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Reconciling Marriage and Care after Stroke

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Abstract

Most research on the impact of stroke on couples has been focused on the transition to caregiving/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 had experienced a stroke. Findings revealed two interrelated themes of the couple 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: reconfirmed around their pre-stroke marriage; recalibrated around care; and a parallel relationship, “his” and “her” marriage. Our findings highlight the need to consider relationship dynamics in addition to knowledge about stroke and care.

Background

Stroke treatment is a success story. With access to effective emergency treatment, dedicated stroke care units, and multidisciplinary rehabilitation, more than 85 per cent of Canadians survive their stroke, and, of those, 85 per cent 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 per cent 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, more 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, and, therefore, spouses are the primary family member 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 emphasizing the need for care and the other focusing on the negative impact of stroke on marriage. To date, the preponderance of studies has focused on the survivors' need for care. About 25 per cent of 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 per cent, those with non-physically disabling stroke, suffer from fatigue, memory, 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 spouses. Reviews link greater spousal strain to more time spent with the survivor and more onerous care (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 well-being. People in satisfying marriages are less likely to succumb to acute illness and chronic illnesses, more likely to recover faster, and less likely to die prematurely (Uchino et al., 2012; Umberson & Montez, 2010). Caregiving spouses who view their relationships with the care receiver positively experience less caregiver burden and continue in their caregiving role 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). The increase in number of stroke survivors living at home, and for longer (Hall et al., 2014; Krueger et al., 2015), as well as the gap in knowledge about post-stroke marriages (Godwin, Ostwald, Cron, & Wasserman, 2013; McCarthy, Lyons & Powers, 2011) make stroke a strategic site for examining marriages. 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 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 each of the two categories of stroke studies: those that have examined the effects on spouses of care work and the few that have examined 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 survivors being discharged home and to their ability to remain there. Married survivors are more likely to be discharged home (Mees, Klein, Yperzeele, Vanacker, & Cras, 2016; Tanwir, Montgomery, Chari, & Nesathurai, 2014) after a shorter hospital stay than single, divorced, or widowed survivors (Bates et al., 2013; Kurichi et al., 2014). Spouses take more severely disabled survivors home, provide more intensive care, and continue to care longer than other family or friend caregivers (Daniel, Wolfe, Busch, & McKeivitt, 2009; Gaugler, 2010).

In light of the importance of survivors' need for care, researchers have focused significant attention on caregivers' preparedness and ability to care, and on the challenges of the care recipient's illness, impairment, and behavioural problems to