communication or commitment, I asked them to give me specific examples of that element in their relationship. Second, to ensure I understood what was going on (e.g., why a particular behavior occurred), I member-checked. Member-checking is confirming with participants that the researcher understood and interpreted the data correctly. In the interviews, I restated what I thought participants had said and then asked if I had interpreted it correctly: “I just want to check if I understood that correctly, I think you said Did I get that right?” Third, I used the reflective interview guide (Roulston, 2010) to critically examine each interview and reflect on how I could capture participants’ experiences more fully in subsequent interviews.

I also used a number of strategies to ensure that my analysis reflected participants’ meanings. First, I checked the accuracy of each transcription. Second, participants’ terms and

words were used as codes and theme labels. Third, participants received a copy of the provisional results from both papers and were invited to provide feedback. Those who responded (10 participants) stated that they thought the results reflected their experience. A few also specified that the relationship types were representative of what they experienced in their face-to-face or Internet stroke support groups.

Reliability describes the dependability of replicating the results if the study was repeated (Kisely & Kendall, 2011; Morse, 2015b). In grounded theory interview research, reliability depends on three factors: collecting thick, rich data that represent the phenomena; verifying the data at each step in the data collection; and representing the phenomena such that others can recognize them (Kisely & Kendall, 2011; Morse, 2015b). In thick data, participants' descriptions of the elements of the categories and themes will not be exactly the same, but the overlap enables the researcher to see the replication (Charmaz, 2006; Morse, 2015a, b).

I used two strategies to ensure reliability. First, I ensured that the initial interview questions were open-ended. Second, I asked participants to elaborate on their experiences with concrete examples to produce rich data. For example, couples quickly responded to the question about the transition to stroke: "Now, tell me about your roles at the time of the stroke" with descriptions of how their husband and wife roles and marriage were subsumed by care. Then the factors associated with negotiating compatible role-identities, or a marriage slowly unravelling, emerged in participants' examples of painting the house or deciding who would drive the car. To see if others recognized the phenomena I had observed, two PhD candidates, one a stroke survivor and the other a registered physiotherapist, and two health professionals who work with stroke survivors read the drafts of the papers included in chapter 3 and chapter 4. The findings resonated with their experiences.

Finally, generalizability refers to the application of findings in another context or population. Charmaz (2006) called this usefulness, and suggested considering whether the analysis: (i) offers interpretations that people can use in everyday life and (ii) whether the findings spark further research questions. I checked my findings with a range of stakeholders for their opinions on the applicability of my findings to other stroke populations. The definitive test will be readers' responses to the publications that will follow from this research.

Dissertation Overview

My dissertation includes the three chapters described below and concludes with a final chapter in which I discuss: the overall findings, the strengths and limitations of the research, the implications of the research for policy, and the study conclusions. In the following overview, I provide a brief description of chapters 2, 3, and 4 and their objectives. Chapter 2 is a thematic mixed study synthesis of 39 peer-reviewed studies in which I determine the state of the research literature on marriage in the context of stroke. Chapter 3 reports on couples' experiences of their changing roles and relationships after stroke and how they developed the meaning of their relationships in the contexts of care and disability. In chapter 4 I describe the themes related to marriage stability.

Chapter 2: Marriage after the Transition to Stroke: A Systematic Review

Objectives. My first objective was to systematically review the literature published in peer-reviewed journals and books to answer research question 1: What is the current state of knowledge about what happens to marriage after one partner has suffered a stroke? The second objective was to identify knowledge gaps that I could address with research.

Description. In chapter 2, thematic synthesis methods for qualitative and quantitative evidence (Pope, Mays, & Popay, 2007) were used to systematically review peer reviewed literature on marriage after stroke. The 39 studies that met the inclusion criteria met the quality criteria. Constant comparison analytic techniques were then used to identify themes.

The synthesis resulted in three themes: chaos in the marriage, work to re-establish marriage, and evolution of marriages. The research synthesis highlighted that while both the condition of stroke and the stroke survivor's need for care undermined the stability and emotional qualities of the marital relationship for some couples, many couples were able to retain or regain the pre-stroke closeness in their relationship. However, as evidenced by decreases in satisfaction with the relationship and experiences of the burden of care, the synthesis also suggests that spouses may be more stressed and distressed by problems with the relationship and relational deprivation than by the actual care tasks. This negative result underscores the need to differentiate between caregiving problems and problems with the relationship between stroke survivors and spouses.

In a review of the literature I detected a gap in knowledge regarding how marriages develop and function in the context of stroke impairments and stroke survivors' need for care.

This knowledge gap provided the rationale for a qualitative study designed to understand what happens to marriage after stroke. The empirical research reported in chapter 3 addresses the gap in knowledge about marriage development after stroke by describing how couples reconcile care and marriage and then by considering the forms in which marriages evolve after stroke.

Chapter 3. Reconciling Marriage and Care after Stroke

Objective. In posing the question “What happens to marriage in the context of care after stroke?” I wanted to test the assumptions that (i) stroke survivors’ and spouses’ main roles were care receiving and caregiving, respectively, and (ii) the meaning of the marriage revolved around caregiving.

Description. The study design was a cross-sectional, qualitative, retrospective survey of 18 couples’ perspectives of marriage development after stroke. Both stroke survivors and spouses participated in individual or couple interviews. The results demonstrated that couples’ thoughts about marriage were submerged while they learned about their new contexts of stroke impairments and care. It was only when they began to achieve a sense of control of their situation that survivors and spouses could begin to think about marriage development. Three stable relationship types emerged: those that (1) were focused on marriage, (2) were centered on care, and (3) evolved parallel relationships. In parallel relationships, stroke survivors and spouses remained married, but lived relatively separate lives. Three couples were separated or divorced. Agreement or conflict on joint role and relationship identities emerged as the difference between couples who separated and couples in stable relationships.

Chapter 4: Staying married after stroke: A constructivist grounded theory qualitative study

Objective. In asking the question: What are the key elements related to marriage stability or breakdown after stroke? my aim was to understand why, after stroke, some couples were able to recreate or maintain a happy marriage and others had difficulty with the relationship.

Description. I conducted further analyses of data from the 18 couples contained in the report in chapter 3. Constant comparison methods were ideal for comparing and contrasting elements related to post-stroke couples in which (i) both partners were satisfied with their marriage development and (ii) couples were separated or one or both partners indicated they were unhappy. Reconstructing compatible role-identities was the overarching theme underlying couples’ examples of how commitment, communication, and agreement worked in their post-

stroke marriages. I identified three themes related to the reconstruction or breakdown of the marital identity: feeling overwhelmed, resolving conflict, and perceiving value in the marriage.

Chapter 5: Summary and Conclusion

In Chapter 5, I discuss the strengths and limitations of the research and the implications my findings have for couples that experience stroke and for therapists who treat such couples. I describe how the knowledge has been translated to date and add concluding remarks.

Chapter 2 Marriage after the Transition to Stroke: A Systematic Review

Abstract¹

In health and chronic illness, satisfying marriages promote wellbeing and life satisfaction, yet stroke research has focused on either the stroke survivor as a patient or the spouse as a caregiver. Using Pope, Mays and Popay's (2007) framework for synthesizing qualitative and quantitative methods, we conducted a systematic review and synthesis of 39 peer-reviewed studies to determine what happens to marital relationships after one partner has suffered a stroke. All the articles examined the impact of stroke. Three overarching themes characterized the evolution of marriage after stroke: chaos in the marriage, work to re-establish the marriage, and evolution of the marriage. While both the stroke condition itself and the survivor's need for care undermined the emotional qualities of the relationship for some couples, about two-thirds were able to retain or regain the relationship closeness. As in other chronic illnesses, the relationship closeness and a couple's ability to collaborate contributed to the stroke survivor's recovery and to the satisfaction with life of the stroke survivor and the spouse. Our results underscore the need to consider the quality of, and the qualities of, the relationship between stroke survivors and their spouses. Future research could include a greater focus on qualitative or mixed methods approaches to explore the interactions between stroke survivors and spouses that impact the wellbeing of both partners.

¹ Submitted to the *Aging and Society* and is currently under review as "Anderson, S., & Keating, N. Marriage after the Transition to Stroke: A Systematic Review." I was responsible for study conceptualization, completing the literature search, quality appraisal, data extraction, data analysis, writing the article, and responding to feedback from the co-author. N. Keating supported study conceptualization, discussed inclusion and exclusion of articles for the review, critically reviewed manuscript drafts and provided substantive feedback.

Introduction

An important contributor to population ageing has been the long term survival of persons with chronic illness and disability (Demiray and Bluck 2014, Kinsella, Beard and Suzman 2013). Medical advances have led to the increased life expectancy of people with heart disease, multiple sclerosis, and many cancers (Goodin and Reder 2012, Huang *et al.* 2008). Extension of life across these chronic conditions has been celebrated as a public health triumph (Goldman *et al.* 2013, Kinsella, Beard and Suzman 2013). Ongoing debates now focus on how to enhance the quality of life in the face of this increased longevity (Jacobs *et al.* 2009, Mortimer and Segal 2008).

Stroke provides a powerful example of the triumphs and challenges arising from impressive healthcare advancements. In developed countries, widespread use of thrombolytic and endovascular clot removal therapies in emergency units and the reduction in early post-stroke complications in dedicated stroke units have reduced mortality rates by over 40% (Feigin *et al.* 2014). Over 85% of people who suffer stroke now survive stroke, and of those, the vast majority (85%) are discharged to their pre-stroke residences (Hall *et al.* 2015, Krueger *et al.* 2015). Yet, only 15% of stroke survivors recover completely (Feigin *et al.* 2014, Teasell *et al.* 2014). Worldwide, stroke remains the leading cause of adult disability (Go *et al.* 2014).

The personal costs of stroke are high. There is considerable evidence that survivors face a range of physical and cognitive impairments (Salter *et al.* 2008, Teasell *et al.* 2014), negative psychological outcomes such as depression (Hackett and Pickles 2014), and difficulty engaging in previously valued roles and activities (Hackett *et al.* 2012, Mayo *et al.* 2002). Trygged, Hedlund and Kåreholt (2011) found that compared to the age-matched population, stroke increases the risk of divorce and separation for both men and women of working age.

Chronic conditions also make stringent and complex demands on stroke survivors and their families (Palmer and Glass 2003, Rohrbaugh *et al.* 2009) who have to reconfigure their responsibilities and roles to meet day-to-day family demands and accommodate the emotional and practical demands of the illness. Stroke survivors' anxiety and depression rates are high (Hackett and Pickles 2014), and these rates are mirrored in spouses (Haley *et al.* 2015, McCarthy, Lyons and Powers 2011). Spouses of stroke survivors experience declines in social participation and have significantly higher depressive symptoms than family and friend

caregivers (Gaugler 2010, Haley *et al.* 2015). Together, these findings suggest that post-stroke disability may be incompatible with a good quality of life for couples.

Despite this somewhat bleak picture of marriage after stroke, research on other adult-onset chronic illness/disability suggests that marital relationships can have a positive influence on the quality of life of those with chronic illness. Indeed, married men and women are more likely to survive cancer than those who never married or who are divorced (Aizer *et al.* 2013, Kravdal and Syse 2011). There is further evidence that it is not just being married, but having a good quality marriage is important (Robles *et al.* 2014, Traa *et al.* 2015). Satisfying marriages are associated with increased survival after coronary bypass surgery (King and Reis 2012), reduced symptom severity in Parkinson disease (Martin 2016, Tanji *et al.* 2008), and memory retention in dementia (Beard *et al.* 2012, McGovern 2011). Partner collaboration increases mutuality, reduces stress, and in turn strengthens the marriage (Berg and Upchurch 2007, Traa, De Vries, Bodenmann and Den Oudsten 2015).

Such findings suggest that how couples manage disability within their relationship may be as important as the disabling features of the condition in the resulting quality of life. Irrespective of the presence of a disability, satisfying marriages are recognized for their role in promoting personal well-being (Holt-Lunstad, Smith and Layton 2010, Pietromonaco, Uchino and Schetter 2013), and satisfaction with life (Bookwala 2012). It is hypothesized that marriage is protective because spouses are the most important sources of social support (Robles *et al.* 2014). Spouses provide emotional and practical support that boosts morale and increases resources to solve problems (Murray and Holmes 2011).

Mutually responsive support behaviours increase spouses' trust in one another, and in turn, their satisfaction with the relationship (Murray and Holmes 2011, Traa, De Vries, Bodenmann and Den Oudsten 2015). This support is lacking in unhappy marriages or in cases in which marital partners are overwhelmed with their own or a spouse's problems (Murray and Holmes 2011, Pietromonaco, Uchino and Schetter 2013). Despite the importance of a marriage in enhancing the quality of life, the preponderance of stroke research has focused on individuals—either the stroke survivor as a patient or the spouse as a caregiver (McCarthy, Lyons and Powers 2011, Ostwald 2008).

Systematic reviews of the experiences of stroke survivors (Salter *et al.* 2008, Satink *et al.* 2013) and caregivers (Gaugler 2010, Salter *et al.* 2010) exist, but we found no reviews that

focused on the marital relationships of couples after stroke. This contrasts with the trend in studies on other chronic conditions, including cancer and heart disease (Dalteg *et al.* 2011, Traa, De Vries, Bodenmann and Den Oudsten 2015), which recognize that interactions with others, in particular the qualities of existing (or desired) marital relationships (Clark-Polner and Clark 2014), are crucial to understanding a person's behaviour and outcomes such as life satisfaction or mental health. To address this gap we conducted a systematic review of qualitative, quantitative, and mixed methods research to determine the current state of the literature on marriage in the context of one spouse's stroke.

Methods

We synthesized the qualitative and quantitative evidence about marriage in the context of stroke to provide a wide evidence base. Customarily, systematic reviews rely on data from qualitative or quantitative studies, however, mixed methods combine the strengths of each method and compensate for the limitations of a single approach (Pearson *et al.* 2015, Pluye and Hong 2014, Pope, Mays and Popay 2007), often leading to an integrated understanding of the topic (Pearson *et al.* 2015). Mixed method reviews draw on the meaning of constructs found in qualitative methodologies and the magnitude and frequency of concepts in quantitative studies to produce a contextual understanding (Pearson *et al.* 2015). In addition to producing an integrated analysis of extant knowledge on the topic, synthesizing the relevant qualitative and quantitative research reduces the need for policy makers and practitioners to perform this function to obtain the needed information.

The design of this review follows Pope, Mays and Popay's (2007) approach to combining qualitative and quantitative evidence. The process involved identifying relevant articles and making decisions about article inclusion, appraising article quality, and analyzing the evidence to find answers to the research question: "What happens to a couple's marital relationship after one partner has suffered a stroke"? In the findings, first we present a synthesis of the qualitative evidence and identify themes in the evidence; we then show how the related quantitative studies support, contradict, or complement the qualitative data about the elements within the themes.

Search strategy

We searched eight electronic databases: Medline, Embase, CINAHL, Web of Science, PsycINFO, SCOPUS, Abstracts in Social Gerontology, and EBMR using the keywords *stroke* or *cerebrovascular accident* and terms related to marriage (*marriage* or *dyad** or *marital* or

*couple** or *spouse** or *wife* or *wives* or *husband*). The following inclusion criteria for the literature were used: (1) written in English, (2) peer-reviewed, (3) participants were married or in a similar partnered relationship, (4) published 1995 to 2015, and (5) the marital relationship was a key theme or variable. Caregiving articles were excluded if other family members or friends were included as partners (caregivers), the relationship was not specified, or articles were not about marriage. Further, articles about hospital discharge planning, impairments, quality of life, or mental health without reference to marriage were excluded. We reasoned that the selected articles would not explicitly answer our question about what happened to the marriage relationship after stroke. Figure 1 is a flow diagram of included/excluded articles.

The search resulted in 3,183 titles and abstracts, many without any reference to stroke or relationships. The challenge of searching databases has been well documented, but the difficulty increases when the search is inter- or multi-disciplinary (Greenhalgh and Peacock 2005). The initial cull of abstracts that clearly did not meet the inclusion criteria left 278 abstracts. We imported the 278 abstracts into the reference manager EndNote, then removed 27 duplicates. After re-reading the resultant 251 abstracts to ensure they met inclusion criteria, we excluded 116. We obtained full texts of the remaining 135 abstracts. Article references and citations were searched for additional relevant articles, but none were identified.

After a first reading of the full articles, 89 articles were excluded (leaving 46 articles). Articles were excluded if they included survivors' or spouses' experience of stroke, but not experience of marriage relationships ($n = 46$); if they aggregated relationships other than spousal or did not specify relationships (spouses, family, friends) ($n = 39$); or if stroke was aggregated with other conditions (e.g., traumatic brain injury) ($n = 3$). Only a few ($n = 6$) of the resultant 46 studies examined post-stroke marital relationships, and a small number ($n = 6$) that considered sexual relationships considered marriage more broadly than sexual intercourse. In addition to these 12 articles that dealt with marriage more specifically than caregiving or sexual intercourse, 35 articles about stroke which measured relationship quality (as a moderator of life satisfaction, burden, depression) or qualitative research in which marriage was a theme were considered by the two authors. After reading the full-texts of the 46 articles, there was disagreement on 16. The authors of the present article agreed to exclude seven of the 46 articles because they focused on individual outcomes (e.g., sexual dysfunction, depression, life satisfaction) rather than on marital relations, leaving 39 articles as a background to the present study.

Assessment of quality

We used two tools to appraise the methodological quality of the 39 articles that met the inclusion criteria: a criteria mixed methods appraisal tool [MMAT] (Pluye 2013) and the Critical Appraisal Skills Programme [CASP] checklists (Spittlehouse, Acton and Enock 2000). The use of these two scales enabled us to rigorously consider methodological quality while sensitizing us to the applicability of the results to our question. MMAT is a validated tool that uses different criteria to assess various methodologies (qualitative, quantitative, mixed methods), but all are rated on a four point scale. CASP checklists vary in length. In addition to adherence to methodological standards and to the quality of the results, CASP also asks evaluators to think about the research papers' applicability to the study question. Both tools clearly define the qualities to be considered in each criterion and both use the same nominal scale (Yes/No/Can't tell) scoring system. MMAT and CASP ratings are included in column 1 of Table 1. Articles included to this stage of the research had acceptable quality.

There are two explanations for all papers meeting the quality criteria. First, in order to select the quality assessment tools used in this study the authors reviewed and discussed a wide range of quality assessment checklists, frameworks, and tools. In assessing full-text articles for inclusion in this study, the authors were aware of quality criteria such as: appropriate selection of a methodology to suit the question; adequate reporting of the methods (research design, participant selection, data collection, and analytical processes); and the trustworthiness of the results. Second, the second author ensured that the papers focused on marriage, and were thus relevant in the review on marriage.

Analysis of the selected literature

Given the heterogeneity of the studies (e.g., diverse questions, research methods, outcomes measured, types of scales used), we chose a critical thematic synthesis to understand concepts that were related to couples' relationships in the context of stroke and also to gaps in the literature. The thematic analysis was inductive, that is, we looked for what was prominent and directly reflected the main concepts in the findings, discussions, and conclusions in the included studies. The articles were imported into NVivo to assist with data management, then analysis proceeded in three steps. First, each study was read to understand its contents. As the emerging codes indicated differences in marriage over time, we separated codes specifically into early after stroke, awareness of marriage reappearing, and the re-development of the relationship.

Second, we collated similar variables (codes with the same understandings) from the qualitative and quantitative studies into these time-framed themes. As all studies referred to stroke impacts, we noted that authors described changes to relationship structures (roles, equity) and functions (support, communication, intimacy) as creating marital chaos, which led to couples wishing for a satisfying marriage but being confronted by how stroke had changed the marriage. As is typical in thematic synthesis (Pope *et al.* 2007), analysis followed these emerging themes. We engaged in the literature reflexively: going back and forth from the original studies to check on our understanding of themes and identifying similar concepts not coded in the initial articles. Memos were used to record analysis and development of the categories. The robustness of the final themes was assessed by re-reading the articles to understand how they reflected main themes and by reviewing the coding in each theme.

Characteristics of the selected studies

A total of 39 articles are included in this three decade review of marital relationships after stroke. Reports were almost evenly divided by quantitative (n = 19) and qualitative (n = 20) methods (see Table 1 Description of the articles). Six research programs reported on different elements of the same study populations in multiple articles (e.g., McCarthy 2; McPherson 2; Kitzmuller 3) (18 articles are identified with + in the References). Articles included spouses' (n = 9), stroke survivors' (n = 3), and couples' (n = 26) perspectives. A few studies specifically recruited younger (n = 5), midlife (n = 1), older (n = 2), or mildly impaired (n = 6) stroke survivors, but over half of the articles included participants with a wide age range (21–90 years) and several impairment levels (e.g., survivors in the U.S. CARES study spent 12 to 405 days in acute care/inpatient rehabilitation) (Godwin *et al.* 2013a, Ostwald *et al.* 2009). Stroke populations were from eight North American and European countries: Sweden, United States, Canada, United Kingdom, Netherlands, Italy, Poland, and Turkey.

Results

Description of the studies

All 39 articles investigated the impact of stroke on marriages. In 12 articles the participants were asked specifically about the impact of stroke on the relationship. Of these, one article used a scaled measure (Dyadic Adjustment Scale) to assess the impact of stroke on marital quality, six articles evaluated the impact of stroke on the sexual relationship, and one article compared the marital stability of the stroke impacted marriage with the marital stability in

an age-matched population. Thirteen articles measured relationship satisfaction as a variable that could moderate the impact of stroke on depression, quality of life, caregiver burden, or stress. The other 14 studies aimed to assess the experience of, or impact of, stroke more generally. In these latter studies, the impact of stroke on the marriage was a main theme (see Table 1).

Themes in the study

The themes elicited from the qualitative studies and echoed in the quantitative studies indicated that stroke was a major marital transition. Each of the qualitative studies found that stroke survivors and spouses focused initially on the most obvious chaos created by the stroke. Only when couples began to perceive they had some control of their situation did they begin to think about what lay ahead for them and their marriage. Comparing and grouping the findings of both quantitative and qualitative studies that described this evolution yielded three themes, namely: chaos in the marriage, work to re-establish the marriage, and evolution of the marriage.

Theme 1: Chaos in the marriage. In the background and/or the findings, all the studies described how stroke disrupted the marriage. The disorder in the marriage was evident in accounts of stroke survivors' difficulty coping with impairments and spouses wondering how to care for someone beleaguered by the cognitive, physical, and communicative impairments caused by stroke. Descriptions of changes to the marriage in the qualitative studies emphasized that structural alterations (roles, distribution of work, balance of power) as well as changes to relationship functioning (support, communication, intimacy) created chaos in the relationship.

Structural alterations in marriages. Changes to taken-for-granted husband and wife roles disrupted the marriage. Authors portrayed sweeping changes in stroke survivors' abilities to fulfil previously valued marital, family, and other roles. These included the husband/wife roles of provider, protector, partner, supporter, and lover. As a result, stroke survivors lost their sense of individual autonomy within the marital relationship. In moderate to severe stroke, for example, there were references to stroke survivors: feeling useless (Banks and Pearson 2004, Kitzmuller, Asplund and Haggstrom 2012, Robinson-Smith and Mahoney 1995), having no position other than a person in a bed (Erikson, Park and Tham 2010, Van Nes, Runge and Jonsson 2009), and feeling helpless because they were unable to do simple tasks such as making a cup of tea or to shower independently (Backstrom, Asplund and Sundin 2010, Coombs 2007). Even mild stroke survivors were depicted as apathetic and unable to organize or complete daily activities independently (Green and King 2009, Tellier, Rochette and Lefebvre 2011, Yilmaz, Gumus and

Yilmaz 2015). One quantitative study of the perceptions of equity in the marital relationships of stroke survivors and spouses found that stroke survivors' distress was highly correlated with loss of productive and family roles and minimally correlated with functional impairment (McPherson *et al.* 2010).

All qualitative studies reported that a married stroke survivor's dependence and need for care necessitated that the spouse assume a caregiver role. The workload previously handled by two people shifted to the spouse of the stroke survivor. From the outset, spouses experienced strain and exhaustion from the new responsibilities and the disruption of established routines. References to spouses prioritizing stroke survivors' needs and foregoing their own needs and preferences demonstrated that stroke survivors' impairments, and their need for care and rehabilitation, dictated how spouses' time was allocated. There were two reports of spouses restricting their personal activities because they felt guilty that the stroke survivors' activities were limited (Coombs 2007, Robinson-Smith and Mahoney 1995). Authors of two American quantitative studies attributed the decrease in marital happiness in the first month after stroke to the chaos resulting from the loss of spousal roles and the transition to stroke survivor and caregiver roles (DeLaune and Brown 2001, Enterlante and Kern 1995).

Decision-making power shifted to spouses, but the changes to the established relationship standards were characterized as stressful for both spouses and stroke survivors. A common finding (10 studies; 8 qualitative, 2 quantitative) was that spouses experienced stress because they had to make decisions for, and about, the stroke survivors—decisions that the stroke survivor would have previously made independently. Stroke survivors were apprehensive about relinquishing control to their spouses (9 studies). Some studies referred to stroke survivors' perceptions that spouses were preventing them from doing activities they thought they could do ($n = 4$) or perceptions that spouses did not recognize their efforts to contribute to the relationship ($n = 5$). Conflict over what stroke survivors could or should do contributed to marital distress.

Changes in relationship functioning. Alterations to the pre-stroke patterns of support and reciprocity between husbands and wives were reported in all studies. Qualitative studies of spouses ($n = 7$), stroke survivors ($n = 2$), and couples ($n = 9$) found that spouses were hypervigilant and over-protective of survivors. Spouses were constantly worried about stroke survivors' health (another stroke, or a fall, could occur), their activity engagement and performance (ability, safety), and their independence when left at home alone. The perceived

overprotection increased survivors' frustration, which triggered anger and bad behaviour that was often directed at spouses. Such behaviours increased spouses' perceptions that the stroke survivors were different from the husband/wife they had married, and some authors reported that spouses referred to the stroke survivors as complete strangers.

All qualitative studies that included stroke survivors referred to the perception of some stroke survivors that the extra care provided by their spouse and their inability to reciprocate support made them feel like they were a burden to their spouse. A stroke survivor's perception of being a burden increased the strain in the relationship. A Canadian quantitative study found that the perception of being a burden to the spouse was prevalent in almost three-quarters of the stroke survivors (70.2%), scoring in the range of "significant distress" Half (49.1%) of the stroke survivors studied restricted communication with their spouses to reduce their spouses' burden (McPherson *et al.* 2010, McPherson *et al.* 2011).

Communication patterns that contributed to marital chaos were reported in all qualitative studies. Misunderstandings and discrepant perceptions of impairments, problems, and the relationship were widely reported. Some authors (4 studies) attributed the difficulty in couples' communicating with each other mainly to impairments in the stroke survivor such as aphasia, memory loss, or face blindness. However, there was considerable evidence that communication patterns typically associated with marital problems—such as withholding emotions, negativity during conflict, and withdrawing from the situation—rather than impairments per se, were causing communication difficulties (21 studies). Authors of 14 qualitative studies reported that to protect their spouses, stroke survivors avoided talking about their feelings or problems with their spouses. In a Canadian quantitative study, half (54.5%) of the stroke survivors agreed or strongly agreed to the statement: "I do not discuss my feelings with my caregiver because I do not want to cause him/her distress" (McPherson *et al.* 2010:197). Authors also reported that stroke survivors abruptly withdrew from conversations with their spouses in order to avoid conflict.

Additionally, articles widely referred to spouses withholding emotions and problems from stroke survivors because spouses worried about increasing stroke survivors' anxiety or distress (15 studies). Spouses were afraid to share the following concerns with the stroke survivor: fears of another stroke, emotions about the stroke impairments, changes in their marriage, and the full extent of their struggles with finances or household problems. Spouses also disengaged from stroke survivors because it was stressful to deal with the survivors' emotional

turmoil or because they might hurt survivors' self-esteem if they provided frank assessments of their role performances. Restricting communication to a partner increased, rather than decreased, distress. The cross-sectional quantitative study that measured the impact of stroke survivors' and spouses' *protective buffering*—that is, withholding emotions, hiding concerns and worries, and/or avoiding disagreements—found that distress increased as protective buffering increased in both stroke survivors and spouses (McCarthy, Lyons and Powers 2012). There were moderate correlations between stroke survivors' and spouses' depression and protective buffering. Higher quality relationships were strongly associated with less depression.

There was also evidence that stroke survivors in satisfying marriages interpreted their spouse's protective communication as helpful (Radcliffe, Lowton and Morgan 2013, Robinson-Smith and Mahoney 1995, Van Nes, Runge and Jonsson 2009). Eight qualitative and five quantitative studies reported on intimacy and sexual relationships. All found that interest in, satisfaction with, and frequency of sexual intercourse diminished significantly in stroke survivors and healthy spouses. Notably, the reasons for changes in intimacy were similar in the qualitative and quantitative studies. Biological factors such as erectile dysfunction, pain, or lubrication accounted for about a third of sexual problems (6 studies). Psychosocial relational problems such as: uncertainty about having sexual intercourse given stroke impairments, difficulty communicating about the relationship, the stroke survivor no longer feeling desirable as a partner, and the spouse no longer regarding the survivor as an appealing sexual partner accounted for most of the decline in intimacy (13 studies). One quantitative study found that some spouses were “turned off,” and even horrified, by the thought of intimacy with a disabled partner (Giaquinto *et al.* 2003). Nine studies found caregiving was a barrier to spouses' perception of themselves as a spouse. A few authors (n = 2) indicated that role overload and fatigue were barriers to intimacy, but eight of the nine studies pointed to the provision of intimate care (e.g., toileting/showering) and/or changes in stroke survivors' personality or behaviour as the factors interfering with spouses' desire.

Theme 2: Work to re-establish marriage. The second theme related to couples wishing that, ideally, they could reinstate the marriage they had, but recognizing that they needed to be realistic about how stroke had changed the stroke survivor and the marriage. Thus the work of re-establishing a marriage required partners to reconcile the discrepancies between expectations

of an ideal and the current post-stroke marriage, and adjust daily interactions and long-term relationship goals to the current marital context.

Reconciling ideal and realistic post-stroke marriages. Each qualitative article reported that stroke survivors and spouses considered the future of their marriage in terms of what they wished would happen. As the authors found that most participants talked about their pre-stroke marriage as a happy partnership, the marriage to which stroke survivors and spouses wanted to return was portrayed as a collaborative union in which husbands and wives were able to love or like, feel closely allied, share problems, and reciprocate emotional support (12 studies). Authors of a Swedish study (Backstrom, Asplund and Sundin 2010) reported that spouses began thinking about their marriage six months after the stroke occurred, but two other authors suggested that it took more than a year for spouses to realize that a return to the hoped for meaningful marriage would not be possible (Brann *et al.* 2010, Kitzmuller *et al.* 2015, Kitzmüller *et al.* 2012).

Eight qualitative studies denoted that realization or acceptance that stroke had irrevocably changed the marital relationship was the transition that began the work of re-negotiating to develop a realistic post-stroke marriage. Striving to achieve a functioning relationship (Backstrom, Asplund and Sundin 2010), adjusting to the loss (Banks and Pearson 2004, Coombs 2007, Quinn, Murray and Malone 2014b), or believing that relationship standards had to change (Buschenfeld, Morris and Lockwood 2009, Erikson, Park and Tham 2010, Thompson and Ryan 2009) were other terms for recognition of permanent changes that required 'new' marriages. After recognition that the changes were permanent, couples redefined their expectations for their relationship (19 studies). For some couples, the marriage was redefined through reinterpreting the meaning of their relationship so that the present reality aligned with the past. Authors found evidence of couples reconciling (Kitzmuller and Ervik 2015, Quinn, Murray and Malone 2014b), re-evaluating (McCarthy and Bauer 2015), or re-balancing (Robinson-Smith and Mahoney 1995) their marriages. Authors portrayed re-definition of the marriage as reconciling to a new way of living together that included: searching for new meaning in their relationship (Backstrom, Asplund and Sundin 2010, Green and King 2009, Kitzmüller *et al.* 2012, Schmitz and Finkelstein 2010, Van Nes, Runge and Jonsson 2009), finding a new path (Kitzmuller, Asplund and Haggstrom 2012), being in transition (Banks and Pearson 2004), or trying to develop a new set of expectations for the relationship (Brann *et al.* 2010, Coombs 2007).

Theme 3: Evolution of the marriage. The third theme highlights that while the marital course couples envisioned was permanently altered, many marriages remained stable. Separation and divorce rates were higher in working aged stroke survivors with children (Trygged, Hedlund and Kåreholt 2011) and for female stroke survivors but not for male stroke survivors in long-term marriages (Karraker and Latham 2015). However, authors of these quantitative studies pointed out that the vast majority of stroke survivors remained married. Marriages evolved in two forms: a relationship of caregiving/care receiving and a marriage in which the meaning had changed. Although both forms were stable, there were some inconsistencies between the qualitative and quantitative studies regarding the emotional qualities of the relationships, in other words, whether a positive attitude toward a partner and/or the marriage relationship was preserved or not.

All the qualitative studies found that the marital relationships developed differently after stroke than couples had envisioned the development pre-stroke. Authors described two forms in which relationships evolved. The most common evolution was toward a caregiving/care receiving relationship, with a smaller proportion of relationships evolving as marriages. Quinn, Murray and Malone (2014a), for example, categorized seven of eight relationships as caregiving because the power in the relationship was similar to the parent/child care dynamic. There was one exception to the caregiving/care receiving marital relationship. One spouse valued the stroke survivor's ability to reciprocate emotional support, so the relationship was deemed typical of emotional reciprocity within marriages. Kitzmuller (2015) characterized 12 of 16 relationships as caregiving/care receiving based on how spouses spoke about sexuality and equity. In contrast to the majority of studies in the literature which depicted significantly more caregiving/care receiving relationships than marital relationships, the proportions of caregiving/care receiving and marriage relationships were almost equal in two studies (Radcliffe, Lowton and Morgan 2013, Robinson-Smith and Mahoney 1995). Radcliffe *et al.* (2013) classified seven relationships as caregiving and six as normal 'united' couples through their narrative analysis of couples' interviews of how stroke affected their lives. Four couples were positive about their caring relationship and three relationships were conflictual.

Caregiving/care receiving relationships. Some marriages became caregiving/care receiving in the transition to stroke and remained focused on caregiving despite the stroke survivors' recovery. Like Radcliffe *et al.* (2013), a few other authors portrayed caregiving/care

receiving relationships as satisfying (Robinson-Smith and Mahoney 1995; Van Nes *et al.* 2009), but far more noted stroke's toll on the emotional qualities of the relationship. Authors referred to: stroke survivors and spouses becoming distanced (Erikson, Park and Tham 2010, Lemieux 2002, Tellier, Rochette and Lefebvre 2011, Thompson and Ryan 2009, Yilmaz, Gumus and Yilmaz 2015) or becoming complete strangers (Backstrom, Asplund and Sundin 2010, Buschenfeld, Morris and Lockwood 2009); couples focusing on their roles as individuals (Backstrom, Asplund and Sundin 2010, Banks and Pearson 2004, McCarthy and Bauer 2015, Quinn, Murray and Malone 2014b, Thompson and Ryan 2009); and spouses feeling ashamed of their ambivalent feelings to stroke survivors (Backstrom, Asplund and Sundin 2010, Brann *et al.* 2010, Buschenfeld, Morris and Lockwood 2009, Coombs 2007).

In the qualitative studies, stroke survivors' and spouses' satisfaction with their caregiving/care receiving relationship decreased over time, with spouses reporting more dissatisfaction than stroke survivors. For instance, the stroke survivors in Thompson and Ryan's (2009) study appreciated their spouses' care, but were distressed by their husband or wife marital roles. Fifteen of 16 thought the shared emotional connection to their spouse had dissolved. They no longer desired a sexual relationship, but hoped a friendship with their spouses would develop. Buschenfeld *et al.* (2009) found that five of seven spouses of stroke survivors referred mainly to their roles as "caregivers." They felt their lives were devalued and meaningless beyond their caregiving roles.

Marriages with new meaning. In contrast to the loss of emotional qualities in caregiving/care receiving relationships, harmony and a new way of relating was the main theme in recalibrated marriages. Couples reconciled to the changes in their marriage by finding new meaning in their relationships (Banks and Pearson 2004, Green and King 2009, Kitzmuller, Asplund and Haggstrom 2012, Schmitz and Finkelstein 2010) or by developing a new set of expectations for the relationship (Brann *et al.* 2010, Kitzmuller, Asplund and Haggstrom 2012, Robinson-Smith and Mahoney 1995). Most frequently, study investigators found couples were able to change their marital expectations or meaning through collaborating to overcome stroke and/or engaging jointly in activities. Examples include: Banks and Pearson (2004) who found that the shared experience of stroke and rehabilitation increased marital closeness for a few couples and Robinson-Smith and Mahoney (1995) who found that the sharing of emotions and activities was associated with the maintenance or return of the emotional qualities of marriage.

The findings about emotional qualities in stroke impacted marriages in the quantitative studies were largely similar to those in the qualitative studies—satisfaction with the relationship declined and the deterioration was greater for spouses than for stroke survivors. Two European studies, three years and one year after stroke, reported that a greater proportion of stroke survivors (92%, 83%) were more satisfied with their relationship than were their spouses (64%, 67%) (Achten *et al.* 2012, Carlsson *et al.* 2007). Longitudinal studies found that satisfaction with the marital relationship declined in spouses of stroke survivors in the first few weeks after stroke (DeLaune and Brown 2001, Enterlante and Kern 1995), in months after stroke (Forsberg-Warleby, Moller and Blomstrand 2004, Green and King 2009, Lapkiewicz *et al.* 2008), a year after stroke (Green and King 2010), and continued to decline significantly at each measurement for three (Visser-Meily *et al.* 2009), and five (Godwin *et al.* 2013) years.

Stroke survivors' satisfaction with the marital relationship declined in the first three months (Green and King 2011), in six months (Lapkiewicz *et al.* 2008), in a year (Green and King 2011, Ostwald *et al.* 2009) after stroke, and continued to decline, but not significantly, for two (Ostwald, Godwin and Cron 2009) and five (Godwin *et al.* 2013) years.

In the discussions, a few qualitative (Brann *et al.* 2010, Buschenfeld, Morris and Lockwood 2009, Coombs 2007) and quantitative (Achten *et al.* 2012, Carlsson *et al.* 2007, DeLaune and Brown 2001, Enterlante and Kern 1995) investigators suggested that spouses experienced greater declines in satisfaction because they bore the brunt of the caregiving task load and because of relationship inequity. The caregiving role overload, being isolated at home, and an overall deterioration in the relationship intensified spouses' perceptions of being trapped in a caregiving role (Backstrom, Asplund and Sundin 2010, Brann *et al.* 2010, Buschenfeld, Morris and Lockwood 2009, Coombs 2007, Radcliffe, Lowton and Morgan 2013). This result was consistent even in one counter case in which the stroke survivor was the caregiver (Radcliffe, Lowton and Morgan 2013).

However, there was far more evidence in the qualitative studies that spouses' dissatisfaction with the relationship was related to perceptions that their partner had changed and/or behaved badly (e.g., was angry, apathetic) (11 studies) and/or stroke survivors could not reciprocate spouses' emotional support (11 studies) than to caregiving or impairments per se. Backstrom *et al.* (2010), for example, reported that spouses had caregiving procedures in place, but by six months love had changed to embarrassment and pity. Brann and colleagues (2010)

also found all spouses were satisfied with the way they provided care, but many were concerned about their ambivalence about their husband or wife roles and their relationship with the stroke survivor.

As in the qualitative studies, in the quantitative studies of American and Belgian couples, spouses' dissatisfaction with the marriage seemed to be tied to relational factors rather than to caregiving tasks (Godwin *et al.* 2013a, Ostwald *et al.* 2009, Visser-Meily *et al.* 2009). Both the burden of care and the satisfaction with the partnered relationship decreased at each time measurement. This indicates that although most spouses successfully learned to manage caregiving demands, some were increasingly unhappy with their marriage.

However, there were two conundrums in the results that concerned couples' satisfaction with the relationship. First, notwithstanding the statistically significant declines in spouses' marital satisfaction over time, in all studies but one (Lapkiewicz *et al.* 2008) stroke survivors' and spouses' mean satisfaction scores remained significantly above the cut scores that would indicate dissatisfaction in both longitudinal (Achten *et al.* 2012, Carlsson *et al.* 2007, Forsberg-Warleby *et al.* 2004, Godwin *et al.* 2013a, Godwin *et al.* 2013b, Green and King 2010, Green and King 2011, Ostwald *et al.* 2009a, Ostwald *et al.* 2009b, Visser-Meily *et al.* 2009) and cross-sectional (McCarthy, Lyons and Powers 2012, McPherson *et al.* 2010, McPherson *et al.* 2011) studies. To illustrate, at 24 months after hospital discharge, American couples' mean scores on the Mutuality Scale were 3.03 (Likert scale: 0 = not at all to 4 = a great deal) (Godwin *et al.* 2013a, Ostwald *et al.* 2009a). Similarly, American (McCarthy, Lyons and Powers, 2012) and Canadian (McPherson *et al.* 2010; McPherson *et al.* 2011) cross-sectional studies found that stroke survivors and spouses rated relationships as satisfying. When asked to rate marital happiness on a scale of one to ten, most Canadian spouses (89.2%) and stroke survivors (94%) rated happiness between six (happy) and ten (perfectly happy).

High relationship satisfaction means suggest that many couples were able to re-establish or maintain mutually satisfactory relationships. A Swedish study that analyzed stability, positive change, and negative change in spouses' satisfaction with the marital relationship showed that half (52%) of spouses rated their relationships to be as satisfying at one year as they had been pre-stroke (Forsberg-Warleby, Moller and Blomstrand 2004). Satisfaction increased for 21% of spouses and decreased for 27% of spouses.

The second conundrum relates to satisfaction with caregiving/care receiving relationships. The qualitative studies portrayed the majority of marriages as caregiving/care receiving, and caregiving/care receiving marriages were often described as dissatisfying; however, the proportions of spouses and stroke survivors who indicated they were happy or very happy with their relationship in the quantitative research would indicate that the emotional qualities of some relationships must have been preserved from the time before stroke, or there were more recalibrated marriages. When asked if they were satisfied with their partnered relationships in the quantitative research, it is not clear whether spouses or stroke survivors were considering a caregiving/care receiving relationship or a marriage relationship.

Discussion

We began this review to explore what happens to marriage after stroke in light of the evidence that close marital relationships play a vital role in wellbeing when people are healthy (Holt-Lunstad, Smith and Layton 2010) and have an even greater impact when people are ill (Robles *et al.* 2014). We found broad agreement in the literature that stroke has a profound effect on the structure and functioning of marriages: the shifts in relationship roles, equity, and power were stressful for all couples who experienced the impact of stroke. However, while both the stroke condition itself and the stroke survivor's need for care undermined the stability and emotional qualities of the marital relationship for some couples, in the 39 studies presented here, both partners indicated they were satisfied with their relationships in at least two-thirds of the couples surveyed (Achten *et al.* 2012, Carlsson *et al.* 2007, McCarthy, Lyons and Powers 2012, McPherson *et al.* 2010, Ostwald *et al.* 2009a).

These findings raise questions about differences after stroke between couples who retain or regain a satisfying marriage and couples whose views of their relationships deteriorate over time, and how stroke survivors and spouses characterize their marriage when one partner requires significant care and support. This is particularly important given that after stroke, as in other chronic illnesses, the closeness in the marital relationship and the couple's ability to collaborate may contribute to the stroke survivor's recovery (Green and King 2010), and to the survivor's and spouse's satisfaction with life and the marital relationship (Ostwald *et al.* 2009a). Our review underscores the need to understand how marriages function after stroke in the context of the stroke survivor's need for care.

How stroke survivors and spouses recalibrate their marriages after stroke and the impact of satisfying marriages on stroke survivors' functional recovery, spouses' burden of care, and both partners' wellbeing has not received much attention in the stroke literature. Clinically oriented research links caregiver outcomes (satisfaction, burden, optimism) mainly to the stroke survivor's functional (physical and cognitive impairment, behaviour) status and the associated care tasks (Lutz and Young 2010, Palmer and Glass 2003) rather than to how husbands and wives relate to each other. Greater declines in spouses' physical and mental health, and higher levels of caregiver burden (compared with the burdens of relative or friend caregivers), have been explained in terms of the amount of time caregiving requires and the difficulty of caregiving tasks rather than in terms of the strain on the marital relationship (Gaugler 2010, McCarthy, Lyons and Powers 2011). To be sure, it is generally true that spouses who live with stroke survivors provide more care, as well as more onerous care (e.g., intimate care, and to survivors with greater functional impairments), than other family or friend caregivers (Cameron *et al.* 2013, Quinn, Murray and Malone 2014a).

Based on the assumption that care tasks are burdensome, stroke caregiving interventions have focused on training spouses in practical care tasks and in finding respite time (e.g., see reviews of spousal caregiving and couple interventions: Quinn, Murray and Malone 2014a, Bakas *et al.* 2014). However, while reviews confirm that caregiver task training reduces stress and burden in the short-term (three months), in the long-term there have been few differences between caregivers who receive skills training and those who do not (Cameron *et al.* 2014, Gaugler 2010, Lutz and Young 2010). Indeed, in a review of longitudinal caregiving studies, Gaugler (2010) found that most stroke caregivers quickly learned care skills. He suggested that the caregiver-receiver relationship had been overlooked as a source of strain. Our findings support that hypothesis. Researchers in the United States and Belgium found that when stroke survivors were discharged from the hospital, spouses were stressed by care tasks. Longitudinally, however, spouses' burden of care and their satisfaction with the marital relationship decreased at each time measurement (Godwin *et al.* 2013a, Ostwald *et al.* 2009a, Visser-Meily *et al.* 2009).

Findings reviewed here show that the majority of couples were able to retain or recalibrate the satisfaction in their marriage relationship despite the stress of impairment and the need for care. Evidence from the research reviewed here also suggests that the support provided in close, satisfying relationships might have effects that are different from the effects of practical

care support. The effects of care and emotional support were disaggregated in one study. Mancini and Bonanno (2006) found the emotional support in close marriages (1,532 married older adults) moderated the negative impacts of functional disability on self-esteem and mental health (anxiety, depression) over and above the effects of instrumental support. Notably, the positive outcomes were not merely a consequence of spousal instrumental care tasks and skills, but also accrued from closeness in the marital relationship. The authors proposed that separating instrumental (care tasks) and emotional (relational) support would provide a better understanding of how people benefit from spousal caregiving and higher quality marriages.

These findings suggest directions for further research. First, it would be useful to know how stroke survivors and spouses characterize their roles and relationships. Differentiating between care and spousal roles could help investigators determine whether caregiver burden/distress relates to care tasks and role overload, to changes in spousal roles, or to marital problems; such differentiation would enable interventions to target specific problems. Interventions to increase caregiving skills are not likely to reduce the strain in marriages in which the spouse is a competent caregiver, but is distressed by the stroke survivor's behaviour or is dissatisfied with the marriage.

Second, findings from this review show that there is a growing body of knowledge on how stroke affects marriages. A next step would be to determine what couples do within their relationships to manage the negative impacts of stroke so that they can (re)create a positive relationship. There is precedent for this type of research in work that has been done with couples in which one partner has cancer or dementia. Knowledge of how stroke impacted couples worked around problems and what elements survivors, spouses, and couples jointly consider important in managing their marriage would inform stroke management with respect to how marriages can be maintained, recalibrated, and even become closer after stroke (Badr and Krebs 2013, Beard *et al.* 2012, Martin 2016).

Third, given the strong links between higher quality marriages and better outcomes in cardiovascular disease (significantly reduced premature mortality, reduced depression), satisfaction with the marital relationship should be included as a variable in stroke research (Pietromonaco, Uchino and Schetter 2013, Robles *et al.* 2014). We hypothesize that marital quality would have similar effects on outcomes of stroke and cardiovascular disease. While the mechanisms by which marital quality influences health outcomes have not been delineated, a

meta-analysis in Robles et al. (2014) found that both positive and negative elements of marital quality were influential. Marital dissatisfaction consistently predicted the biological markers for cardiovascular disease risk (increased intermedia thickness, reactive blood pressure), while satisfaction with the marriage was associated with better mental health and longevity.

Because stroke impairments threaten taken-for-granted identity and self-esteem, we hypothesize that high marital quality will positively influence a stroke survivor's self-confidence, self-esteem, and morale to cope with impairment and role loss. Positive interpersonal processes such as support to develop one's management skills, assistance to reframe the situation, and encouragement to carry on can increase self-esteem. Conversely, withholding support, responding in ways that makes the recipient feel weak or inadequate, or berating and blaming the recipient for the problem can reduce self-confidence. In dementia and Parkinson disease, which have effects similar to stroke on identity and self-esteem, studies demonstrate that a positive sense of self can be preserved in a survivor if it is reflected in the attitude of the spouse (Beard *et al.* 2012, Martin 2016).

Strengths and Limitations

Established methods were used to review, appraise, and synthesize the studies presented in this review. The thematic synthesis adhered to the Preferred Reporting Items of Systematic Reviews and Meta-Analysis (PRISMA) Statement (2009). A strength in our review is the inclusion of qualitative and quantitative studies. Comparing and contrasting the findings in the two methods produced a stronger synthesis. There are limitations, however, that are important to note. Although our search strategy included a robust search of eight databases, as well as a search of article references and citations, it is possible that we missed studies of stroke and marriage. We may have excluded articles that others might have included (see Dixon-Woods *et al.* 2007). Including general studies of stroke may be considered a limitation. We found only a few studies specifically about post-stroke marital relationships, but the impact of stroke on marriage was nevertheless a significant theme in several studies of the stroke experience. Aligned with our aim to understand what is known about marriage after stroke, we chose to include studies that had relationships as a theme. Changes in the marital relationship after stroke were clearly a cause of distress in these studies.

We were not able to report on the influence of age and gender, because these were not included in the analysis or discussions in the majority of the included studies. More recent

articles had more references to gender and age than earlier articles. To illustrate, one study reported an association between higher marital quality and being a male spouse (Visser-Meily *et al.* 2009). A few articles mentioned that younger couples have stressors (e.g., young children, loss of employment, stigma of stroke at a younger age) that older couples lack (Kitzmuller *et al.* 2012, McCarthy and Bauer 2015, Quinn *et al.* 2014b), but stressed that having to adapt to changes in their reciprocal relationship roles was the main challenge for husbands and wives at younger and older ages (McCarthy and Bauer, 2015; Kitzmuller *et al.* 2012, Quinn *et al.* 2014b). Future research should specifically consider how age and gender might impact or moderate stroke outcomes in married couples.

Conclusion

There is substantial evidence in the assessed literature that having a spouse and a marital relationship provides a unique contribution to stroke management. While both the condition of stroke itself and the stroke survivor's need for care undermined the stability and emotional qualities of the marital relationship in some couples, about two-thirds were able to retain or regain the closeness in their relationship. This finding is particularly important given that closeness in the post-stroke relationship was associated with better outcomes for stroke survivors (e.g., survivors' functional recovery was improved) and for married couples (both partners experienced satisfaction with life and depression was reduced). Similar findings have been reported for other chronic illnesses. Such results underscore the need to consider the quality of the relationship between the stroke survivor and the spouse as husband and wife as well as caregiver and care receiver. Future research could include a greater focus on qualitative or mixed methods approaches to explore the processes by which interactions between stroke survivors and spouses can impact outcomes for both partners.

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* indicates articles included in review

+ indicates multiple studies of the same population

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Table 1 Description of Studies: participants, methodology, recruitment, theoretical framework, and findings

Author; Quality Rating: MMAT ² CASP ³	Participants	Methodology (data collection points)	Recruitment, Country	Research Aim (Theoretical Framework)	Findings
Achten <i>et al.</i> 2012 MMAT**** CASP 11/12	Couples Patients with stroke n=78 (59; NR) Spouses n=78 (55; NR) Same cohort as Visser-Meily <i>et al.</i> 2009	Quantitative Cross-sectional (3 years)	In-patient rehabilitation, Netherlands	Compare couples' life satisfaction (Life satisfaction as rehab outcome)	Associations between survivors' and spouses' satisfaction with relationship were not significant. Satisfied with partnered relationship: Survivors 92%; Spouses 64%.
Visser-Meily <i>et al.</i> 2009 MMAT**** CASP 11/12	Couples Patients with stroke n=121 (56; NR) Spouses n=121 (54;	Quantitative Longitudinal (in rehabilitation, 2	Rehabilitation cohort, Netherlands	Predictors of the course of spouses' psychosocial functioning	Harmony in relationships decreased significantly at each measurement. Patient mental & cognitive functioning improved to

² Mixed methods appraisal tool assessment (Scores varying from 25% (*) -one criterion met- to 100% (****) –all four criteria met-

³ Critical skills appraisal program (Score/ # of criteria. Number of criteria vary by type: qualitative and quantitative cohort, comparison, or randomized)

⁴ Terms used by authors to describe survivors & spouses are used

	NR) Same cohort as <i>Achten et al. 2012</i>	months, 1 & 3 years)		(Stress & coping)	1 year. Caregiver burden decreased. Better marital relations (spouses only assessed) associated with male spouse, not having young children, more support seeking & less passive coping.
<i>Backstrom et al. 2010</i> MMAT*** CASP 9/10	Spouses Female spouses n= 4 (52; 40-58) Partner who suffered a stroke (52.25; 42-58)	Qualitative Longitudinal (1, 6, & 12 months)	In-patient rehabilitation, Sweden	Spouses' lived experience of the relationship (Phenomenological)	2 months: care was paramount; spouses didn't feel they were married to the same person. 6 months: strove to move back to spousal relationship, 1 year: irreversibly altered relationship & lack of reciprocity.
<i>Banks and Pearson, 2004</i> MMAT**** CASP 10/10	Couples Younger stroke survivors n=38 (44; 20-49) Informal carers/ spouses n= 36 (NR)	Qualitative Longitudinal (3, 6-9 & 12-15 months)	Community stroke groups, United Kingdom	Impact of stroke on relationships	Lack of communication & miscommunication were common. Survivors took difficulties & frustrations out on spouses. Survivors reported that partners could not relate to their situation & partners felt survivors had changed. 12-15 months: parallel lives, spouses in caring and

					survivors in stroke.
Brann <i>et al.</i> 2010 MMAT**** CASP 10/10	Spouses Survivors (NR) Spouses n=16 (NR; 19-93)	Qualitative Cross-sectional	Extended care & Community stroke group, United States	Spousal caregivers experiences of stroke (Dialectical tensions)	Roles & reciprocity altered. Spouses prioritized survivors’ needs over theirs. Survivors unable to reciprocate emotional support. Spouses ashamed of ambivalent feelings to survivors.
Buschenfeld <i>et al.</i> 2009 MMAT**** CASP 10/10	Spouses Partners n= 7 (NR; 47-60)	Qualitative Cross-sectional	Community stroke groups, United Kingdom	Experiences of partners (Phenomenology)	Two themes: (1) Loss of person to whom they were married/ Changed marital roles and relationship; (2) Enduring: Spouses committed to remaining married.
Carlsson <i>et al.</i> 2007 MMAT**** CASP 11/12	Couples Patients n=56 (60; 38-74) Spouses/partners, (59; 34-79) Same cohort as Forsberg-Warleby,	Quantitative Longitudinal (1 week, 1 year)	Acute stroke admission cohort, Sweden	Compare couples’ life satisfaction (Life satisfaction as rehab outcome)	Highest proportion of couples in which both partners satisfied: family life (66%) and relationship with partner (60%). Spouses (67%) were significantly less satisfied with relationship with survivor (83%) (Pop norm, 86%).

	<i>et al.</i> 2004				
Forsberg-Warleby, Moller, and Blomstrand, 2004 MMAT **** CASP 12/12	Spouses ⁵ Survivors (58; 23-75) Spouses n=67 (57; 27-79) Same cohort as Carlsson <i>et al.</i> 2007	Quantitative Longitudinal (4 and 12 months)	Consecutively admitted to acute care survivors (1994-1997), Sweden	Spouses' Life Satisfaction	Relationship satisfaction decreased 30%, unchanged 60%, & increased 10%. Spouses' mean satisfaction lower than Swedish population. Dissatisfaction in depression/cognitive impairments not functional impairment.
Coombs , 2007 MMAT**** CASP 10/10	Spouses Partners & Spousal caregivers n=8 (65.5; 57-81)	Qualitative Cross-sectional	In-patient rehabilitation, Canada	Spousal caregivers' experience (Phenomenology)	Marital relationship had been a partnership. Moving from spousal to care relationship was challenging because of loss of shared perspective.
DeLaune and Brown, 2001 MMAT*** CASP 9/12	Spouses/ caregiving role n=17 (62.5; 44-78)	Quantitative Longitudinal (in hospital and 1 week after discharge home)	In-patient rehabilitation, United States	Factors affecting husbands and wives adjustment to caregiving role (Gendered roles)	Husbands' and wives' role responsibilities increased and role enjoyment, joint social activities and wives personally meaningful activities decreased. Marital unhappiness increased.

Enterlante and Kern, 1995 MMAT*** CASP 7/12	Wives Spouses n=10 (NR; 48-70)	Quantitative Longitudinal (in hospital & 2 weeks post-discharge)	In-patient rehabilitation, United States.	Wives' role changes after husbands are disabled by stroke	Wives' role responsibilities increased and role satisfaction and marital happiness decreased.
Erikson, Park and Tham, 2010 MMAT**** CASP 10/10	Stroke survivors of working age N=9 (51.22; 45-61)	Qualitative Longitudinal (1, 3, 6, & 12 months post stroke)	In-patient rehabilitation, Sweden.	Meaning of interactions with others (Engagement in Occupation Theory)	Core category of a process of needing to belong for integration and 4 sub categories: (1) not recognized as the person I am, (2) burden of burden, (3) inspiration & belonging through social interactions, and (4) reality adjustment through other's feedback.
Giaquinto <i>et al.</i> 2003 MMAT**** CASP 12/12	Couples Patients n=62 (64 NR) Partners n=62 (NR)	Quantitative Longitudinal (1 month and 1 year post-stroke)	In-patient rehabilitation, Italy	Evaluating and quantifying sexual changes 1 year after stroke	Sexual decline was common. Only age and disability significant. Spouses & psychosocial aspects than medical account for decline. Spouses experienced fear of relapse, anguish, lack of excitement, or even horror, which withheld them from encouraging

					sexual activities.
Godwin <i>et al.</i> 2013a MMAT**** CASP 11/12	Couples Stroke survivors n = 30 (70.8; NR) Spousal caregivers n = 30 (64.9; NR) Same cohort as Godwin <i>et al.</i> 2013 a, b; Oswald <i>et al.</i> 2009a, b	Quantitative Longitudinal (1, 3, & 5 years)	(CARES Intervention Cohort) Hospitals & Rehabilitation centers, United States	Impact of stroke on survivor's and spouse's health related quality of life	Spouses', but not survivors', mutuality decreases significantly over time although caregivers' burden and depression decreased.
Godwin <i>et al.</i> 2013b MMAT**** CASP 12/12	Couples Stroke survivors n = 134 (66.4, NR) Spousal caregivers n = 134 (62.5;NR) Same cohort as Godwin <i>et al.</i> 2013 a, b; Oswald <i>et al.</i> 2009a, b	Quantitative Longitudinal (Baseline, 6, & 12 months)	As above	Effect of mutuality on stress	Caregivers' mutuality decreased their stress, but not survivors' stress. Survivors' stress affected spouses' stress, but spouses' stress didn't affect survivors' stress.
Oswald <i>et al.</i>	Couples	Quantitative	As above	Variables associated	Survivors (3.3/ 0-4) and spouses

2009a MMAT**** CASP 12/12	Stroke survivors n=113 (66.9; 51-88.6) Spousal caregivers n=113(63; 41-87) Same cohort as Godwin <i>et al.</i> 2013 a, b; Oswald <i>et al.</i> 2009a, b	Longitudinal (12 & 24 months)		with life satisfaction (Life satisfaction as rehabilitation outcome)	(3.0) mutuality scores at 12 months were high, but had decreased. Spouses' life satisfaction associated with higher mutuality. Couples with a high degree of mutuality were most satisfied with their lives.
Oswald <i>et al.</i> 2009 b MMAT**** CASP 12/12	Couples Stroke survivors n=159 (66.4) Spousal caregivers n=159(62.5) Same cohort as Godwin <i>et al.</i> 2013 a, b; Oswald <i>et al.</i> 2009a, b	Quantitative Longitudinal (Baseline, 6, & 12 months)	As above	Levels of stress and predictors of stress in first year home	Survivors (3.46/ 0-4) and spouses (3.27) baseline mutuality scores were high. Mutuality reduced survivors' but not spouses' stress. Stress was increased by poor function, but mediated by a good relationship.
Green and King, 2009 MMAT**** CASP 9/10	Couples Male stroke patients n=26 (63.9; 33-83)	Qualitative Longitudinal (1, 2, 3, 6, 9, & 12 months)	Urban hospital (less than 15 days in hospital), Canada	Factors affecting quality of life (Life satisfaction as rehabilitation outcome)	Marital roles disrupted. Wives managed day-to-day demands. Spouses' uncertainty over possibility of another stroke &

	Wife-caregivers n=26 (58.5; 33-75) Same cohort as Green and King, 2009, 2010,2011				overprotectiveness increased tension in the relationship. Survivors' masculine sense of self was threatened.
Green and King, 2010 MMAT **** CASP 12/12	Couples As above Same cohort as Green and King, 2009, 2010,2011	Quantitative Longitudinal (Discharge, 1, 2, 3, & 12 months)	As above	Recovery trajectory for male patients and wife- caregivers (Effects of mild stroke impairments)	Worsening of depression & marital functioning for both the patients & wife-caregivers, although the wife-caregivers' perceptions of caregiver strain improved. None of the measured variables were associated with marital functioning 1 year post discharge.
Green and King, 2011 MMAT*** CASP10/12	Couples As above Same cohort as Green and King, 2009, 2010,2011	Quantitative Longitudinal (Discharge, 1, 2, & 3 months) (See above)	As above	Biophysical and psychosocial effects of stroke (Stress & coping theory)	Poorer marital function was associated with poorer mental health & functional outcomes. Improvement in wives' mental health improved marital functioning.
Kitzmüller <i>et al.</i> 2012a	Couples Stroke survivors, n-	Qualitative Cross-sectional	Convenience sample In-	Illuminate the long- term experience of	Role and marital changes caused fear & insecurity. Some survivors

MMAT**** CASP 8/10	=23 (51; 32-68) Spouses n=17 (51; 32-65) Same cohort as Kitzmuller et al., 2012 b and Kitzmuller and Ervik, 2015		patient rehabilitation & community groups, Sweden	family life after stroke particularly regarding marital relationships. (Phenomenology, Van Manen & Heidegger)	were worried that spouses would abandon them because of bad temper, disengagement, & burden. Spouses viewed survivors as childlike, even as strangers. Couples who remained together enjoyed their lives/perceived that relationships improved.
Kitzmüller <i>et al.</i> 2012b MMAT**** CASP 8/10	As above	Qualitative Cross-sectional	As above	Existential meaning of couples' experiences of stroke (Phenomenology, Van Manen & Heidegger)	Sudden onset exaggerated devastating impact on life. Stroke survivors felt stigmatized and dismissed. Dealing with post- stroke changes made couples reinterpret their life-world and gave couples a deeper appreciation for life.
Kitzmuller and Ervik, 2015 MMAT**** CASP 8/10	Spouses Stroke ridden partner (NR) Spouses n=12 (52, 40-62) Same cohort as	Qualitative Cross-sectional	As above	Influence of stroke on female spouses' sexual relationship (Phenomenology, Van Manen & Heidegger)	Four main themes: (1) married to a stranger, (2) the shift from partner to caregiver, (3) sexuality wrapped in silence, and (4) a void to live with.

	Kitzmuller et al., 2012 a, b				
Korpelainen <i>et al.</i> 1999 MMAT**** CASP 12/12	Stroke patients n=50 (53.5 32-65) Spouses n= 50 (NR)	Quantitative Longitudinal (2 & 6 months post stroke)	In-patient rehabilitation, Norway	Impact of stroke on sex lives of stroke patients and spouses	Sexual arousal, frequency, and satisfaction decreased after stroke. Related to biological (1/3), but mainly (2/3) to psychosocial factors.
Lapkiewicz <i>et al.</i> 2008 MMAT**** ⁶ CASP 8/12	Couples Patients with aphasia n=22 with stroke n=21 (55.9;NR) Partners n=43 (56.2; NR)	Quantitative Longitudinal, (within 7 days of onset & 6 months)	In-patient rehabilitation, Poland	Impact of stroke on quality of marriage (Ecological-Marriage as context)	Overall, marriage quality, cohesion and satisfaction declined for couples dealing with stroke and aphasia, but more for aphasic survivors. Emotional expression declined in aphasia.
Lemieux <i>et al.</i> 2002 MMAT**** CASP 10/10	Couples Aphasic individuals n=6 (65, 53-70) Spouses n=6 (NR)	Qualitative Cross-sectional	Aphasia Centre Clients, Canada	Impact of stroke on sex lives of stroke survivors with aphasia and spouses	Frequency of intercourse, desire for (1/2 of survivors, 2/3 of spouses) & importance of sex reduced. Other sexual activities

⁶ Not all marital satisfaction scores reported

					increased. Lack of communication was barrier to sex.
McCarthy <i>et al.</i> 2012 MMAT**** CASP 12/12	Couples Survivors n=36 (60.03; 21-90) Spouses n=36 (58.67; NR) Same cohort as McCarthy & Bauer, 2015	Quantitative Cross-sectional	Convenience sample In- patient rehabilitation & community groups, United States	Relational factors associated with depression (Stress & coping, developmental –contextual model)	Partner protective buffering, perceived misunderstandings & perceptions that spouse’s expectations unrealistic associated with survivor’s depressive symptoms. Passive coping & survivor protective buffering associated with spouse’s depressive symptoms.
McCarthy & Bauer, 2015 MMAT**** CASP 10/10	As above Same cohort as McCarthy <i>et al.</i> 2012	Qualitative Cross-sectional	As above	Couples experience of stroke	Loss of individual autonomy, compromised intimacy, shifts in marital roles, inequity strained relationships. Satisfying relationships a coping resource.
McPherson <i>et al.</i> 2010 MMAT**** CASP 12/12	Couples Former inpatients/ Care recipients n= 57 (65.5; NR) Partner caregivers n= 57 (61.9; NR)	Quantitative Cross-sectional	In-patient rehabilitation, Canada	Impact of stroke on equity and survivors quality of life	Survivors highly satisfied with relationship although self- perceived burden was higher in stroke (70%) than in advanced cancer (19-38%). Self-perceived burden moderately correlated with

	Same cohort as McPherson <i>et al.</i> 2011				functional impairment ($r=-.21$) & highly correlated with family roles ($r=-.61$).
McPherson <i>et al.</i> 2011 MMAT**** CASP 12/12	As above Same cohort as McPherson <i>et al.</i> 2010	As above	As above	Impact of stroke on relationship equity, partners' quality of life and caregiver burden	Spouses: 89.2% satisfied with marriage despite 60.7% doing more. Satisfaction with marital relationship & intrinsic caregiving rewards accounted for 24% of the + reactions to care.
Quinn, Murray, and Malone, 2014b MMAT**** CASP 10/10	Couples Survivors n=8 (47; 36-61) Spouses n=8 (45; 36-65)	Qualitative Cross-sectional (1-9 years post-stroke)	2 stroke associations and Facebook groups, United Kingdom	Experience of young survivors & partners (Shared experiences)	All couples referred to shift in roles from partners to caregiving and cared for. Both partners had difficulty adapting to reciprocal relationship roles. Spouses marital/care roles not congruent.
Radcliffe <i>et al.</i> 2013 MMAT**** CASP 10/10	Couples Survivors n=13 (NR; 75-85) Spouses n=13 (NR; 59-85)	Qualitative Cross-sectional	Randomly selected from London Stroke Register, United Kingdom	Stroke survivors' and spouses' description of how stroke affected lives (Narrative)	Emphasis on: "United couples, normality as couple;" "Positive caring couples, mutual-reliance managing care;" "Frustrated couples, care & marriage hardships."
Robinson-	Couples	Qualitative	Rehabilitation	Factors affecting	Stroke had major impact.

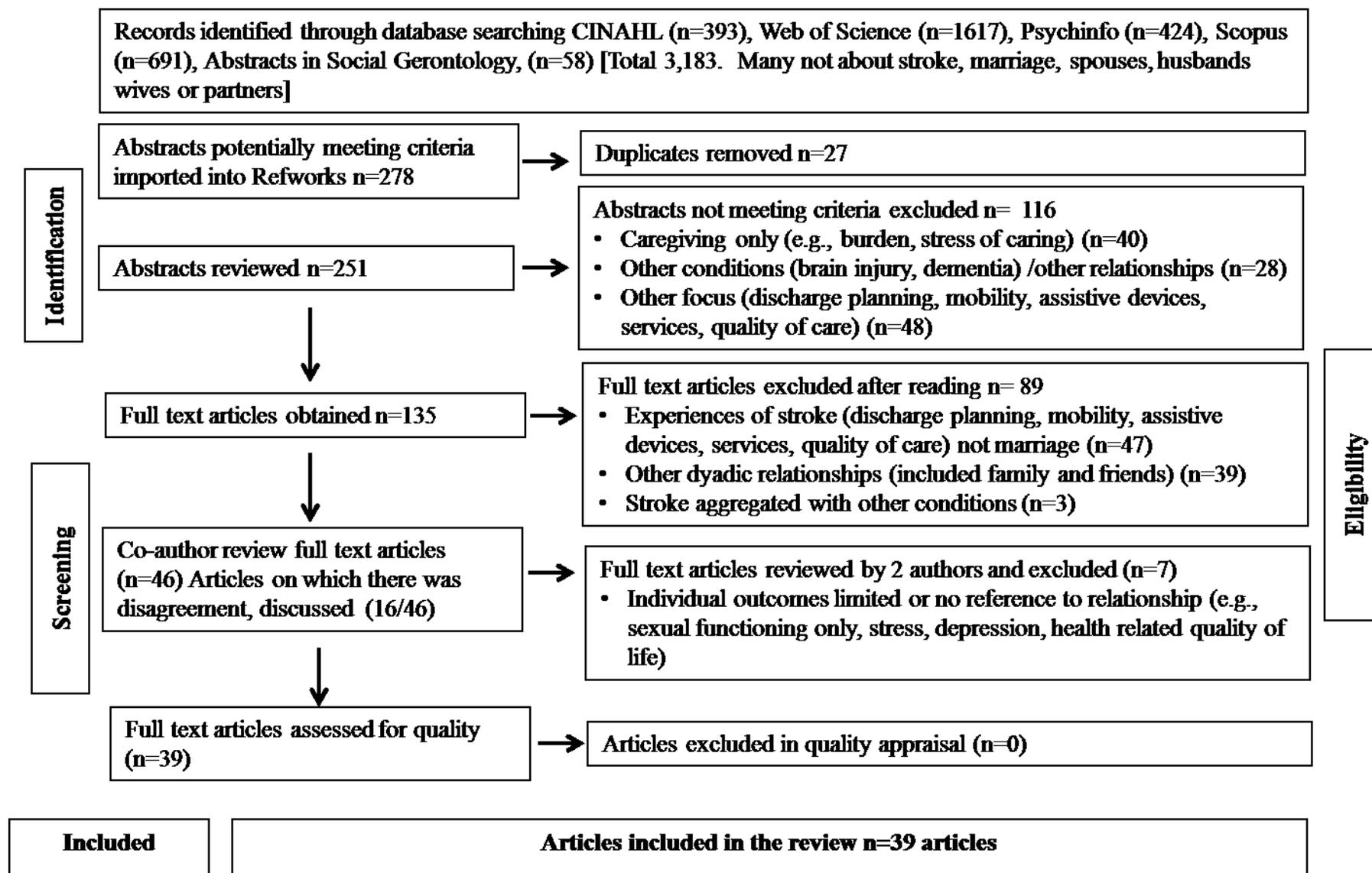
Smith and Mahoney, 1995 MMAT**** CASP 10/10	Survivors n= 7 (NR; 60-79) Spouses n= 7 (NR; 62-82)	Cross-sectional	and community group (6 months post stroke), United States	marital equilibrium	Survivors reported feeling useless, uncertain, & frustrated about getting better. One couple in conflict but rest coordinated activities & were working out a new relationship balance.
Schmitz and Finkelstein, 2010 MMAT**** CASP 10/10	Couples ⁷ Stroke survivors n=15 (65; 29-85) Partners of stroke survivors n=14 (65; 29-85)	Qualitative Cross-sectional	Opportunistic sample, United States	Experiences of sexual issues	Two stroke effects: physical and relationship changes. Dynamics of caregiving alter role-identity & established interaction patterns which affect sexual confidence, desirability, & interest.
Tellier <i>et al</i> 2011 MMAT**** CASP 10/10	Spouses n=8 (56.9; 45-69)	Qualitative Cross-sectional (3 months after discharge)	Hospitalized patients, Canada	Factors influencing mild stroke survivors'/ spouses' Quality of Life	The conjugal relationship was an important theme. Half of the spouses identified changes in roles with 6/8 citing conflict
Thompson 2009	Survivors Survivors of stroke	Qualitative Cross-sectional	Stroke Nurse specialist	Impact of stroke on spousal relationships	Unable to continue with traditional roles. Anger &

⁷ Husbands and wives, but not necessarily couples married to each other

MMAT**** CASP 10/10	n=16 (56; 33-78) Spouse (NR)		registrar, United Kingdom	(Importance of survivor's perspective)	agitation frequent. Impairments and dependence frustrating
Trygged <i>et al.</i> 2011 MMAT**** CASP 12/12	People aged 18 to 64 who suffered a first stroke between 1992 and 2005	Quantitative Longitudinal Population Health	Patient records, Household Survey, Sweden	Impact of stroke on post-stroke divorce and separation	Risk of separation is much higher in the incident year and for women than for age-matched population.
Van Nes <i>et al.</i> 2009 MMAT**** CASP 10/10	Couple Stroke survivor n=1 (81) Partner n-1 (84)	Qualitative Case Study Longitudinal (1 to 3 years)	Selected from larger study, Netherlands	Older couple's experience (Occupation)	Couple acted as one entity/collaborated. Mutual relationship strengthened by stroke.
Yilmaz <i>et al.</i> 2015 MMAT*** CASP 8/10 ⁸	Survivors Post-stroke women n=16 (NR)	Qualitative Cross-sectional	In-patient rehabilitation cohort, Turkey	Impact of stroke on women's sex lives and relationships	Negative impact on roles (wives, mothers, marriage). All but one experienced decrease in sexual desire, no longer felt desirable.

⁸ Demographics other than sex not reported

Figure 1 Literature Search



Chapter 3 Reconciling Marriage and Care after Stroke

Abstract⁸

Most research on the impact of stroke on couples has focused on the transition to caregiving/care receiving. Despite considerable evidence that marriage is the primary source of support in the face of chronic conditions, little is known about what happens to marriage in the context of care after stroke. To address this gap we undertook a qualitative grounded theory study of 18 couples in which one member of each couple had experienced a stroke. Findings revealed two interrelated themes in the couples' post-stroke processes: *working out care*, which involved discovering and addressing disruptions in day-to-day activities; and *rethinking marriage*, which involved determining the meaning of their relationship in the new context of care and disability. Three distinct types of marriages evolved from these processes: the relationship was reconfirmed around the pre-stroke marriage; the relationship was recalibrated around care; or a parallel relationship, a “his” and “her” marriage, evolved. Our findings highlight that in order to promote the wellbeing of couples after stroke, the marital relationship dynamics must be considered in addition to knowledge about stroke and caregiving.

⁸ This paper was accepted for publication on December 10, 2016 by *The Canadian Journal on Aging* as “Anderson, S., Keating, N., and Wilson, D.M. Reconciling Marriage and Care after Stroke.” It is scheduled for inclusion in Volume 36, Number (3), 2017. I was responsible for study conceptualization and design, submitting the ethics application, data collection and analysis, writing the article and responding to feedback from the co-authors. N. Keating and D.M. Wilson critically reviewed manuscript drafts and provided substantive feedback.

Background

Stroke treatment is a success story. With access to effective emergency treatment, dedicated stroke care units, and multidisciplinary rehabilitation, over 85% of Canadians survive their stroke and, of those, 85% return home (Hall et al., 2014; Krueger et al., 2015). Stroke has gone from the third leading cause of death, just behind heart disease and all types of cancer, to fourth or fifth place in many countries (Feigin et al., 2014; Krueger et al., 2015). Despite these successes, only 15% of survivors recover completely (Hall et al., 2014). Worldwide, stroke remains the leading cause of adult disability (Hall et al., 2014; Teasell, Fernandez, McIntyre, & Mehta, 2014). Although lives have been saved, stroke survivors and their families are challenged to live with a broad array of physical, social, and psychological impairments.

Stroke is a condition mainly of older adults, therefore, spouses are the primary family member who is involved in care for about three-quarters of survivors (Hall et al., 2014). Surprisingly, there has been little emphasis on what happens to marriage in the context of often permanent stroke-care needs. Rather, there have been two separate themes in stroke research, one emphasizes the need for care and the other focuses on the negative impact of stroke on marriage. To date, the preponderance of studies has focused on the stroke survivors' need for care. About 25% of stroke survivors require full-time assistance with basic activities such as preparing a meal or getting out of bed (Feigin et al., 2014; Mayo, Wood-Dauphinee, Carlton, Durcan, & Carlton, 2002). A further 60%, those with non-physically disabling stroke, suffer from fatigue, memory loss, and/or cognitive impairments. These issues make it difficult for them to return to work or organize their daily lives (Adamit et al., 2015, Teasell et al., 2014).

Research on marriage after stroke has often emphasized the negative impact of stroke on the spouse of the stroke survivor. Reviews link greater spousal strain to more time spent with the stroke survivor and to the fact that spouses perform more onerous care requirements (Gaugler, 2010; Quinn, Murray, & Malone, 2014a). Divorce rates are significantly higher in the three years after a first stroke than they are for an age-matched population (Trygged, Hedlund, & Kåreholt, 2011).

Declines in relationship satisfaction are troubling because the benefits of satisfying marital relationships are now well documented (Holt-Lunstad, Smith, & Layton, 2010; Robles, Slatcher, Trombello, & McGinn, 2014). The degree to which husbands and wives view their relationship positively predicts future wellbeing. People in satisfying marriages are less likely to

succumb to acute or chronic illness, are more likely to recover faster, and are less likely to die prematurely (Uchino et al., 2012; Umberson & Montez, 2010). Caregiving spouses who view their relationship with the care receiver positively experience less caregiver burden and continue in their caregiving roles longer (Park & Schumacher, 2014).

Given the importance of marital relationships, there have been calls for research to understand how couples negotiate their relationships in the presence of chronic illness and the need for care (Umberson & Montez, 2010). An increase in the number of stroke survivors who live at home, and who live longer lives (Hall et al., 2014; Krueger et al., 2015), and the limited knowledge about post-stroke marriages (Godwin, Ostwald, Cron, & Wasserman, 2013; McCarthy, Lyons, & Powers, 2011), make stroke a strategic site to examine marriages after stroke. Consequently the focus of this research study was to address the question: What happens to marriage in the context of care after stroke?

Review of the stroke literature

Stroke researchers have not typically sought to understand experiences of survivors and their spouses as a unit (McCarthy et al., 2011). Rather, researchers have looked separately at caregivers' experiences of care work and at survivors' experiences with impairment, setting aside questions of how they relate as a couple (Green & King, 2010; McCarthy et al., 2011). In the following section, we summarize the state of knowledge in two categories of stroke studies: studies that examine the effects of care work on spouses of stroke survivors, and studies that examine the impacts of stroke on marriage. We augment these findings with evidence from research on other chronic conditions.

Spousal care. Caregiving by spouses is crucial to stroke survivors who are discharged from the hospital to their homes and to their ability to remain at home. Married stroke survivors are more likely to be discharged to their homes (Mees et al., 2014; Tanwir, Montgomery, Chari, & Nesathurai, 2014), and are more likely to be discharged after a shorter hospital stay, than single, divorced, or widowed stroke survivors (Bates et al., 2013; Kurichi et al., 2014). Spouses take more severely disabled stroke survivors home, provide more intensive care, and continue to care longer than other family or friend caregivers (Daniel, Wolfe, Busch, & McKevitt, 2009; Gaugler, 2010).

In light of the importance of stroke survivors' need for care, researchers have focused on caregivers' preparedness and ability to care, and on the challenges of the care recipient's level of

impairment and behavioural problems, than on the caregiver's wellbeing. For example, Cameron and colleagues' (2014) "Timing it Right" intervention assumed that caregivers' educational needs and the types of care tasks will change as the stroke survivor moves from acute care (preparation) to hospital discharge to home (implementation) and to community integration (adaptation). The study found that spousal caregivers and those providing high levels of assistance were at highest risk of caregiver burden (Grigorovich et al., 2015). As the study centred on caregiving, elements in the spousal relationship that might have been distressing were not delineated.

A small amount of evidence indicates that relationship dynamics can be a source of distress for spousal caregivers (Gaugler, 2010; McCarthy et al., 2011; Quinn, Murray & Malone, 2014b). Quinn and colleagues (2014b) studied young couples post-stroke and found that changes in the husband or wife they loved and married, feeling like they were living with a stranger, missing mutual conversations and problem sharing, and the absence of validation from the stroke survivor were points of distress for the caregiving spouses. Such spouses perceived that the stroke survivors were no longer able to support them, but still felt a relational obligation to provide care (Quinn et al., 2014b; Visser-Meily et al., 2006).

Impact of stroke on marriage. In contrast to the large number of caregiving studies, a smaller group of studies specifically considered the views of stroke survivors and their spouses regarding their marital relationships. The main findings in these studies pointed to a post-stroke emergence of caregiver/survivor roles akin to that of parent and child, disturbances in marital equity, decreases in couple communication, and diminished intimacy (Backstrom, Asplund, & Sundin, 2010; Banks & Pearson, 2004; Buschenfeld, Morris, & Lockwood, 2009; Quinn et al., 2014b; Thompson & Ryan, 2009). Although most stroke survivors in these studies experienced some recovery or adaptation, marriages did not recover or were rendered invisible. Two studies of couples undertaken a decade apart illustrate this point. Quinn, Murray, and Malone (2014b) and Banks & Pearson (2004) both characterized relationships as separate careers with spouses focused on caregiving and stroke survivors focused on impairments. While knowledge of the negative impacts of stroke on relationships is useful, gaps remain in our understanding of the variation potential in relationships and the ways in which couples can maintain, adjust, or adapt their relationships in the face of impairments and the need for care.

A small number of studies that measured relationship quality found post-stroke marital stability. Godwin et al. (2013) and Ostwald, Godwin, & Cron (2009) found that relationship satisfaction of a caregiving spouse declined longitudinally, but overall both stroke survivors' and spouses' means remained high. Others highlighted a variation in marital satisfaction post-stroke. Two European studies reported that both partners were satisfied or highly satisfied in about two thirds of couples, with less than 10% dissatisfied and the remainder discordant (Achten, Visser-Meily, Post, & Schepers, 2012; Carlsson, Forsberg-Warleby, Moller, & Blomstrand, 2007). Forsberg-Warleby and colleagues (2004) added a longitudinal dimension to the examination of relationship satisfaction by studying satisfaction trajectories one year post-stroke. About half (52%) of spouses perceived that their relationships remained as satisfying at one year as they had been pre-stroke. Satisfaction increased for 21% and decreased for 27% over that time (Forsberg-Warleby, Moller, & Blomstrand, 2004). Significantly higher proportions of stroke survivors compared to spouses were satisfied with their relationships, leading the authors to speculate that stroke survivors were considering support from their spouse whereas some spouses had difficulty separating caregiving roles from spousal roles (Achten et al., 2012; Carlsson et al., 2007).

Evidence from chronic conditions other than stroke. Couple-based research in chronic conditions other than stroke has also been theorized around the assumption that transitions such as the impairment and the need for care will increase marital stress. A second assumption also is apparent—that the way couples interact will influence the trajectory of the marital relationship and of the illness. Researchers have found that marital relationships can be preserved, restructured, and even improved while couples manage chronic conditions such as cancer and heart disease (Berg & Upchurch, 2007; Manne & Badr, 2008; Rohrbaugh & Shoham, 2012). Studies consistently demonstrate that higher quality marriages and/or positive dyadic coping significantly improve outcomes like symptom control and premature death rates (King & Reis, 2012; Rottmann et al., 2015), and can increase relationship satisfaction (Berg & Upchurch, 2007). Less is known about the specific elements of marital quality that contribute to illness management (Robles et al., 2014) or how couples rearrange their relationships in the face of illness and the need for care (Agard, Egerod, Tonnesen, & Lomborg, 2015).

Recent work in Parkinson disease, cancer, heart disease, and with older adults discharged from intensive care adds to our understanding of how couples rearrange domestic relationships in the presence of disability (Agard et al., 2015; Buck et al., 2015; Martin, 2016; Miller &

Caughlin, 2013). Agard (2015) portrayed the process of leaving the caregiving role and resuming the marriage as being primarily under the healthy spouse's control. In a study of healthy spouses' perspectives only, they found that the ill spouse's re-engagement in marriage depended on the extent to which the spouse assisted and coached their ill partner. In contrast, Martin (2016) examined couples' perspectives of their relationship after the diagnosis of Parkinson disease. She found the potential for both the person with Parkinson's and his or her spouse to undermine or support each other's role performance. It was difficult for the ill spouse to refuse the individual illness role without the spouse's support. Also, it was difficult for a spouse to refuse the caregiving role when the Parkinson survivor regarded him/herself as a patient. Further, relationship closeness influenced whether spousal support of a Parkinson survivor was perceived as being helpful or paternalistic.

In their developmental contextual relationship model, Berg and Upchurch (2007) hypothesized that over time, chronic illnesses influence relationship development and that, in turn, relationships influence the course of the illness. Stroke researchers have investigated spousal caregiving and survivor care receiving, but scant attention has been paid to joint perspectives or how marriages develop in the context of caregiving and survivors' impairments and dependence (McCarthy et al., 2011; Green & King, 2010). The current study seeks to address this gap.

Methods

Given the lack of research on how couples construct their marriages after stroke, we used a constructivist qualitative approach (Charmaz, 2006) for this study. Transitions from life course theory and roles from symbolic interaction theory served as sensitizing concepts (Charmaz, 2006; Charon, 2010; Alwin, 2012). Both life course and symbolic interaction theory are concerned with understanding why people do things and with the meanings that they give to their actions (Charon, 2010; Turner, 2011). Life course theory examines how people's lives are shaped over time (Elder, 1985; Alwin, 2012), while symbolic interaction is valuable for understanding how husbands and wives shape each other's roles (Charon, 2010; Turner, 2011).

The concept of transitions is central to life course theory and to this research study. Originally, transitions were conceptualized as "changes in state that are more or less abrupt" (Elder, 1985, p. 31-32), although, more recently Alwin (2012) has argued that adjustments to transitions occur over time. Both types of changes occur after a stroke transition. Survivors

experience an abrupt transition from being able-bodied to being impaired (Taule & Råheim, 2014, Dowswell et al., 2000); however, the ways in which disability and marriage are understood likely evolve with time. Older stroke survivors often have other chronic illnesses, but still find that even mild physical and cognitive impairments from stroke profoundly change how they perceive themselves and how they are able take part in society (Adamit et al., 2015, Pallesen, 2014).

Symbolic interactionism provides a conceptual understanding of how husbands and wives construct their marriages. Meaning and roles are posited as fluid and negotiated in social interactions within marriage. Agreement on mutual meaning of husbands' and wives' roles depends on negotiation. Partners are assumed to adjust and accommodate their role behaviours and the meanings they ascribe to them as individuals and as a couple (Charon, 2010; Turner, 2011). In turn, symbolic interactionists assume that conflict may arise when role expectations and behaviour are not congruent (Charon, 2010). Within the stroke literature, the survivor's and the spouse's role changes are well documented, but there has been little exploration of the co-construction of marriage. For that reason, we sought couples' perspectives on how they reorganized their roles after stroke.

Data Collection

We used Charmaz's (2006) approach to grounded theory, which evolved from symbolic interactionism, to inform participant recruitment, data collection, and data analysis. The constructivist approach fits with the symbolic interaction theory assumption that the co-creation of meaning arises through interaction. The goal is to understand the 'why' questions of social life, as well as the complexities of 'what is' constructed and how. Our constructivist assumption was that we, as researchers, collected data to "discern and document" an interpretivist understanding of how stroke survivors and their spouses constructed their roles and marriages (Charmaz, 2006, p. 403).

Recruitment. Recruitment and data collection commenced once the study was approved by the University of Alberta's Health Research Ethics committee. Posters, flyers, and an exemplar recruitment email or newsletter story were then provided to health and community venues frequented by survivors. Those who expressed interest in the study were asked to contact the researcher. The first author phoned all those who made contact, provided them with information about the study, and screened them for eligibility. Inclusion criteria were: a

physician's diagnosis of stroke, discharge of the stroke survivor from hospital to home six months or more prior to the study, consent of both partners in the couple to participate in interviews, and being married or in a committed relationship for five or more years pre-stroke. The final criterion allowed us to investigate the experiences of couples in established relationships.

We used theoretical sampling, looking for cases that would explicate the developing categories (Charmaz, 2006). We continually updated the recruitment material to seek couples who could expand emerging codes on relationship development after stroke. For example, after interviewing several couples who felt secure in their relationships, we searched for couples who had separated or who had turned a conflictual post-stroke relationship around.

Interviews. A semi-structured interview guide was designed based on the literature review and the theoretical framework. Aligned with life course theory—that the past will influence the future—and to establish rapport with participants and sensitize them to relationship development as the focus, our initial questions were selected from a couples' oral history interview (Buehlman, Gottman, & Katz, 1992). We included questions about what attracted them to each other: *“Tell me how the two of you met and got together?”* and *“Of all the people in the world, what led you to decide that this was the person you wanted to marry?”* We asked how they worked together: *“As you look back, what are some of the good things that happened in your marriage?”* and *“Any tough transitions that stand out? How did you get through that?”* The second set of questions focused on their current situation. We queried their roles: *“Tell me about the hats you wear now or the jobs you juggle?”* and how they organized their days: *“Could you describe a usual day?”* We also asked about specific moments: *“What about fun times?”* and *“What do you do to get through those inevitable problems?”*

Finally, participants were asked about their roles and relationship when the stroke survivors' arrived home: *“What kind of hats did you wear then?”*; *“What events stand out now?”*; *“How did you figure out what to do?”*; and *“How did this affect your relationship?”* The goal of asking about post-stroke experiences last was to avoid a direct pre- and post-stroke relationship comparison. At the end of the interview, survivors and spouses were asked to complete separate demographic forms that included questions about age, education, number and types of chronic conditions, length of marriage, and time elapsed since the stroke.

All interviews were conducted by the first author from October, 2014, to March, 2015. Interviews ranged from 45 minutes to two hours. Couples were offered a choice of venues. All but one couple and a spouse chose to be interviewed in their own homes. Alternate venues were public settings. Participants were not compensated for their participation. Before data collection commenced, participants were informed in writing and verbally about the aim of the study, voluntary participation, and the maintenance of confidentiality. In individual interviews, participants were assured that the interviewer would not disclose any information from the interview to their spouse, and would not use any information from the interview to inform the interview with their spouse. Husbands and wives completed separate written consent forms. All participants gave oral consent to be digitally recorded.

To ensure that couples in all types of relationships were comfortable talking about their partner and their marriage, we offered couples individual or joint interviews. Couple interviews provide a joint relational account and are therefore an appropriate approach to a study of marriage that requires both partners' perspectives (Eisikovits & Koren, 2010; Mellor, Slaymaker, & Cleland, 2013). There are advantages and disadvantages to separate and joint interviews. Dyadic interviews can jog memories as well as offer opportunities for partners to expand on, modify, and/or validate each other's accounts. The content of the dialogue and the couples' interactions are both data in joint interviews.

Individual interviews offer participants a chance to speak frankly about sensitive issues in their relationships that might not be disclosed in a joint interview (Eisikovits & Koren, 2010; Mellor et al., 2013). Our participants seemed to speak freely about their relationships in both joint and individual interviews. Individuals in dyadic interviews often completed each other's sentences and expanded on their partners' examples. In the individual interviews, the rendition of events and the interactions in the marriage were described similarly by survivors and spouses.

Participants were also asked if they could be contacted for follow-up interviews to clarify the findings. All participants, except one spouse, consented to further interviews. Field notes were completed immediately after each interview. The interviews were transcribed by the first author. All identifying information was removed, participants were assigned pseudonyms, then field notes and interviews were imported into the NVivo 10 qualitative data management software program (QSR International) for ease of data management.

Data Analysis

Data were analyzed using grounded theory constant comparison methods (Charmaz 2006). All analyses were inductive, as the research aimed to conceptualize/describe the patterns in the appropriate contexts (circumstances, situations), and to record interactions (actions, responses) and consequences (outcomes), rather than to test an explicit hypothesis (Charmaz, 2006). The data analysis began with reading each interview as a whole to gain an overall perspective of the relationship contexts. Analysis then proceeded in three steps. First, we looked at survivors' and spouses' actions and interactions and asked: Why is this behaviour present? What does each partner expect of the other partner? What was the participant thinking as he/she responded? Within actions, we looked for "identifying moments," that is, moments when a participant regarded his/her self or the partner differently (Charmaz, 1991). We began by assigning primary codes to participants' actions.

Second, we began axial coding to synthesize similar primary codes into conceptual categories. As we compared our primary codes from the first two interviews, we observed that two themes emerged: marriages were submerged by stroke survivors' need for care, then the couples' attempts to return to marriage. Following Glaser and Strauss (1967), we used sensitizing concepts to "give an initial direction in developing relevant categories and properties" (p. 79), but also kept in mind Charmaz's (2006) caution to use sensitizing concepts tentatively, discarding those not reflected in the data.

Third, the developing insights from the axial codes related to caregiving/care receiving or marital contexts were collated and synthesized into subthemes. To confirm final themes and subthemes, we used constant comparison techniques with a case-by-case analysis. We began by considering the disparate cases—couples who claimed they were comfortable with the relationship and couples who specified they were struggling. Finally, we compared the codes identified in our secondary case-by-case analysis with the initial theoretical codes to ensure that no new themes had emerged (saturation) (Charmaz, 2006).

Participants

Participants included 18 heterosexual couples, 15 who remained together and three who had separated two (couple 7), three (couple 15), and six (couple 16) years after the stroke. Couples were recruited through community stroke groups, secondary stroke prevention clinics, and rehabilitation clinics. Stroke survivors were 45 to 91 (mean 62.6) years of age and spouses

were 35 to 91 (mean 62.3) years of age. Seven stroke survivors were female and 11 were male. All stroke survivors had returned home to their partner. Married couples (n = 16) had been together for an average of 36.5 (range 11–72) years and those in common-law relationships (n = 2) had been together for an average of 22.5 (19–25) years before the stroke. Those in common-law relationships considered they were married and referred to themselves as husbands/wives. The median time from the stroke to the first interview was 4.3 years (range 6 months to 26 years).

Survivors were discharged home with a range of physical, cognitive, and communicative impairments. Four survivors had little visible physical impairment. They were discharged after a few days in acute care. Fourteen had moderate to severe impairments, including four who had been in a coma (one week to three months). The 14 stroke survivors with moderate to severe impairments had arrived home with mobility aids (wheelchairs, n = 7; walkers or canes, n = 5), and/or with instructions that they needed to be monitored “24/7” because of impaired cognitive functioning (n = 4). All survivors, even those with mild stroke who had separated from their partners, said they could not have functioned at home without their spouses for some time (range 1 month to 5 years). Both survivors and spouses thought the survivors had made a significant recovery after hospital discharge.

Four of the survivors’ spouses had no chronic conditions. Six spouses had one chronic condition (e.g., benign enlargement of the prostate, Crohn disease, arthritis). The other eight spouses had three to seven conditions, all of which included two or more risk factors for cardiovascular disease or stroke (e.g., hypertension, diabetes, atrial fibrillation, heart attack, high cholesterol). Four spouses specified that arthritis or heart condition limited the amount of physical support they could provide to the survivor.

Findings

The analysis of the interview transcripts revealed two themes related to post-stroke marriage development processes. Theme 1, *working out care*, involved discovering and then addressing disruptions in previously taken-for-granted activities. Theme 2, *rethinking marriage*, involved turning their gaze back on marriage and determining the meaning of their relationship in light of the new context of care and disability. The two themes were found to be interconnected. Marriage was seen as underpinning the caregiving relationship, while caregiving in turn required new perspectives on marriage.

Theme 1: Working out care

Both members of each couple described the stroke survivor's homecoming as comforting, yet unnerving. Coming home was a milestone toward resuming life after stroke. However, once home, stroke survivors and spouses found themselves in uncharted territory, with new roles related to the survivor's need for care (disabled person/care receiver, caregiver), but with little knowledge of what those roles entailed. "working out care" involved learning the territory of stroke impairment and finding the right balance in terms of the amount and kinds of care and assistance that were needed or useful to the stroke survivor, as well as how best to deliver that help. A spouse characterized the uncertainty that both partners felt regarding all these elements: *"We were like actors being thrust into the middle of an action movie without a director, script, or acting experience"* (Spouse, Couple 12).

Learning the territory of stroke impairment. For both survivors and spouses, learning about stroke impairments involved noticing and coming to understand the impairments in their lives. Mild stroke survivors and their spouses had been told that the survivor was lucky and could likely expect a full recovery. Yet they were often confronted with invisible impairments as they re-engaged in activities. Gaps in knowledge and memory lapses interfered with ordinary activities such as making a meal or buying coffee: *"I said 'Go and make a sandwich.' When I came downstairs. He had a piece of bread in his hand and that's as far as he got"* (Spouse, Couple 11). Attempts to return to usual roles at home or work resulted in a difficult confrontation with impairments that survivors and spouses had been unaware of.

I had significant cognitive damage which went undiagnosed. I was cleared to return to work as a special education teaching assistant. Work was an epic fail! I couldn't even do some of the puzzles my pre-school students were doing (Survivor, Couple 18).

It was difficult for survivors and spouses to know when they could trust that the survivor was or was not able to perform an activity. Uncertainty, fear, and frustration brought emotions close to the surface: *"I couldn't remember if I took my medication or not, I was just bawling, emptying out the bottle, and counting the medication"* (Survivor, Couple 5).

Survivors of moderate or severe strokes and their spouses also had to learn about impairments in their home contexts. In some ways, they were better prepared than those with

mild stroke who had been quickly discharged home. Survivors of moderate or severe strokes had been diagnosed, they had received rehabilitation, and they had been told that they could expect some, but not complete, recovery. Spouses of survivors of moderate or severe strokes had been warned that the survivor might be untrustworthy at decision making, unable to find his/her way home, and/or incapable of expressing emotions appropriately. Unlike survivors of mild stroke who were surprised by impairments, survivors of moderate to severe stroke expected impairments. The difficulty came in knowing what to do:

Survivor: You know we just grazed the surface of what stroke really was until it happened to us.

Spouse: Like her grandpa talked funny, but I didn't know it was aphasia. We didn't know it inside out like we know it six years later. (Survivor and Spouse, Couple 1)

Spouses had challenges that were different from those of the stroke survivors. The spouse of the stroke survivor had to determine what kinds of support the survivor needed. While spouses of stroke survivors received some assistance in providing care and training to provide care, there were huge gaps in these provisions. Task training (such as the transfer of an individual to or from a wheelchair) was helpful, but there was little guidance on how to get the stroke survivor doing activities: “*Like it was easy to let him sit on the couch and watch TV, but how do you teach him to move or to read?*” (Spouse, Couple 12) and “*She's very driven before... but that deal is over*” (Spouse, Couple 7).

Survivors' emotional reactions were particularly difficult for spouses to manage: “After he called me at work on his smartphone, he was screaming at me because he couldn't figure out how to make a call on this smartphone” (Spouse, Couple 17). Spouses were unsure whether to be sympathetic, to explain why the response was inappropriate, or to ignore the problem.

That was a pretty stressful period ... you know very inflexible thinking was hard to deal with ... her doctor told her to take B12 every day. She was dead set against this, and we fought about that ...[pause] ... but I never gave up.
(Spouse, Couple 6)

Finding an agreeable balance. As survivors and spouses learned the territory of stroke impairment, they had to find a balance between giving and receiving assistance that was agreeable to both partners. This was not easy. There was tension between spouses' views of their care roles and survivors' views of their independence. Couples had to think about risk, the survivor's capabilities, and the locus of responsibility for activities. Survivors were not sure what activities they could manage.

I was worried to be on my own, independent and alone in the house while she worked. She worried about me falling. I promised I wouldn't get out of the wheelchair until she came home. (Survivor, Couple 15)

Spouses struggled as well. Responsibility for making decisions about what the survivor could or should do weighed heavily on the spouse: "So you take somebody who I consider could do everything better than I could. How do you start telling them what to do?" (Spouse, Couple 11). Most spouses referred to feeling like a parent or custodian rather than a partner:

We would go for daily walks around the neighbourhood, and she would ask me "when can I go alone?" and I would say "well, pretty soon" ... I was thinking like Christ, what if something happens, but on the other hand she wants to do this ... I worried a little bit, but she came back and she was happy. (Spouse Couple 6)

Spouses differed in their approaches to finding a balance between giving and receiving assistance. One approach was to assist the stroke survivor to increase his/her capacity through helping, encouraging, and challenging.

I just try to figure out the limits of what he could do ... like he loved doing puzzles. So we got kids' puzzles and we put one over there and I said, "Now we're going to leave this here until you can do it." So he kept telling me, "I can't do this." And I just said, "Yeah you can." So that's how we worked. (Spouse, Couple 11)

A second spousal approach was to do most activities *for* survivors. Many of these spouses worried that the survivor would hurt him/her self or were cautious about others' safety.

Other spouses said doing things for the survivor became habitual *“I just did everything for him all day. I helped him put on his shoes. Well, he couldn’t put on socks”* (Spouse, Couple 16). A few spouses found it was easier for them to do activities for survivors than to watch them struggle: *“Basically I wind up doing a lot even though she could do it because it’s just painful to watch”* (Spouse, Couple 2).

Regardless of the approach, tensions rose when there was disagreement on roles. Some spouses were frustrated by the stroke survivor’s apparent unwillingness to do more for him/her self: *“He did stuff with the therapist, but the minute he walked in the front door, that’s where it ended. He knew I wouldn’t let him go out with his shirt unbuttoned”* (Spouse, Couple 16). All survivors disliked being dependent, but a few resented how their spouses provided support:

Spouse: So ... that was really hard because he didn't want to do it, and I was screaming at him to do whatever he needed to do, and he was saying “no, leave me alone.”

Survivor: I believe that a stroke survivor should not force himself to try and do things which they know are not good for them. (Couple 8)

Survivors often felt guilty about their spouses having to take over responsibility for their tasks and activities: *“I feel like I wrecked where he meant to go ... [pause] ... what he meant to do”* (Survivor, Couple 2). One survivor even admitted that she transferred her resentment of post-stroke dependence to her husband:

Oh there were lots of fights. I’d be crying my eyes out on the couch, watching him in the kitchen, doing all that he could and knowing he was not having an easy time with it. But, like sometimes that I hated him so bad cause he could just get up and leave, I didn’t have that choice. (Survivor, Couple 1)

Regardless of the tensions inherent in working out care, participants emphasized that marriage underpinned the caregiving relationship. All survivors credited their spouses’ care for the recovery and quality of the life they had achieved.

After my stroke it took me like five years to get back to where the lights were on and someone was home because my brain was so scrambled. So, she got me

back on track ... basically did whatever she had to do to keep our heads above water, you know, financially and medically, and everything else, too. (Survivor, Couple 16)

Willingness to give and receive help was seen as part of their commitment to the marriage. Survivors and spouses had higher expectations of support from a spouse and also thought their spouse's help and advice was more influential than that given by family or friends.

Spouse: Caring for a husband or wife is very different, than if it is a friend because this is your soul mate, you would do anything for your soul mate.

Survivor: Yeah, a husband or wife is different because they have a much more profound influence on the stroke victim. Like when she makes a suggestion to me, I'm more apt to do it because she is my wife. (Couple 10)

The interconnection between care and marriage was also evident in how the intensive process of working out care consumed much of survivors' and spouses' energy. During that time, marriage was not a main preoccupation. Looking back, both survivors and spouses described marriage as being in the background: "*in my mind I guess the relationship was there but it was somewhat submerged*" (Survivor, Couple 11) or "*the relationship dipped down with worry and care*" (Spouse, Couple 4). Marriage provided the impetus to care: "*It's that for better or for worse, richer or poorer, sickness and health. I believed in those words, you know, and that's what you do when you care about somebody*" (Spouse, Couple 16).

Theme 2: Rethinking marriage

Eventually, an awareness of marriage began to re-emerge. These were important times for couples who were confronted with the need to rethink their marriage in the light of their new situation. For some, turning their gaze back onto marriage was gratifying. Old relationships were reconfirmed or changed relationships were acknowledged and accepted. We identified three stable relationship patterns: (i) the relationship was reconfirmed around the pre-stroke marriage; (ii) the relationship was recalibrated around care; and (iii) the relationship became parallel, a his and her marriage. Three couples divorced.

Reconfirmed marriages. Some relationships were characterized by reaching new understandings of the husband and wife roles and on the re-establishment of emotional connections.

Survivor: I can't say that we haven't had bad patches, sometimes she's unreasonable, but usually she's okay. But I think we've really been in love since we met and that hasn't changed much.

Spouse: It just was tested for a while and [we] sort of had to find a new balance, but yeah, we started with a really strong base. (Couple 11)

Shared history and a willingness to work together helped couples come to these understandings. Narratives of friendship and teamwork were hallmarks within these couples' conversations.

Spouse: The doctor said to take that book home, he would never read. He talked to him like he was a child. I didn't! We read that book together. We are the kind of couple that sticks up for each other. We work together, especially when the going is tough.

Survivor: Yeah, that's it in a nut shell. We are a team. It's attitude towards life. Accept what life throws at us. (Couple 12)

Frankness about the impact of changes resulting from stroke and willingness to compromise helped couples learn about each other and how to live together in new ways.

Spouse: What she was saying didn't always make sense. The group in rehab would laugh. She thought she was being funny, but I decided to tell her what was wrong.

Survivor: Yeah, he was able to tell me, explicitly where I was on the ball and not on the ball, basically. I was ... totally devoted to his opinion. (Couple 6)

Working out mutually agreeable marital roles could be difficult. Several couples spoke about conflict over different perspectives.

I don't know if I verbalized divorce, but I was ready to give it up. He just wouldn't do anything. I called the ambulance and he spent two weeks in the psych ward. The psychiatrist also asked to see me. That was the turning point in our relationship. We had to re-learn how to relate to each other. (Spouse, Couple 17)

Regardless of differences, respect for each other's position was evident in these couples' interactions in the interviews and also their descriptions: "We don't always agree, but we listen

to what each other says” (Survivor, Couple 5). The route to consensus was often a circuitous process in which survivors and spouses had to adapt pre-stroke relationship rules or develop new standards that fit the new context of the survivors’ impairments. Participants used terms such as learning or realizing to describe the process of coming to agreement on post-stroke roles.

Survivor: What she saw as an encouragement, I saw as interference. My argument was if I don't try it I'll never know what my limits are, it's the only way I'll learn.

Spouse: And my argument was you're going to get hurt.

Survivor: But ultimately, I think we both realize that each of us has valid point, and we've both learnt to live with each other's warts again. (Couple 8)

Belief in the importance of reciprocity and mutuality in the relationships was an important driver of recreating marriage. Both survivors and spouses wanted to feel that their partners loved or liked them and that they were contributing emotionally to their partners.

The underlying reason you're willing to persevere, and to work through situations that present problems is that you love the person, but you do really want them to show the same for you. That's when it's a marriage again.

(Spouse, Couple 18)

We've always been husband and wife, but our sexual life changed after stroke.

Completely! But if there's closeness it doesn't matter. There's so much closeness and just love. (Spouse, Couple 4)

To summarize, the processes associated with these reconfirmed marriage patterns were working together, being able to resolve conflicts, and each partner feeling that he or she mattered to the other partner.

Re-calibrated marriages. Some couples re-calibrated their relationships around care. They referred to loving or respecting each other and considered themselves husbands and wives, but care had changed the dynamics of the relationship. Couples stated they continued to love

each other, but also referred to the changes in the stroke survivor and the spouse's main role as caregiver.

It's just really hard things to deal with not ... to destroy the love in the marriage unless you let it happen. Well it's different now, I am a caregiver. It doesn't mean it's [the marriage] no good anymore. (Spouse, Couple 1)

Spouses raised the extra work and responsibility associated with the stroke survivor's dependence:

I know he's my husband, I know I love him but you're right in the thick of having to care too. You're always thinking about what needs to be done. Before you didn't even have to think, he would do everything himself, right? (Spouse, Couple 10)

Survivors and spouses referred to commitment as a defining feature of their relationships: "You've made a commitment to each other when you got married 'In sickness and in health, 'til death do you part'" (Survivor, Couple 10) and "Yes, I made a commitment to keep the family together" (Survivor, Couple 14). Loyalty to the survivor and/or to the marriage vows was the initial impetus to bring the stroke survivor home and to work at regenerating the meaning of the relationship.

Survivor: Oh baby, love her.

Spouse: Couples have to realize how much commitment you have to each other, and you either have to be the kind of person where you cry and feel sorry for yourself or you just get on with it. (Couple 3)

Caregiving spouses and survivors agreed that spouses held the balance of power in the relationship. "I would say that I do the majority of everything, now. In our business [he] did a lot more. Things have changed" (Spouse, Couple 3). Spouses compensated for the survivors' impairments while acknowledging the survivors' preserved abilities and what they did in the relationship. Survivors agreed with their spouses about their situation and credited their spouses' efforts to make them autonomous and independent.

Survivor: Since my aneurysm there has been a change in the way we make decisions in that I lean more on her to help me and guide me in my decision making. Before, I was fairly controlling in many ways.

Spouse: I also will also say that I have tried to help him be independent; John does the finances like he used to, but with other things John had the tendency to say, 'Could you help me?' And I am tough, 'You do it', but I've have to be tough and I was never was before like that, never. (Couple 10)

Both survivors and spouses emphasized that they enjoyed their lives and continued to enjoy a range of activities in which the survivors could successfully engage. Some couples emphasized what they did as a couple: *"She and I still do everything together. She just needs help to get into the boat now"* (Spouse, Couple 1). Others focused on joint activities with their family: *"He likes looking after the grandkids. Go right to him. I watch"* (Survivor, Couple 14). Couples, however, stressed that re-defining their roles and relationships had been difficult at times but that they had negotiated relationships that incorporated care and impairments:

But we have now come to a place where we're satisfied with each day and what I can do in that day, and I'm not feeling inadequate or that I'm not contributing to my marriage or society. I'm feeling that I have a place and I'm very focused on trying to be a good husband and father and grandfather. (Survivor, Couple 10)

The critical processes in marriages recalibrated around care were being committed to a partner or marriage, reaching agreement on changed roles, and finding activities they both enjoyed.

Parallel or separated. Some couples were unable to reconnect. Three couples lived parallel lives as survivor and partner (his and her marriages) and three couples separated. While they were able to work out care, differences in expectations around emotional involvement and roles ignited friction in the relationship. Initially, disagreements about what survivors should do or could do safely often triggered arguments and hurt feelings. Some disconnected spouses thought the survivors weren't trying hard enough: *"I've potentially walked into a situation where my wife can't or won't do 50% of what she was doing"* (Spouse, Couple 7), and *"He is just lazy. He can do things, but he doesn't"* (Spouse, Couple 16). Others responded ambivalently about the

survivor's efforts: *"Yes, he should exercise, but he doesn't. He wants to chop the wood instead and I think he will hurt himself"* (Spouse, Couple 9).

Survivors thought their spouses' ambivalence diminished their efforts: "After I painted this room, all he said was 'I thought you were going to tape the rest of the house'" (Survivor, Couple 7), and "She would just jump in and put it together. She didn't give me a chance" (Survivor, Couple 16). Several survivors indicated that their spouses only saw their impairments and therefore could no longer see them as partners in a marriage.

When I started to become a man again she really started to pull away. Being me, I was like an instructor again. But I was still the guy who could drown in his own spit. You're damned if you try and dammed if you stay in your chair, you're still broken baggage. (Survivor, Couple, 15)

Other survivors claimed their spouses regarded themselves as caregivers, and they no longer saw themselves as spouses: *"He thinks care, not husband"* (Survivor, Couple 2). Perceptions that their partners regarded them differently than how they saw themselves sensitized survivors to spouses' responses to them: *"You are not really a husband because you're a guy who ends up paying bills twice, you know, always needing to be watched"* (Survivor, Couple 9).

Spouses agreed that their expectations were mismatched with those of the stroke survivors, but gave different reasons for the discrepancies than the survivors. Loss of common interests was a main concern: *"The main thing we did together was sports, and now she can't do that. There's nothing left"* (Spouse, Couple 7). Time spent together was less enjoyable: *"And he became really dependent upon me, which I think was very difficult. We don't like doing the same things"* (Spouse, Couple 9). Spouses in parallel marriages or who divorced claimed the survivor continued to be focused on his/her own needs: *"It was all about him. He would say, 'My days are hard. I need to go to bed at nine.' Oliver didn't consider me"* (Spouse, Couple 15).

Some couples had different perspectives of their partners' emotional needs. A spouse complained about the survivor not caring about her emotionally: *"... when he'd come to bed he just crept in the bed and that was it. No roll over, put his arms around me, comfort me, cuddle me"* (Spouse, Couple 16). The survivor agreed, but said he didn't have the energy and she didn't understand that he was too tired to do both.

With my ex and I, she wanted so much mental and emotional intimacy before she was willing to do the physical intimacy, and I just didn't have the energy or stamina to give her everything she needed in order to get what I needed or wanted. (Survivor, Couple 16)

A stroke survivor who separated six months after the interview thought the lack of emotional connection would likely end the relationship: *"I just got back from a week with him. He was more interested in his work friends than me. I felt like, I was an inconvenience"* (Survivor, Couple 7). Couples avoided discussing anything that might trigger emotions because such conversations would usually underscore the differences. *"I don't think we talk as much as we should ... Neither of us like confrontation"* (Survivor, Couple 9). Ambivalence went unresolved: *"We don't talk. We don't work it out. He just does things that I can do"* (Survivor, Couple 2). Whether couples remained together (n = 3) or separated (n = 3), there were few physical or emotional connections between partners:

We're very individual. I do my thing, she does her thing, you know, her hiking and biking, and we sleep in separate bedrooms. It's not my first choice. No, like she's going to take a trip and I get the impression that she doesn't want me to come with her. (Survivor, Couple 9)

She says she lost me, but I lost her as well. I was desperate for her loving arms. Desperate for her touch, I didn't mean sexually either. I got used to that stopping. I mean just feeling loved. After a while, she never held my hand, never touched me. Now we have split I am recovering better. Happy being me. Don't have to feel a failure. Don't have worry about not pleasing her.
(Survivor, Couple 15)

In summary, the patterns associated with disconnected marriages were difficulty resolving divergent expectations, being unable to reach agreement on reciprocal roles, and finally, the stroke survivors' feelings that their partners no longer loved or liked them.

Discussion

This study demonstrates that the transition to stroke precipitates dramatic changes to marriage. At the outset, the multitude of care and illness tasks put care into the forefront. Yet in

the early days of finding their way, marriage underpinned couples' care work and commitment. Subsequently, as they attempted to bring marriage back into focus, it was care that required attention as they considered its salience in relation to marriage. Some reconfirmed marriage as the pre-eminent role, while others recalibrated marriage to incorporate care. A third group were unable to reconnect. They disagreed on expectations, were unable to resolve ambivalence about their marriages, and lived with emotional distance in parallel his and her marriages.

The Role of the Marriage Relationship in Caregiving. The committed relationship, married or common-law, between stroke survivors and spouses was important in working out care. Spouses took on caregiving responsibilities because they were committed to the survivor or to the marriage as a long term commitment. All survivors, even those who had separated, credited their spouses for their current wellbeing. Both spouses and survivors, however, found that the new caregiving and care receiving roles presented a steep learning curve. They responded differently: they took a collaborative approach, with spouses doing activities with survivors who helped as they could; they allowed the spouse to assume all responsibilities; or they worked through a volatile period of disagreements about conflicting expectations, but trusted that their partners had their best interests at heart.

Marriage influenced participants' perceptions of their caregiving and receiving interactions. Spouses cared because of their marriage or love for their partner. Several spouses explained that they would do much more for their husband or wife than for more distant family or friends. Survivors trusted their spouses' feedback.

Our findings point to a key gap how we intervene in post-stroke relationships. While stroke caregiving reviews often recommend augmentation of spouses' caregiving skills or the provision of respite care to reduce spouses' burden of care and the impact of stroke survivors' characteristics (e.g., impairments, behaviour, depression) on spouses' wellbeing (Bakas et al., 2014; Quinn et al., 2014a), our findings highlight that we need to consider how relationship dynamics and relationship quality influence the wellbeing of both partners. This relationship dynamic has been clearly recognized in studies related to other chronic conditions (Pretter, Raveis, Carrero, & Maurer, 2014; Robles et al., 2014; Traa, De Vries, Bodenmann, & Den Oudsten, 2015). The quality of the relationship may influence not only a stroke survivor's recovery and a spouse's burden of care, it can influence the mortality and quality of life of both partners, as has been demonstrated in other chronic conditions (King & Reis, 2012; see also

reviews Badr & Krebs 2013; Falconier et al., 2015; Martire, Schulz, Helgeson, Small, & Saghafi, 2010; Park & Schumacher, 2014; Robles et al., 2014).

The Effects of Care on the Marriage Relationship. As the stroke survivors began to recover and adapt, they wanted to return to as many of their pre-stroke roles as possible. Spouses were faced with decisions about how to use their considerable power as caregivers. Difficulty coming to agreement on relational roles and power issues were at the root of couples' distress, a finding that stands in contrast with that of previous studies. For instance, Rochette and colleagues (2007) hypothesized that at six months post-stroke, a slowing recovery accounted for survivors' perceptions of taking back control and spouses' perceptions that they were losing control. Similar to research in other chronic conditions (Agard et al., 2015; Berg & Upchurch, 2007; Manne & Badr, 2008), our work suggests that in addition to illness and caregiving, changes in the relationship itself are stressful. Couples faced the uncertainty of two transitions, the first to caregiving/care receiving, then a second to the recalibration of the meaning of the relationship. It would be useful in future research to differentiate between the stress of care tasks and the stress related to changes in the structure and functioning of the marital relationship.

Stroke has been theorized and researched mainly as an illness transition. Changing the theoretical focus from illness to marriage in this research rendered the marital transitions and couples' relationship work visible. Our findings revealed that in addition to rehabilitation and respite care, the marriage relationship may offer additional opportunities to improve stroke survivors' and spouses' outcomes. Precisely the elements of marriages amenable to intervention were beyond the scope of this research, but couples suggested that communication and working together were critical elements in managing stroke and improving their relationships. Reviews of interventions with couples facing chronic illness find that interventions targeted to enhance couples' communication (expression of emotion, shared concerns, communication of needs) had the largest positive effects on health and relationships (Badr & Krebs, 2013; Martire et al., 2010; Shields, Finley, Chawala, & Meadors, 2012).

The benefits of working together. Our findings add to evidence that working together to address care in the face of impairment can help preserve or even enhance satisfaction with marriage [See, for example, a recent meta-analysis that indicates that dyadic coping is associated with relationship satisfaction in health and in illness (Falconier et al., 2015)]. There were no timelines for adjustment. However, coming to agreement on role changes and the pattern of their

couple identity distinguished couples who were able to recalibrate their relationships from those who disconnected. Similar to previous findings, smooth relationship functioning and marital satisfaction depended on husbands and wives being able to agree and co-create their relationships (Gottman & Notarius, 2002; Murray & Holmes, 2011).

Implications: The Importance of Relationships

In transitions to illness where caregiving is necessary, stress is often attributed to problems of spousal coping with care rather than to the relationship between caregivers and receivers. Survivors in this study believed that their spouses' care skills increased their physical and emotional recovery. Care receivers are generally seen as passive recipients of the caregivers' help rather than as contributing partners (Agard et al., 2015; Park & Schumacher, 2014). A novel finding is the extent to which stroke survivors and spouses perceived that survivors were active participants in recreating the marital relationship. Similar to other research on chronic conditions, marital closeness contributed to the wellbeing of stroke survivors and spouses, above and beyond the caregiving and care receiving (Mancini & Bonanno, 2006; Martin, 2016; Falconier et al., 2015; Robles et al., 2014; Traa et al., 2015).

These findings are also relevant to questions of what dimensions of satisfying marital relationships contribute to wellbeing after older adult's transition to chronic illness. We found that the way stroke survivors and spouses responded to their marital partners' caregiving/ care receiving and husband/wife role-making efforts was an important factor in how couples (re)create closeness or feel increasingly separate from their marital partners. The relationship dynamics by which older couples develop positive caregiver, survivor, spouse, and/or couple identities are worthy of further research. While it is premature to suggest that group stroke interventions should include relationship advice, the couples in our study who received marital counselling recommended that others should be offered this opportunity.

Next Steps in Research on Marriage and Stroke

The methodological approach we used in this research was taken advisedly as we were examining uncharted questions about marriage and chronic illness. We now have a foundation upon which to build our understanding of the diverse ways in which couples recreate their marriages after stroke. We now have insights into distinctions between marriage and care and a sense of the considerable efforts made by couples to move forward with their lives. Other approaches are needed to move forward our understanding of what contributes to trajectories of

marriage after stroke. These include taking into account demographic factors such as age and sex, contextual factors such as family support and social networks, and the quality of pre-stroke relationships.

Intersectionality may offer a research framework by which to examine marital role construction within the stressful context of illness and disability. An intersectionality approach presumes that culture, and, in turn, relations, are shaped by the distribution of power, privilege, and position in society (Calasanti & King, 2015). The assumption is that diversity operates to subordinate some people and license others. Differences in social location, such as the privileges of marriage or gender and the stigma of age/disability, can overlap. Jeopardy cannot be captured by looking at each difference independently because the synergy between a couple alters experiences in more complex ways (Calasanti & King, 2015).

With our small sample size and constant comparison thematic analysis, it was not possible to take into account these intersectionalities. However, there were signs in the data that such things as gender and pre-stroke marital relationship might be better understood through an intersectional theoretical framework and a larger and more diverse sample. For example, there is evidence that women are less likely to be discharged home after stroke because they lack a caregiver at home; and there is evidence that female spouses are more likely than male spouses to bring disabled stroke survivors home (Mees et al., 2016; Smurawska, Alexandrov, Blandin, & Norris 1994). There were also hints in our research that relationship processes could be influenced by gender. Women were referred to as natural caregivers, or labelled “mothering,” by the individuals interviewed. Parallel findings from the caregiving literature indicate that women caregivers provide more instrumental help than men and that women caregivers experience more stress, more depressive symptoms, and lower well-being and physical health than male caregivers (Gaugler, 2010; Pinquart & Sörensen, 2006). Similarly, marital researchers find that stress in the relationship affects the mental and physical health of wives more than it affects husbands (Robles et al., 2014; Uchino et al., 2012).

Broader contexts of marriage also may be important in understanding marital processes after stroke. Neff and Karney (2016) argue that stressful environmental contexts such as poverty and lack of support are stronger contributors to marital conflict and marriage breakdown than interactions between individuals. There were some indications in our study that support external to the relationship might influence how couples reconstruct their marriages. Some couples

mentioned that their networks disappeared, leaving them to cope alone. Further, there were hints that younger couples' lack of resources (e.g., spouses had to return to employment) may have added to the stress. Research that specifically includes resources and stressors external to the marriage may help tease out any lifecourse differences between younger and older couples after stroke.

Finally, longitudinal research on marriage trajectories after stroke is warranted. Our study was cross-sectional and analyses were based on participants' reminiscences of their marriages. Given these constraints, we began to consider time by looking for "identifying moments" (Charmaz, 1991, p. 207), that is, moments when survivors become aware of themselves as partners. Notably, after the stroke event, it took some survivors much longer than others before they began to think about marriage. There may well be other turning points in marriage that have yet to be explored. It would be useful to follow couples longitudinally to explicate variations in trajectories over time and how relationships continue to develop.

In this study, stroke survivors and spouses credited the survivor's recovery to being married and able to return home to a spouse. Participants in this research recommended research on the impact of marriage on stroke recovery. Participants described the stroke survivors' recoveries as "remarkable." As reviews and meta-analyses, specifically of cancer and heart disease as well as those combining chronic conditions, demonstrate significant associations between marital quality and health (Badr & Krebs, 2013; Martire et al., 2010; Robles et al., 2014; Shields et al., 2010), future studies should examine whether marital quality impacts stroke recovery. There has been little causal research to determine "*how and for whom* marital quality impacts health" (Robles, 2014, p. 431, italics in original). Longitudinal research combining levels and types of post-stroke physical and cognitive impairments, marital satisfaction, and relational processes could provide important new knowledge about how marriage influences health as well as how illness contributes to marital quality.

Conclusion

Our findings illustrate a kind of dance between marriage and care after stroke. Some couples connected around their pre-stroke relationship pattern and others focused on a relationship that centered on care. They were in uncharted territory, as uncertain about how to relate to each other in the presence of chronic illness as they were about stroke management and caregiving. Neither stroke management and caregiving nor marriage can be understood in

isolation from relational dynamics. In research and in practice, the needs and wellbeing of married couples should be assessed in terms of the individuals and in terms of the couple. It is important to determine if the post-stroke stress is related to caregiving tasks or to the survivor/spouse relationship.

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**Chapter 4 Staying married after stroke: A constructivist grounded theory
qualitative study**

Abstract⁹

Background: Marriages are one of the most powerful predictors of health and longevity, yet research in stroke has focused separately on survivors' experience of impairments and how spouses confront caregiving.

Objectives: The purpose of this constructivist grounded theory study was to understand the key themes related to reconstruction or breakdown of marriages after stroke.

Methods: In semi-structured interviews, 18 couples in long-term marriages discussed how their marriages were reconstructed or broke down after one member of the couple returned home after being hospitalized for a stroke. Constant comparison methods were used to compare the experiences of 12 couples in which both partners indicated their relationship was going well with six couples who either separated or remained in parallel marriages.

Results: Analysis revealed an overarching process of reconstructing compatible role-identities and three themes related to the reconstruction or breakdown of the marital identity: feeling overwhelmed, resolving conflict, and perceiving value in the marriage.

Conclusions: Our findings highlight that marriages are contexts in which survivors and spouses can recalibrate their role-identities. Marriage relationships are not peripheral to survivors' and

⁹ This article has been resubmitted to *Topics in Stroke Rehabilitation* and is currently under review as "Anderson, S., & Keating, N. Staying Married after Stroke." I was responsible for manuscript conceptualization, drafting the manuscript, and responding to feedback from the coauthor. N. Keating contributed to and supported manuscript conceptualization, critically reviewed the manuscript draft, and provided substantive feedback.

spouses' outcomes after stroke; rather, marriage is fundamental to the management of impairments and to the wellbeing of the couple.

Introduction

Marriage has been shown to be a particularly important relationship throughout the life course. The positive qualities of the marriage relationship, such as affection, enjoyment of mutual activities, and the ability to share successes and problems (emotional support) with a confidante are key indicators of life satisfaction and personal wellbeing.^{1,2} In fact, people with strong ties to their spouses, families, and friends, and who enjoy time spent in these relationships experience the lowest depression³ and premature mortality rates;⁴ and, are the happiest.⁵

Marriage may also be what sustains couples.^{1,6} Growing evidence demonstrates that married couples navigate transitions such as retirement or chronic illness/disability more successfully than their unmarried counterparts.^{7,8} Couples with similar hopes and expectations collaborate on their goals and solve problems more efficiently.^{8,9} Joint problem-solving enhances the perception of support gained from the relationship and increases wellbeing and marital satisfaction.^{8,10}

Not surprisingly, marriage is one of the most powerful predictors of health and longevity (see reviews^{1,4,11}). Married men and women are less likely to have cancer progression (metastatic disease), are more likely to receive therapy, and are less likely to die prematurely than those who are single or divorced.¹² Studies in heart disease¹³⁻¹⁵ and a recent study in stroke¹⁶ have also linked survival to marriage. The risks of dying after stroke were significantly higher for those who were never married, who were remarried, who were divorced, or who were widowed than for those who had been continuously married.¹⁶ Higher marriage quality amplifies survival even more than marital status alone.¹ For example, 15 years after coronary artery bypass surgery, married men and women were 2.5 times more likely to be alive than their unmarried, widowed, or divorced counterparts.¹⁵ Those who were satisfied with their marriage were 3.2 times as likely to be alive.¹⁵

Illness creates stress in marriages, so much so that some authors suggest that illness is a predictor of marital satisfaction as well as of separation and divorce.¹⁷ Illness and treatments interfere with daily routines. Couples have to manage the hassles of medical care and changes in their marital and family roles.^{6,8} There is also evidence that the more stressful and impairing the condition, the greater the risk of divorce.^{17,18} Gender also plays a role. Rates of divorce are significantly higher for ill women than for ill men.^{17,19}

Worldwide, stroke is a common transition to disability for mid- and later-life couples.²⁰ In the United States, someone has a stroke every 40 seconds.²¹ Although the majority (85%) survive and over 80% of stroke survivors return to their pre-stroke residence, less than 15% of survivors recover completely.^{22, 23} Stroke survivors must cope with a wide range and many levels of physical, cognitive, and communicative impairments that necessitate support. For three quarters of stroke survivors, the person providing support and care is the spouse.²²⁻²⁴

Despite evidence that marriage can moderate the impact of chronic illness and disability, stroke research has focused separately on survivors' experience of impairments and spouses' experience of caregiving.^{25, 26} The limited research on marriages after stroke has investigated the impact of stroke impairments on marriage, rather than on how marriage impacts stroke, or how couples reconstruct their marriage after stroke.²⁵⁻²⁷ Stroke interventions usually focus on preparing spouses to provide care and support stroke survivors,^{24, 28} however, such interventions have not produced the impacts expected or hoped for by researchers.^{24, 28, 29} Stroke interventions increase survivors' and spouses' knowledge of stroke, but have little sustained impact on the caregiver burden of the spouse, or the quality of life of survivors and spouses.^{24, 28}

Stroke is a particularly difficult challenge to marital stability. Divorce rates of stroke survivors are significantly higher for working age (18–64 years of age) men and women with children than for the age-matched population.³⁰ Older age and longer-term marriage are protective factors for men who have a stroke, but divorce rates are higher for older women who have a stroke.¹⁷ Despite the higher divorce rates, the vast majority of stroke survivors remain married.^{17, 30} As marriages are dynamic and negotiated, it is important to gain an understanding of the processes that shape the long-term stability of older adults' marriages post-stroke.

This study considers couples' experiences of reconstruction or breakdown of their marriages after stroke. Without an understanding of the inter-partner dynamics that follow a stroke, health professionals and couples are forced to rely on anecdotal experiences of other professionals or couples. Knowledge of the elements that maintain or destabilize a marriage could inform the design of post-stroke interventions for couples.

Methods

The experiences of marriages that accommodate chronic neurological illnesses are complex and subjective; therefore we used constructivist grounded theory (CGT) methods to analyse them.^{31, 32} CGT is an approach to understand the social processes that guide peoples'

actions and interactions.^{31, 33} Rather than assuming that researchers begin the study without prior knowledge of the topic, researchers using CGT acknowledge extant theory and their prior knowledge as sensitizing concepts.^{31, 34} Theory and knowledge are starting points to be subjected to rigorous scrutiny in analysis of the data. The goal is an explanation of participant's accounts of the phenomenon. According to Charmaz, only a few grounded theory studies construct a theory.³² Most are an interpretive, analytic account of the processes and their properties.³³

We drew on transitions and linked lives from life course theory² as well as the looking-glass self from symbolic interaction theory³⁵ as sensitizing concepts to better understand marriage after stroke. Life course theorists view transitions such as stroke as turning points that may trigger changes in roles and status.^{2, 36} Individuals experiencing transitions can no longer count on their previously established roles and social positions. Those are thrown into doubt, have dissolved, or may even be reversed.^{36, 37} Research on marital transitions (e.g., to marriage, parenthood, retirement) suggests that the critical tasks are: defining husband and wife roles and the marital identity, working out the emotional dynamics, and negotiating the division of labour.^{37, 38} The key feature of these tasks is that they are communal.²

The primary assumption of linked lives and the reflected appraisals of a looking-glass self³⁵ is that husband and wife roles are products of social interaction. Husbands and wives assess whether they think their partner supports or rejects how they played his or her role. They use their judgements to make the necessary adjustments that will facilitate cooperation. Accordingly in transitions, individuals don't only think of themselves differently; the others with whom their lives are linked also have to see and think of them differently if they are to feel comfortable in their new roles.²

The criteria for participation in our study were: both members of the couple had to (i) agree to participate in the study, (ii) be able to be understood in the interviews, (iii) live at home rather than in long-term care or communal living, (iv) be at least six months post-stroke, and (v) be married or cohabitating for at least five years prior to stroke. Once approval from the University of Alberta's Human Research Ethics Board was secured, we proceeded to contact community stroke support organizations, secondary prevention stroke clinics, and outpatient rehabilitation centers to recruit post-stroke couples living in the community.

We used theoretical sampling³¹ to find participants who could expand on insights found in the initial interviews. When early data suggested that conflict and agreement were key

processes influencing stroke impacted marriages, we looked for couples who had conflicts but remained married, and couples who had separated or divorced. This enabled us to compare and contrast participants' chief concerns about their marriage and how they acted to resolve those concerns.^{31, 32}

Data Collection

A semi-structured interview guide consisted of primary questions formulated specifically to elicit views of marriage rather than of care or stroke-related disability and probes to encourage in-depth descriptions of how the couple experienced their relationship. The guide promoted consistency across interviews and gave the researchers flexibility to follow the direction suggested by participants' responses and probe more deeply to define the meaning participants ascribed to their activities. First, to develop rapport with participants and ensure they were focused on the marriage, we asked participants about their initial meeting and their wedding. Then we moved to questions about their current roles and relationship. After asking questions such as: "What has been important in making your marriage work?" or "What do you think made your marriage go off the rails?" we probed for the processes that caused such results: "Can you give me an example of the communication in your relationship?" or (in the case of a marriage working well) "Can you tell me about the strategies you used to accomplish that?" Finally, we turned to how the couple regarded marriage in the first weeks after the stroke survivor returned home after the stroke. We left the immediate post-stroke period until last to enable participants to reminisce about their progress and what elements of their relationship influenced change. The questions led to a revealing and detailed conversation on how participants' marriages evolved.

The interviews were conducted by the first author, a graduate student trained in responsive interviewing.³⁹ This is a conversational interview style. The goal in the interview is to establish a rapport that fosters a fulsome description of the phenomena. Couples given a choice, chose separate (n = 4 couples) or joint (n = 14) interviews and were asked about a preferred location for the interviews. All but three participants chose their homes. One couple was interviewed in a private office at a recreation centre and a spouse was interviewed in a quiet corner of a restaurant. Interviews were transcribed by the first author, pseudonyms were alphabetically assigned, and all identifying information was removed from the transcripts.

Data Analysis

As the goal of CGT is the development of data driven themes, data collection and analysis were undertaken concurrently.^{31, 33} All interviews were digitally recorded and transcribed verbatim by the first author. Identifying information was removed and pseudonyms were inserted. The interviews were imported into the qualitative data management program NVivo for ease of data management. Aligned with the principles of CGT, we assumed that the researcher constructed the codes through actively naming the meaning of “what is happening” data.^{31, 33} The findings were co-constructed with the research participants through the researcher’s attention to the meaning they ascribed to their narratives in the CGT constant comparison process.³¹

Constant comparison analysis proceeded in four steps.^{31, 33} First, each interview was read in its entirety to gain a holistic understanding of what the couple was saying about their marriage. Second, the first author began the initial coding^{31, 33} by assigning codes to participants’ actions and their rationale for their actions.³³ Chamaz’s⁴⁰ concept of “identifying moments,” the times when someone conferred a role-identity (e.g., caregiver) on the participant or the participant recognized a change in his or her role-identity was useful for identifying turning points in the relationship and the processes associated with them. Interviewee’s words were used in the initial codes. Themes emerging in earlier interviews were added to the interview guide in subsequent interviews so that participants could disconfirm, verify, and elaborate on the categories and the elements describing the categories. In the third stage, focused coding,^{31, 33} we systematically compared the initial codes to collate them into the most significant codes. Last, we compared and contrasted the way the themes interacted and contributed to marital development or breakdown. Analysis continued until no new themes emerged (saturation).^{31, 33}

Results

Participants

The final sample comprised 18 heterosexual couples from three Canadian provinces. Stroke survivors were 45 to 91 (mean 62.6) years of age and spouses were 35 to 91 (mean 62.3) years of age. Couples had known each other for 11 to 72 years before the stroke. Twelve couples indicated they were satisfied with their post-stroke relationships. Some of these couples reconnected with their pre-stroke roles and relationships (n = 7) while others recalibrated their marriages around caregiving/care receiving (n = 5). Three couples remained married despite

indications from one or both partners that they were dissatisfied with the relationship. By their own description, these survivors and spouses lived in a ‘his’ and ‘her’ parallel marriage, where there was little mutuality. Each partner focused on his or her activities; interconnecting only for family tasks, and rarely as a couple. Three couples separated (2, 3, and 6 years post-stroke). Marriage relationship development and the three types of marriage that evolved are described in an earlier paper.²⁷

Findings

Stroke survivors and spouses both spoke about the survivor’s dramatic loss of abilities in the transition to stroke. All couples, even those dealing with mild stroke, characterized their roles as care giving/care receiving: nurse/patient, parent/child, or caregiver/survivor. Couples made it clear that at homecoming the marriage was submerged by illness management; nevertheless, marriage underpinned the giving and receiving of care. Spouses also took on a mentoring role to assist stroke survivors to resume roles and activities. It was when stroke survivors attempted to resume their pre-stroke activities or try new activities that couples began to clash. This conflict signaled a new marital transition, in which participants began to determine who they were as partners and as a couple going forward. Comparing and contrasting the interviews of the 12 couples in which both partners indicated their relationship was going well with the six couples who either separated or remained in parallel marriages revealed an overarching process of *reconstructing compatible role-identities* and three intertwined themes related to the relational dynamics of marriage reconstruction or breakdown: *feeling overwhelmed*, *resolving conflict*, and *perceiving value in the marriage*.

Relational roles and the marital identity were reconstructed, or broke down, as survivors and spouses reacted to their perceptions of how their partners responded in each of their day-to-day interactions. Survivors and spouses interpreted their partners’ expectations, behaviors, and inevitable conflicts more negatively when they were feeling overwhelmed than when they thought they had greater control. Similarly, perceptions of whether their partner personally valued them or was withdrawing emotionally influenced how partners’ advice and actions were interpreted. In what follows we describe the characteristics of these processes, first from the perspectives of satisfied couples and then from the perspectives of couples who divorced or who remained married in parallel stroke survivor and spouse marriages. To highlight the differences in perspective, illustrative quotes from satisfied couples and from couples who divorced or

remained in parallel marriages are collated in Table 2. A model of the three themes related to the reconstruction or breakdown of the marital identity is displayed in Figure 1.

Feeling overwhelmed

Survivors and spouses all described being physically and mentally overwhelmed by the stroke survivor's need for care and support, by the uncertain prognosis, by the impairments, and by the process of rehabilitation. When stroke survivors and spouses had enough sleep they felt they had greater control of the situation; they also had more self-control and more patience. In situations where stroke survivors and spouses were overwhelmed, small incidents such as the survivor being unable to make a sandwich or a spouse burning the meal could trigger misunderstandings and frustration. Such incidents could be opportunities to support and mentor when couples were more relaxed.

Financial resources, external supports from health systems, and support from family or friends were mentioned by participants as resources that increased a couple's ability to manage their situation. Couples with greater wealth, savings, secure incomes, or insurance were able to purchase additional supports such as meal delivery, house cleaning, rehabilitation, counselling, and specialized assistive devices (e.g., WalkAide or a left foot gas pedal). First, these types of resources provided respite, giving couples more time to devote to activities of their choice, including much needed sleep. Second, rehabilitation improved stroke survivors' and spouses' mental health and stroke survivors' physical and cognitive functioning. Third, stroke survivors and spouses learned useful ways to deal with fatigue and frustration from working with professionals. Fourth, being retired reduced stress. Retired couples had more discretionary time than younger couples who needed to work for income.

A third of the couples reported being strained financially, having difficulty accessing rehabilitation and supports, and noted a decrease over time of the support of family and friends. The majority of couples reported moving from crisis to crisis. Just as they would get one problem solved, another hardship would crop up. Time had to be dedicated to care and home management tasks. Survivors were forced to spend more time alone. Spouses, who became the sole source of family support, often left survivors alone while they worked. There were few opportunities to interact with rehabilitation or counselling professionals together, so survivors and spouses relied on their own resources. There was little time to work on relationship maintenance. Financial troubles, stress, and fatigue thwarted attempts to keep contact with others

in their social networks. In addition, when couples were stressed and fatigued, misunderstandings, frustration, and conflicts escalated.

Resolving conflict

All couples spoke about disagreements, with some mentioning significant conflicts that almost came to blows or in which the survivor or spouse stormed out of the situation. At first, conflict revolved around rehabilitation and how much rehabilitation the spouse expected the survivor to pursue versus how much rehabilitation the survivor wanted to undertake. Then, as stroke survivors tried to re-establish their roles, couples quarrelled about what each partner thought the survivor was capable of and the degree of safety such a pursuit would entail for the stroke survivor and for others. Following the narrative threads of how conflicts started and were resolved revealed that these disagreements were veiled negotiations about who the stroke survivor and the spouse were becoming as individuals and as a couple. However, it was how couples described resolving the conflict that differentiated couples who divorced or remained in parallel marriages from couples who were satisfied with the marital relationship.

The couples who were satisfied with their relationships talked about the importance of learning to discuss problems so that they could find mutually acceptable solutions. Conflicts were resolved in ways such that stroke survivors and spouses felt the partner had considered and understood their position. Two elements were common in couples' examples of dealing with problems: partner awareness and problem attribution. The partner awareness category represented a mindfulness of a partner's self-esteem and role-identity. The stroke survivor and the spouse were each sensitive to the partner's position even when they did not agree with that position. In her field notes, the first author noted that partners in some couples subtly supported each other in ways that positioned them as capable. The spouse in couple 6, for example, would carefully rephrase interview questions so that the stroke survivor's comprehension problem (mild aphasia) was not obvious. Similarly, the survivor in couple 12 helped his partner to remember important bits of the story while ensuring that she got to tell the punchline. In their narratives about problems, the happier couples attributed problems to the stroke or to factors external to the situation or the marriage, rather than to individual failings of a partner, such as laziness or bossiness.

In contrast, in couples who separated or remained in parallel marriages, some individuals described feeling that their partners didn't listen to them, and some felt that their partners

personally attacked their character for problems over which they had no control. There were many instances of problems going unresolved because one or both partners felt the need to comply to keep the peace. It was difficult for these stroke survivors to feel positive about the development of their post-stroke role-identities when their partners were critical of their efforts. Spouses also acknowledged that their sense of self was undermined when the stroke survivors failed to recognize their efforts. One spouse noted that she felt like a “nobody” because the stroke survivor did not appreciate her, either as his wife or as a caregiver.

Perceiving value in the marriage

All participants referred to the importance of good communication. When they were asked for examples of how communication worked in their relationships, the term “mattering” cropped up frequently, a term they related to a perception of whether their partner valued them individually and/or as marital partner. Before the stroke, a partner’s behaviors such as: scrupulous about being on time, paying attention and listening, showing concern for the other partner’s wellbeing, increased the recipient’s perception that he or she was valued. After the stroke, both survivors and spouses were trying to determine if their partner still cared for, or valued, them as an individual and as a partner.

Stroke survivors and spouses all remarked that stroke impairments challenged the role-identity of the survivor and changed the personal characteristics of the survivor. Stroke survivors said they had wondered if their spouses would take them home, and then they wondered if their spouses would like them now that they were disabled. Just over half of the stroke survivors referred to feelings of being “a burden” to their spouses and in the marital relationships. Spouses also wanted stroke survivors to recognize their values as caregivers and spouses.

Stroke survivors and spouses who said they were doing well were able to maintain or regain feelings that they were important to their partners and still had a valued place in the marriage. As they talked about the difficulties of the stroke, they often talked about how their partners had assisted them or what they had done together. Even in situations where their partners had been critical of their efforts, they tended to explain the behavior critiques as being for their own good, as ways to help them build and refine their role-identities.

In contrast, stroke survivors and spouses who divorced or remained in parallel marriages described a specific turning point at which they realized their partners no longer felt the same way about them or about the marriage. When survivors or spouses were worried about whether

they mattered in the marriage, they described being more watchful of their behavior and their partners' responses. Some tried to behave in ways that they thought would please their spouses. Others chose to keep to themselves or avoid certain topics to circumvent conflict. Stroke survivors or spouses who were worried about their relationships had a tendency to interpret interactions with their partners more negatively than those who were more secure about their partners' commitment to the marriage. Their preferred role-identities were different, spouse and caregiver/ receiver rather than reciprocal spousal or care role-identities.

Discussion

The results of this study highlight the joint-construction of survivors' and spouses' individual and marital role-identities. The stroke experience changed how participants regarded themselves and understood their relationship with their partners. In their daily interactions, partners had to renegotiate who they were as individuals and as a couple. Feeling overwhelmed, being able to resolve conflicts, and perceiving that their partner valued them were the themes associated with reconstructing compatible role-identities as friends, husbands, and wives, or exclusively as caregivers and care receivers.

Losses of identity and role(s) are the most common themes in the stroke literature.⁴¹⁻⁴³ Survivors' impairments and dependency also necessitate changes in the spouse's role identities^{44, 45} The key assumption in the stroke and caregiving literature is that survivors and spouses respond to these challenges by rebuilding meaningful role identities.^{44, 46} The reconstruction process, however, is portrayed as an individual rather than as a relational process. The couples in our study were trying to work out reciprocal roles in their daily interactions. Dyadic coping,⁶ life course linked lives,² and marital relationship^{7, 47} researchers all have theorized that both spouses are affected by one partner's illness. The strong associations between collaborative approaches and higher quality illness management and satisfying marriages in the extensive literature based on this theorizing has led to couple interventions designed to improve couples' coping skills and their marriages (see reviews^{48, 49}), but there is a gap in evidence regarding how partners negotiate collaborative coping within the relationship.^{1, 6} Our research compared the experiences of couples who were happy with their relationship development with those who divorced or lived in parallel his and her relationships after stroke. The results are a step toward understanding the dyadic relationship processes in the context of coping with stroke impairments and the survivor's need for care.

In this study, couples' construction of compatible roles after stroke was shaped within broad environmental contexts. Couples who were satisfied with the evolution of their marriage had access to more resources that enabled them to navigate the challenges in their marriage more successfully. Neff and Karney⁵⁰ argue that poverty and stressful environments put couples in the untenable position of having to overcome greater challenges to their marriage with fewer resources for relationship maintenance. They contend that stressful contexts (e.g., from poverty, working multiple jobs) increase fatigue and tax the cognitive resources needed to manage marriage's inevitable conflicts. Rather than providing low resourced couples with relationship skills training, they recommend increasing external resources that will enable them to use the relationship skills they already possess.

As married stroke survivors are discharged from the hospital earlier than unmarried stroke survivors, it is likely they received less rehabilitation.⁵¹⁻⁵⁴ Thus a spouse in a caregiving role will be taxed more heavily than other caregivers. Understandably, the couples who could access expensive resources such as meal delivery, house cleaning, rehabilitation, counselling, and specialized assistive devices fared better in their marital relationships because they relieved some of the role overload.

Often the assumption is that stroke impacted couples who are dealing with marriage breakdown were dissatisfied with their marriage before the illness or are dealing with greater impairment. However, in our study, two of the three couples who divorced after the stroke said they were very happy before the stroke, and one couple who called the previous marriage "stale," credited the stroke for the present satisfying marriage. It is notable that the majority of these couples were dealing with moderate to severe stroke impairments, and their marriages recovered. Compared to other caregivers, spousal caregivers experience significantly higher rates of depression and stress because spousal caregivers usually undertake the more onerous care duties and because the roles of spouse and caregiver tend to conflict.^{44, 55} Neff and Karney⁵⁰ hypothesize that resources enable couples to utilize the relationship resources they already possess. Caregiving research demonstrates that small increases in resources enable families to provide more care and longer care.^{56, 57} The role that resources play in stroke impacted marriages should be explored in future stroke research.

Our work suggests that the couples in long term marriages had skills that enabled them to resolve conflicts. At the stroke survivor's homecoming, stroke impairments caused conflict

between the stroke survivor and the spouse. Conflicts changed as the survivors began to try to resume his or her domestic roles, prompting attempts to work out compatible relational and marital role-identities. Essentially, they were trying to answer the questions: who am I as a partner? and who are we as a couple? Similar to marital transitions such as the transition to parenthood or retirement the stroke transition can trigger conflicts over identities, roles, and responsibilities.^{2, 11}

We found that stroke survivors questioned their place in the marital relationship. Some revealed that they felt like they were a burden to their spouse. One couple even related the stroke survivor's depression to thoughts that his wife would be in a better position if he had died. Authors of an early study conducted in Norway suggested that the spouse's reception of the stroke survivor's impairment foretold the stroke survivor's sense of coherence more than the level of impairment per se.⁵⁸ More recently, a study of post-stroke sexual relationships found that some spouses were "turned off" by the thought of intimacy with a disabled partner.⁵⁹ However, some relationship researchers would argue that perhaps all positive relationships⁶⁰ are based on the perception that your partner likes you and wants to be with you.⁶¹

Survivors and spouses participating in this research interpreted a partner's communication as guidance when they thought their partner personally valued them, whereas those who thought their partner was disengaging tended to become wary—they were inclined to withdraw to avoid conflict, and have a tendency to interpret their partner's communication negatively. While significant evidence demonstrates that wellbeing is associated with higher marital quality, the factors within the marriage that influence wellbeing have yet to be delineated.^{1, 6} Our study of stroke, in which there is significant physical, cognitive, and communicative disorder suggests that the perceived value to a partner and in the marriage influences how couples negotiate the marital context. Studies of support-seeking have consistently demonstrated that a spouse is the most valued source of help in a crisis.⁶² Problematic interactions (e.g., critical comments, overprotection, conflict), however, have greater impacts on psychosocial outcomes than supportive behaviors.^{62, 63} Marriage is threatened when a partner is disengaging.⁶ It is also difficult to develop a positive marital role-identity without some support for that identity by the marital partner.^{2, 7, 64}

Limitations

There are several limitations to this study. All couples were Caucasian and all were recruited in Canada. Canada has a universal health system, so the experiences of couples in countries that do not have universal health care might be different. However, a universal health system does not mean that rehabilitation and support are available after hospital discharge,^{23,64} and for the couples in our research there were few health system resources available for survivors once they had arrived home. Therefore, this study would be expected to have some relevance to stroke survivors in other countries.

External contextual factors—for instance, having children at home or obtaining support from others—likely to have an impact on the marital relationship, but did not appear as themes in this study. Our sample was recruited theoretically based on the topics that emerged in the interviews. Couples focused on how they constructed their relationship after stroke, rather than how others helped them to cope with stroke.

Implications

The ability of the couples in our study to adapt to changes in their relationship after stroke, and the fact that the majority of couples remain married after stroke,^{17,30} have implications for how we study and intervene in long-term stroke impacted marriages. Post-stroke interventions for couples, and for caregivers, have focused on preparing spouses to support the stroke survivor.^{24,28} Our research suggests that health professionals need to assess both partners' needs individually and as a couple. Several of the spouses in these later life marriages were in need of care themselves. Half of the spouses had as many (or more) chronic conditions as the stroke survivor.

While plasticity and adaptation are recognized to be necessary after stroke, these traits can be overlooked when the stroke survivor is in a long-term marriage.^{65,66} In many cases, counselling is not offered to couples in long-term marriages on the assumption that they are set in their ways.⁶⁷ We found evidence in this study that post-stroke marriages are amenable to intervention. Notably, Robinson-Smith's⁶⁸ successful pilot intervention for couples included two of the factors considered in our study: helping couples resolve conflicts and finding ways to integrate body image changes into the relationship. Additional research on how marriages are reconstructed after stroke could reveal other elements of marriage that could be modified with education or professional support.

Conclusion

This study began to address the question of what processes relate to marriage stability or breakdown after stroke. Our findings highlight that the marital context is critical to recalibrating survivors' and spouses' role-identities. The couples who participated in this research worked hard to overcome the difficulties associated with stroke. Not all were able to do so, but the main implication for stroke clinicians, community professionals, and couples dealing with stroke is to view stroke management as a joint endeavour rather than as an individual project.

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Table 1 Demographics

Couple Number	Gender of survivor	Years together	Marital status	Number of children living at home	Days survivor spent in acute care	Days survivor spent in in-patient rehab	Survivor Number of Other Health Conditions	Spouse Number of Other health conditions
1	Female	28	Married	0	60	60	0	4
2	Female	28	Married	0	5	21	5	0
3	Male	26	Married	0	10	365	3	5
4	Male	72	Married	0	40	25	3	7
5			Common-					
	Female	26	law	0	14	0	1	1
6			Common-					
	Female	19	law	0	90	90	3	1
7	Female	15	Divorced	2	21	30	0	0
8	Male	52	Married	0	90	90	1	2
9	Male	51	Married	0	14	0	2	1
10	Male	54	Married	0	63	45	3	2
11	Male	30	Married	0	14	0	1	0
12	Male	64	Married	0	45	60	3	2
13	Male	32	Married	1	45	60	0	1
14	Female	35	Married	0	120	60	1	1
15	Male	11	Divorced	0	90	90	0	0
16	Male	11	Divorced	0	21	90	4	6
17	Male	33	Married	0	7	30	5	5
18	Female	34	Married	0	7	0	2	3

Table 2 Illustrative data of satisfied and dissatisfied participants by theme

Both partners satisfied with their marriage	One or both partners were dissatisfied with marriage or divorced
Findings	
<i>Care predominated but marriage underpinned decisions</i>	
<p>Male spouse: All of what I have described was just really hard things to deal with not... to destroy the love in the marriage unless you let it happen. It is what you commit to, and that love, should be rock solid, perfect. (Couple 1)</p>	<p>Female spouse: You know, it's a vow, a commitment. If you really loved them, well you know, you hope and pray that they're gonna get better. You don't' just walk out. (Couple 16)</p>
<i>Turning back to marriage</i>	
<p>Male Survivor: I kind of peg my recovery into a couple of phases. The first one was probably until about Christmas last year, basically I wasn't really here. And then the next two or three months you know, sort of the beginnings of... I started to learn. Then, I think our relationship changed, probably last April, when I started to think outside myself. When I think of it, I'm still thinking in terms of me more, but I'm getting there.(Couple 10)</p>	<p>Male Survivor: After my stroke it took me like five years to get back to being somebody because my brain was so scrambled because of the stroke. But then I told her, I need you to be my partner, however, she could not make the transition back to being a partner from a caregiver. (Couple 16)</p>
Theme 1: Feeling overwhelmed	
<i>Resources: Adequate or stretched</i>	
<p>Male Survivor: [Name] had a stroke like mine. The only difference was I had a good insurance policy which allowed me to get private therapy. It was a year before I got out</p>	<p>Male Spouse: One thing that makes our situation potentially different is having adequate resources. ...finances are a major problem for marriages (Couple 2).</p>

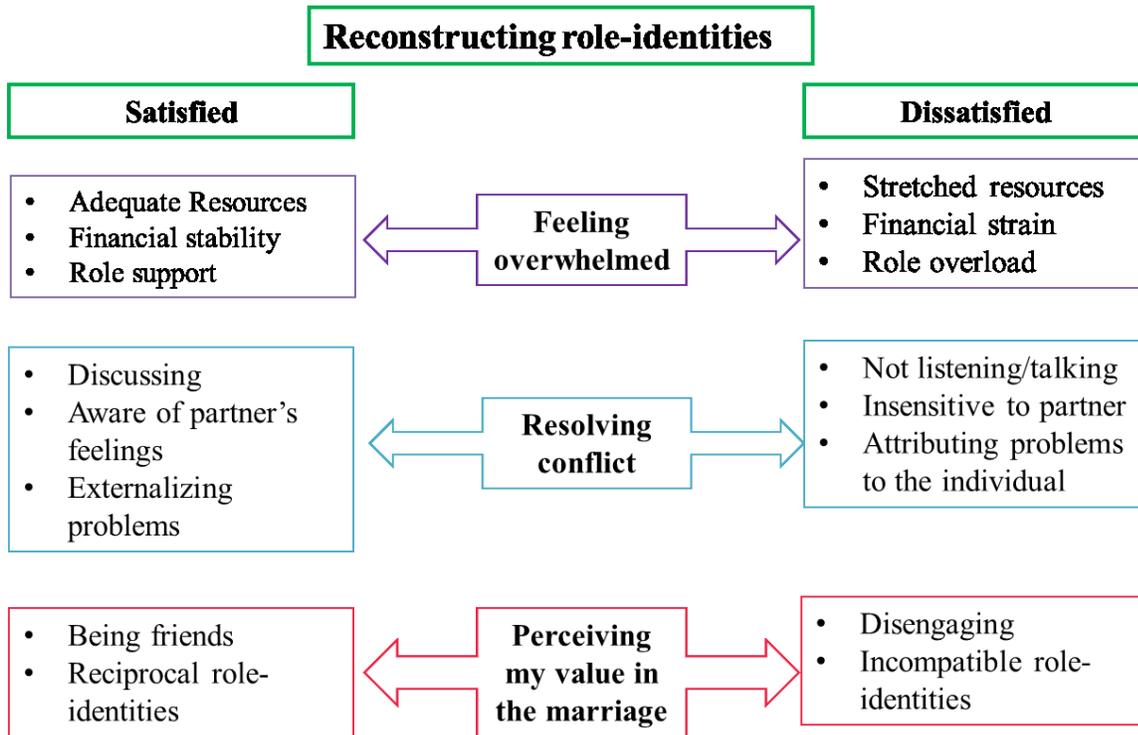
<p>of the wheelchair. She never got out of that wheelchair. (Couple 8)</p>	
<p><i>Affordable or a financial strain</i></p>	
<p>Male Spouse: We went together to see this counsellor.... Female Survivor: Kind of emergency counselling cause it was at a point I think you were pissed off about everything that had happened, was happening, and you were punching holes in walls. I left for a couple of days. Then we were on the phone talking and decided we still loved each other, and counselling, let's give that a shot ... so we had 4 or 5 appointments. (Couple 1)</p>	<p>Male Survivor: [spouse] found a physiotherapist that would take me. The therapy really made a difference. After 3 months, I was able to go to the gym. As time went on, I was pushing harder and harder with exercise. And I was mopping floors 6 months after I came home. But she had her life at work and I had mine at the gym. We just drifted I guess. (Couple 15)</p>
<p><i>Role support or role overload</i></p>	
<p>Male spouse: I learned from [Name of therapist]. She worked with [spouse] right here, so I heard how she repeated sentences in a different way so [spouse] could understand. Suddenly we weren't arguing. It's a small thing, but I wouldn't have known if I hadn't been able to watch her working. (Couple 6)</p>	<p>Female Spouse: When he had the stroke, I would get up at two o'clock in the morning, be at work at four, so I could leave at noon. I just have to get up in the morning, and survive. Marriage, I don't have time for marriage. I always have to think about paying the bills and worry about him being alone all day. (Couple 13)</p>
<p>Theme 2:Resolving conflict</p>	
<p><i>Discussing versus not listening or talking</i></p>	
<p>Female Survivor: We learned to talk about our problems. You know, he wasn't very good about telling me what he needed and we fought. Like painting, he didn't like to paint</p>	<p>Female Spouse: I don't know that he has ever really listened to me, likely he will tell you I am a tyrant because I have to tell him what to do. Male Survivor: We don't talk. Neither of us like</p>

<p>and did a sloppy job. I would get mad. So he learned to tell me more of what he wanted and I learned to ask more.</p> <p>Male spouse: So it was natural when she had the stroke, we talked about everything. It [the stroke] might have made the relationship better because now we know we care for each other. (Couple 5)</p>	<p>confrontation and I'm nervous that it would bring up some stuff that it will start to cover you know, start to cause confrontation. I think maybe [spouse] doesn't want to hurt me, you know that type of thing. (Couple 9)</p>
<p><i>Aware or insensitive to partner's feelings</i></p>	
<p>Female Spouse: You know when we talked about our marriage being stale before the stroke. I felt like only his opinion mattered. We did what he wanted. But once he was over the depression, it has been like when we were first married. What I want to do matters now, you know.</p> <p>Male survivor: She is that one person that was there... you know, at the hospital... so I want to do what she wants to do. (Couple 17)</p>	<p>Female Spouse: He didn't look at me and see how tired I am. He didn't ask me what I was going through. We would fight about stupid shit, you know, things that I did that he didn't think I should have done and I did because you know you do things for your kids and grandkids. And it was okay for him to do it, but it wasn't okay for me to do it. No one had the time to ask about me about my feelings or what I was going through. My self-worth, lost. I was a nobody, I didn't matter" (Couple 16).</p>
<p><i>Positioning a partner as capable or impaired</i></p>	
<p>Female Spouse: There's a very nice man in there, he really is. He's a funny person, but, and when he had a stroke, the doctor said, "You know people change. And he said he thought [spouse] could become very dower. Well, he's not. With [spouse] the cup is always half full. He's an optimist. (Couple 4)</p>	<p>Female Spouse: Wait till you talk to [spouse], he may not agree because he is really dependent. He's just like a three year old sometimes, and sometimes he's just like a teenager and he's not gonna grow out of it. (Couple 9)</p>

<i>Attributing problem as external or personal</i>	
Female Survivor: I tried to pay for coffee and the cashier said it was a dollar six. And I couldn't figure out numbers. ...When I told [spouse], he said, "[survivor], It's the stroke. You were trying to do too many things at once. Just worry about the bills; just give him two dollars, no time to make change. You trying to be there, and to be standing up and taking it all that visual stimulation, and think at the same time, it was too much for you" That was [spouse] that brought multi-tasking to my attention. He was the one that was mindful of it for me. (Couple 18)	Male survivor: When I had my stroke and it was five years after when I wasn't really ah, a productive member of society, she was the one that switched that roles and did all that stuff, and then when I started doing it again; I was putting something together and because of my stroke, my fuse wasn't as long as it used to be, so I would be short tempered. She would just come and treat me like I was stupid. I'm in a relationship right now with this woman and she likes me for, you know, who I am, my personality you know, not the before stroke person.(Couple 16)
Theme 3: Perceiving my value in the marriage	
<i>Feeling like they mattered to their partner or not</i>	
Female Spouse: I mattered to [spouse], we were concerned about what each other needed. Like because my first marriage, if I said anything to my ex-husband about being there for me or the kids it didn't matter to him, but it really mattered to Kalen, like if he was there, and he was there on time. (Couple 11).	Male Survivor: Well [spouse] has a hard time being on time. She knows that I know it, and I guess I pace around when we're going someplace. But I just like to be on time you know. That's just one example of what I want that doesn't mean as much to her. (Couple 9)
<i>Being friends or disengaging</i>	
Male survivor: You don't like you this way; you wonder if she will like you, you know, (singing) "Will you still need me? (Female Spouse joining in) "Will you still feed me, when I'm sixty-four" (Couple 12)	Male Survivor: Yeah, she loved me unconditionally. But that changed once I had the stroke. I wasn't working hard enough. No matter what I did it wasn't good enough" (Couple 15)

<p>Male Survivor: Well it is different now, like my emotions are kind of muted, but we are husband and wife. ... Well no, more... I think best friends.</p> <p>Female Spouse: Yeah that makes sense. We started with a really strong base because there really was love there so yeah... husband and wife, but I still worry more so that caregiver role never leaves, but definitely friends.</p> <p>(Couple 11)</p>	<p>Female Spouse: Whether it would be a stroke survivor or in a normal relationship, the relationship is not gonna work if you don't validate each other. He never once told me I was a good caregiver or a good person. I was a nobody. Communication died, the emotions died, the passion died, there isn't anything left there but a caregiver and a survivor. You know you might as well pay somebody to come in and do it. (Couple 16)</p>
<p><i>Reciprocal or incompatible roles</i></p>	
<p>Male Spouse: You think you are the same, but stroke changes you too. In our case it changed both of us in good ways. She is more empathetic</p> <p>Female Survivor: And I got him to worry less... not so much of a perfectionist. (Couple 5)</p>	<p>Female spouse: It's been 3 years and he still wants a caregiver. It time to be independent again. (Couple 9)</p> <p>Male Survivor Yeah I told her I didn't need a caregiver anymore I needed a wife. That's when she started to seal herself off from me (Couple 16)</p>

Figure 1: Evolution of Marriages after Stroke



Chapter 5 Summary and Conclusion

In this final chapter, I review the research contributions, the strengths and limitations of the findings, and the implications of the study. I conclude with a section on my dissemination of this research to date and the importance of understanding stroke within relational contexts.

Summary of Contributions to Knowledge

My literature review and empirical study focused on the marital context after one member of a couple has suffered a stroke. Here, I briefly describe the contributions of this dissertation to the understanding of marriage relationships after stroke in the contexts of care, marital processes, and marital role-identity development.

Marriage Relationships When One Partner Requires Care

In the couples recruited in the study, all had one member who had survived a stroke. All of the 18 couples recruited had been married at the time of the stroke, but three couples had separated after the stroke. My primary interest was marriage development. I began by asking the individuals to describe how they regarded their roles in the marriage and the marriage itself. What emerged was a complex and nuanced view of marriages in which marriage and caregiving were intertwined. Marriage underpinned caregiving and marriage development was informed by expectations and perceptions of stroke survivors' (while receiving) and their spouses (while giving) care. My study demonstrated that neither marriage nor caregiving can be understood in isolation from the other. When the stroke survivor came home from the hospital or the in-patient rehabilitation centre, all marriages revolved around caregiving. Stroke survivors received care because they were dependent on their partners and spouses gave care because they were committed to their partners. The spouse held the power both as a caregiver and as a decision maker and the relationship revolved around the new circumstances. Couples faced a second transition when the stroke survivor tried to resume his or her role in the marriage. Then, couples had to negotiate the meaning and functioning of the relationship going forward.

Working out their individual and marital relational roles was a significant source of tension for these couples. This challenges the notion that stroke impairments and caregiving tasks are the primary stressors after stroke (Gaugler, 2010; Satink et al., 2013; Taule & Råheim, 2014). Partner conflict that typically begins about six months after stroke has been explained as: skirmishes over a slowdown in recovery (Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007); unrealistic expectations of stroke survivors or spouses regarding the extent and

impact of impairments, and the potential for recovery from impairments (McCarthy et al., 2012; Rashid, Clarke, & Rogish, 2013); incompatibility in spousal and caregiving roles (Backstrom & Sundin, 2010; Giaquinto et al., 2003); or lack of knowledge about stroke and caregiving tasks (Cameron, Cheung, Streiner, Coyte, & Stewart, 2006; Cameron, Naglie, Warner, et al., 2014; Gaugler, 2010).

My relational approach offered a different lens to examine the marital challenges of stroke. Stroke exposes stroke survivors and spouses to the challenges of dependency and caregiving. As the extent of recovery is unknown, the marital relationship is strained by the prospect of living with stroke and caregiving. Rather than assuming post-stroke problems are rooted in lack of knowledge about stroke or caregiving tasks and management of impairments, a marital lens regards stroke survivors and spouses as part of a unit, as well as individuals with goals, needs, and contributions. This behoves stroke researchers and practitioners to adopt a couple-based approach in stroke and stroke caregiving research.

Marriage Processes after Stroke

The couples' lens, interviews with both stroke survivors and spouses, and my approach to interviews revealed some of the post-stroke relationship maintenance processes. Researchers who study the impact of marriage on wellbeing emphasize the importance of understanding relationship maintenance processes (Badr & Acitelli, 2017; Berg & Upchurch, 2007; Pietromonaco et al., 2013; Robles, 2014; Uchino, 2013). In my research I found that couples spoke directly about how the extra stress left them with fewer resources with which to manage the inevitable ups and downs in daily interactions. Typically, a stroke survivor's inappropriate behavior or anger is attributed to his or her cognitive and communication impairments, frustration with disabilities, or depression (Clark, Dunbar, Aycock, Courtney, & Wolf, 2006; Robinson & Spalletta, 2010) rather than to partner fatigue or stress that may have initially triggered the behavior. A partner's response to this behavior is equally important. Does the partner's response make the perpetrator of the behavior feel understood, validated, and cared for?

Neff and Karney (2016) attributed higher rates of conflict in marriage and marriage breakdown of couples living in poverty to stress and fatigue from lack of resources rather than to the couple's individual personalities or their inferior relationship skills. They suggested that low resourced couples are often overwhelmed by working one or more jobs, long commutes on public transportation, and living in unsafe neighborhoods. All these factors reduce the time

couples can spend together in pleasant relationship restoring activities. In addition, stress and fatigue decrease the cognitive resources that an individual normally possesses, leaving her or him more reactive to negative interactions. In this research, stroke survivors and spouses spoke about how behaviors such as the rolling of eyes in frustration could trigger a negative response from a partner. They testified that having to focus on caregiving tasks rather than a partner's emotions could trigger resentment from the partner. The strength of this research lies in the dual perspectives of partner activity in a marriage under stress.

I propose that some of the spousal role conflict identified in the stroke caregiving literature simply resulted from role overload. Spousal caregivers of stroke survivors experience more depression, stress, and burden than caregivers who are family or friends (Bakas et al., 2014; Cameron et al., 2013; Lutz & Young, 2010) for several reasons: (1) spouses provide more onerous care than nonspousal family and friends, and thus are subject to conflict between spousal and caregiver roles, (2) stroke survivors who are married are discharged from a hospital with less rehabilitation and more impairments than stroke survivors who are single or who are discharged to family caregivers (Appelros et al., 2014; Bates et al., 2013; Mees et al., 2016; Tanwir, Montgomery, Chari, & Nesathurai, 2014), and (3) educational interventions focus on training spouses to support and care for the stroke survivor but do not show spouses how to maintain their own wellbeing (Bakas et al., 2014; Cheng, Chair, & Chau, 2014; Lutz & Young, 2010).

The conflicts described by the couples participating in the research revolved around relational power: control of finances, activities that stroke survivors should or should not perform, the support desired and required, and the authority to make decisions. In a study of couples dealing with a wife's mild cognitive impairment from dementia, Pasymowski, Roberto, and Blieszner (2013) attributed similar conflicts to the ambiguity in marital roles and the relationship between husband and wife. Drawing on family systems theory, the authors pointed out that relationships are constantly being defined in daily interactions: "every communication represents an attempt to confirm, deny, or modify relational roles and rules" (Pasymowski et al., 2013, p. 230).

My study challenges the commonly held assumption that impairments and care tasks are the primary stressors after stroke. Recommendations that typically follow that notion comprise more rehabilitation, education about stroke, and task oriented caregiver training to improve the quality of life of stroke survivors and their spouses. My research highlights that couples who

were dealing with few functional impairments or who received clot-busters that can significantly reduce impairment had difficulties modifying their roles and relationships. Notably the role and relationship challenges of the couples dealing with mild stroke were similar to the couples who were dealing with moderate to severe functional limitations from stroke.

When survivors or spouses perceived that their partner valued them as an individual and a partner, they were more likely to interpret conflict and frank communication as positive incidents enacted for their own good or to make excuses for a partner's negative behavior. Indeed, making sense of impairments, giving and receiving care, and recalibrating who they were as individuals and as a married couple were relational activities, negotiated in every interaction. I propose that non-contingent acceptance from a partner contributes a feeling of security to the receiving partner, whether stroke survivor or spouse. Authors of a small study of ten stroke survivors and their spouses suggested that it was not the disability per se, but the spouse's reception of the impairment that had the strongest influence on the stroke survivor's sense of coherence (Nilsson, Axelsson, Gustafson, Lundman, & Norberg, 2001). In my study, spouses also valued stroke survivors' recognition of their contributions (care, mentoring, support).

Role-Identity Construction

I found that (re) constructing marital role-identities was a main theme, but also a joint effort. Stroke survivors influenced how spouses created their caregiver role-identities and spouses had a strong impact on the development of stroke survivor role-identities. Each partner gave feedback and responded to feedback from the other partner about role-behaviors. In fact, some survivors and spouses noted that they valued a spouse's feedback more than advice from a family member or friend because they trusted their long-term partner to provide a realistic assessment of their role playing. According to the stroke survivors and spouses who participated in this research, a partner's responsive feedback could help the other partner to align his or her role with the partner's expectations. My findings of joint role-identity construction expand the extant research—which currently focusses on stroke survivors and spouses as individuals—to stroke impacted couples who jointly consider their contributions to rehabilitation.

Common themes in the stroke and stroke caregiving literature are loss of individual identity and loss of marital role after stroke (Braun et al., 2009; Quinn et al., 2014; Satink et al., 2013; Taule & Råheim, 2014). Stroke impacted couples hope to return to post-stroke roles (Backstrom & Sundin, 2010; Edwards, Hahn, Baum, & Dromerick, 2006; Wood, Connelly, &

Maly, 2010). For the most part, role-identity re-construction has been theorized as the individual responsibility of the stroke survivor or the spouse (Ellis-Hill, Payne, & Ward, 2008; Lutz & Young, 2010; Satink et al., 2013; Walsh, Galvin, Loughnane, Macey, & Horgan, 2015).

Spouses and stroke survivors who participated in this study had some agency to reject or accept a partner's perception of the other's role in the stroke impacted marriage. Stroke survivors said that the stroke had made them much more dependent on others to support them in exerting their wishes. Research in dementia using the theoretical frameworks of personhood (Dewing, 2008; Harre, 1995) and responsive behaviors (Brémault-Phillips, Germani, Sacrey, Friesen, & Lee, 2015; Brémault-Phillips et al., 2016) demonstrates that it is difficult for older adults with limited resources to reframe the ways in which others perceive them. While the findings of this study expanded on the relational influences on role-identity construction, more work on how others (e.g., spouse, family, friends, health professionals) influence survivor and spousal post-stroke role-identities is warranted.

Strengths and Limitations

My aim in undertaking this dissertation was to understand what happens to marriages after stroke. The dissertation has both strengths and limitations that affect the extent to which I have added to the knowledge about marriages after stroke. Both strengths and limitations prompt a number of questions that should be explored with further research and could be useful in practice.

Participant interviews provided knowledge of how the couples characterized their post-stroke marriages. The impact of marriage on stroke survivors' recovery and survivors' and spouses' quality of life was identified as a gap in my systematic review. My findings show that a stroke survivor's perception that he or she is valued by his or her spouse plays a positive role in the stroke survivor's recovery.

The finding that "submerged" marriages re-emerge, even many years after stroke, is a contribution from this research. I was surprised to hear how much time was involved in marriage re-emergence. Some stroke survivors said that they couldn't think outside of their own situation for over a year, and one couple said it was five years. My research demonstrates a need to consider that relationships between stroke survivors and spouses as care receivers and caregivers, respectively, and as partners in a marriage, may evolve over many years from the time of the stroke.

Using cross-sectional interviews to study post-stroke marriage development was a limitation in the study. The themes are dependent on couples' memories of their post-stroke marriage and some couples were many years post-stroke. However, I used Buehlman, Gottman, and Katz's (1992) interview technique which was specifically designed to encourage couples to talk about relationship development. Couples' memories of their marriage may not be fully reflective of what unfolded, but the positive or negative tone of the narratives were associated with marital stability or breakdown, respectively. Participants identified the point when they thought their partner was disengaging from the marriage. Couples' positive or negative assessments of the way their marriage has been developing after the stroke seem to be reasonable predictions of how stroke impacted marriages evolve (Buehlman, Gottman, Katz, 1992; Bradbury & Karney, 2004).

Implications

There are implications for practice and policy in this research. The first implication related to a stroke impacted couple's relational dynamic is the language around marriage and care. Professionals should not assume that spouses are caregivers or that they want to be called caregivers. Results of one study showed that Australians who provide care to a relative object to the caregiving label being used on educational materials and by professionals (Olson, 2015). Some of my participants also objected to the caregiving label being applied to their husband and wife relationships. For example, one couple thought that referring to the caregiving spouse as a "caregiver" subtly reduced the meaning of the marriage and detracted from the positions of stroke survivor and spouse as equal partners in decision making. Professionals need to increase their sensitivity to labels such as "caregiver" and "stroke victim" as these labels position stroke survivors and their spouses relationally.

In my study, providing more onerous care increased fatigue and stress and made it difficult for stroke survivors and spouses to respond to each other as they might have if they were less fatigued and stressed. The extra stress may increase the fragility of the marriage in which the caregiving takes place. Policy makers acknowledge the important role that spouses play in enabling older adults with chronic illnesses and impairments such as stroke to remain at home (Romanow, 2002, for example), yet there is pressure to discharge stroke survivors from hospital quickly to reduce health system costs. Married stroke survivors seem to be discharged earlier and with greater impairments than those who live alone (Bates et al., 2013; Mees et al.,

2016; Tanwir et al., 2014). Care costs don't go away when care is provided at home, they are transferred to the caregiver (Fast, Williamson, & Keating, 1999; Keating, Fast, Lero, Lucas, & Eales, 2014). The costs to the marriage relationship and the spousal caregiver's wellbeing need to be factored into the costs of early discharge.

The needs of the stroke survivor, the spouse, and the couple should be assessed together from the outset of stroke treatment. Currently, health professionals are concerned with the patient's needs; the spouse's needs are not typically assessed at the same time (Bakas et al., 2014; Cameron et al., 2013; Lutz & Young, 2010). Research in New Zealand demonstrates that health professionals tend to exclude spouses when there is disagreement between patient and spouse (Levack, Dean, Siegert, & McPherson, 2011; Levack, Siegert, Dean, & McPherson, 2009). Yet, when a stroke survivor is discharged from the hospital, the spouse is unavoidably included in the couple's efforts to solve relational problems without professional support. The spouse may receive instruction on how to care for the stroke survivor, but typically the relationship between survivor and spouse is outside the purview of the health system (Bakas et al., 2014; Green & King, 2010; Levack et al., 2011). Health and community professionals working with stroke survivors and their spouses should consider models of practice that recognize the impact of relationships on wellbeing (Beach et al., 2006; Brémault-Phillips et al., 2015; Brémault-Phillips et al., 2016; Nundy & Oswald, 2014).

Knowledge Dissemination and Ongoing Research

One of my goals in investigating marriage and stroke is to build and mobilize knowledge that will improve conditions for couples who have been impacted by stroke. I have done several oral presentations of portions of this research project. The systematic review was presented as part of a seminar on family caregiving at the Canadian Association of Gerontology Conference 2014. Then *Reconciling Marriage and Care* was part of a symposium on older adults' relationships at the Canadian Association on Gerontology Conference 2015 in Calgary. My research was also one of the four abstracts selected from several hundred abstracts for a podium presentation at the Canadian Stroke Congress 2015 in Quebec City. As a result of the presentation, I was invited to be part of Accessible Media's television program about marriage in the face of a sudden and drastic change in partner abilities (<http://www.ami.ca/category/canada-perspective/media/sickness-and-health>). A synopsis of the systematic review and my research on *Staying married after stroke: A constructivist grounded theory qualitative study* (chapter 4) was

offered in Dr. Joohong Min's undergraduate and graduate level courses on aging in 2015 and 2016. The PEI Heart and Stroke Foundation also requested that I present a seminar about *Reconciling Marriage and Care* and the factors related to stable post-stroke marriages in June 2016 at their annual stroke research symposium. The presentation that preceded mine was given by a healthcare professional who described how her marriage slowly unravelled in the first year after her husband's stroke. While many of the professionals attending were shocked by the raw emotions in her revelations, the presentation reminded me of the knowledge I have gained and the progress that has been made to improve the quality of life of a stroke survivor after hospital discharge.

My husband John and I are approaching the 20th anniversary of his stroke (November 30, 2017). In that time, there has been significant progress in stroke treatment. The clot-dissolving emergency treatment (tPA) moved from the research bench to emergency rooms in January 1998, just a month after John's stroke. It changed stroke from a condition in which there was little the health system could do to a chronic condition with greatly improved rates of survival and discharge from hospital. The newer thrombus removal therapies reduce impairments even more than tPA, but do not eliminate impairments. I hypothesize that being discharged from a hospital to a home that provides a high quality marital context is an important therapy for a stroke survivor. Seemingly mild impairments in memory, speech, and cognition can have significant impacts on a person's quality of life, even more so if the impairment precludes resuming one's role in a marriage. Thus my research agenda will be to continue to explore the impact of marriage and other relational contexts in the lives of stroke survivors and their spouses.

Alberta is an ideal place to study the impact of marriage relationships on community integration after stroke. Alberta has the highest rate of stroke in Canada, accompanied by one of the most advanced provincial stroke treatment systems in Canada, factors that have led to one of the highest rates of hospital discharge in Canada. In the Alberta Community Health Survey which is completed yearly, researchers' questions can be added to the survey. I am currently investigating the health impacts of social isolation with the group responsible for this survey, and I hope there will be opportunities to include questions about the effects of marital relationships on health quality.

Conclusion

Marriage after stroke is an understudied area, even though the positive impacts of marriage on health are being investigated in other chronic conditions. My dissertation promotes an understanding of marriage after stroke from the perspectives of both survivor and spouse. While this project confirms the psychosocial challenges and relational issues that couples face after the transition to stroke, it extends the knowledge about how marriages are maintained or break down after stroke. Importantly, role-identities cannot be reconstructed by considering individual activity in the marriage. Stroke survivors and their spouses influence each other's role construction. As stroke significantly threatens stroke survivors' roles, other influences on their role construction is a rich area for future research. Relationship quality in a marriage after stroke is also an understudied area. As has been shown for other chronic conditions, the findings in my empirical study indicate that spousal relationships have a great impact on the wellbeing of stroke survivors and their spouses. This area of research is wide open to additional opportunities to build on this premise.

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Appendix A: Interview Guide

Questions informed by: Life course (LC), Symbolic interaction (SI)

Introduction to participants

Thank you for agreeing to participate in this study. You know from the consent form that I am interested in what happens to relationships after stroke and how survivors and spouses construct their roles and relationships after stroke. First, is it okay with you if I record this interview? I want to make sure I don't have to take notes or try to remember everything you said.

I will be using this interview for my dissertation so I will transcribe the interview. To ensure your privacy, I will remove anything that might identify you in the transcripts that I will work from. I hope that I can present what I find out at conferences and that some results will be published in a journal. Again, I will ensure that anything that might identify you will be removed in conference presentations and in journal articles.

As we go through the questions, you don't have to answer a question if you feel uncomfortable. Please tell me as much as you want about your situation. You are the expert(s) on your relationship.

Dyadic interview script

I would like to hear from each of you, so would you like me to alternate who I start with or do you want someone to start and the other person continue? Again, I want to remind you that you don't have to answer the questions if you don't want to and that we can stop at any time. If you get tired, we can stop and take a break or I can come back another day. If you remember something later on in the interview, just jump in and add it. I am interested in what you have to tell me.

I want to start with some questions about how you met and married, then talk about some of the transitions you have gone through together. People often learn things about their partner or the relationship that they use in transition like this one to stroke. For example you might have won the lottery, had to move a lot, or learned things from work or friends. Then I want to know about how you see your relationship now. We'll finish up with what advice you would offer other married couples.

Do you have any questions for me before we start?

Section 1: Relationship history

Why don't we start from the beginning.....

1. Tell me how the two of you met and got together. [Priming on purpose of study: Relationship]
2. Of all the people in the world, what led you to decide that this was the person you wanted to marry? [SI: Act on meaning symbol has for them; MIM: Role expectations/Reflections on roles, happy with person/relationship?]
3. A lot of the young people today think that marriages are going to be all fun and romance. What did you think that marriage would be or should be like when you got married? [SI, Role expectations/implicit beliefs]

Section 2: Life Transitions

4. Many of the couples we've talked to say they went through periods of ups and downs. What important life transitions stand out? (Getting a job? Having children? Moving? Aunt Lizzie coming to live with you?) [SI, LC, Past transitions influence the present e.g., transferable skills, advantages/disadvantages]
 - As you look back, what are some of the good things that happened in your marriage? (Alternate: happy times?) Can you tell me about ____? [SI Role behaviors]
 - Any tough transitions that stand out (difficult times)? How did you get through? [SI, Role behaviors]
5. What kinds of things would you say are important to making a marriage work? [SI Role expectations]

Section 3: Current Relationship

1. Can you tell me about your relationship now? [SI: Meaning of relationship, Role behaviors, Reflections on roles]
2. Can you describe the roles you (both) have now? (The hats you wear?) [SI: Roles, Role behaviors, Reflections on roles]
 - Could you describe a typical day? [SI: Roles, Role behaviors, Reflections on roles]
 - What helps you to manage? [SI: Roles, Role behaviors, Reflections on roles]
3. Sometimes people tell us that something that happened earlier in marriage influences how they handle things now. One person said that stroke was easy compared to losing a job. Another person mentioned humor. What about your experience? [LC, Relationship history]

Section 4: Relationships at time of stroke/on arrival home

Next I'd like to take you back to coming home right after the stroke.

4. Can you tell me about your relationship like when you first got home? [SI: role making; Role behaviors, Reflections on roles]
5. What kind of hats did you wear then? [SI: role making, Role behaviors, Reflections on roles]
 - Any events that stand out? How did you manage? (Figure out what to do?) How did this affect your relationship? [SI, role behaviors and reflections on role behaviors; agreement, disagreement, ambivalence]
6. How do you think being married influenced what's happened after the stroke? [SI, Reflections on roles, Role behaviors]
 - Can you tell me about some times when marriage was helpful?
 - What about things that have been challenging to your marriage? Can you tell me about the ways you managed ____?
7. Before this happened, had you had any experience with stroke? How did you expect you might deal with it? [SI, Role expectations]

Section 5: End of interview

We are coming to the end of the interview,

8. So if you were writing a handbook for couples after stroke, what advice would you give?
9. What else do you think we need to know about marriage after a stroke?

Often people think of things after the interview. If you think of anything, my phone number and email are here on the consent form. Please call me. We can talk over the phone or arrange to meet and talk.

Now, if we can complete the demographic form—when you were born, how many years you have been married.

Appendix B: Demographic Form Survivor

Couple ID Number _____

1. Date of Birth _____
2. Male _____ 2. Female _____
3. What is the highest certificate, diploma or degree you completed?
 1. Less than high school diploma or its equivalent
 2. High school diploma
 3. Trade certificate or diploma
 4. College, CEGEP or other non-university certificate or diploma (other than trades)
 5. University certificate or diploma below the bachelor's level
 6. Bachelor's degree (e.g. B.A., B.Sc., LL.B.)
 7. University certificate, diploma, degree above the bachelor's level
4. Are you currently employed?
 1. Yes
 2. No
 3. Retired
5. What kind of work do/did you perform?
6. How would you rate your health? (Visual analogue scale 1-5)
 1. Excellent
 2. Very good
 3. Good
 4. Fair
 5. Poor
7. Have you been diagnosed with other health conditions?
 1. Yes
 2. No

Other conditions _____

8. Were you hospitalized after your stroke?

- 1. Yes
- 2. No

If YES, please give details? (e.g., how long).....

9. Did you have any rehabilitation after your stroke?

- 1. Yes
- 2. No

If YES, please give details

Sometimes other things come up in interviews and it is good to check to see if you had the same experiences. Would you be interested in talking to me again after I have done some other interviews? Please check yes or no.

Yes_____ No_____

Appendix C: Demographic Form Spouse/Partner

Couple ID Number _____

1. Date of Birth _____
2. Male _____ 2. Female _____
3. Highest Level of Education Completed
 1. Master or Doctoral degree
 2. College or University degree
 3. Some College Training
 4. High School Diploma
 5. Partial High School (grade 10- 11)
 6. Less than junior high school
4. Are you currently employed?
 1. Yes
 2. No
 3. Retired
5. What kind of work do/did you perform?
6. How would you rate your health? (Visual analogue scale 1-5)
 1. Excellent
 2. Very good
 3. Good
 4. Fair
 5. Poor
7. Have you been diagnosed with other health conditions?
 1. Yes
 2. No

Other conditions _____

8. Marital Status
 1. Married
 2. Common-law
 3. Other
9. Is this a first marriage?

1. Yes
2. No

10. Do you have children?

1. Yes
2. No

If yes, How many? _____

11. How many people live in your home? _____

Sometimes other things come up in interviews and it is good to check to see if you had the same experiences. Would you be interested in talking to me again after I have done some other interviews? Please check yes or no.

Yes _____ No _____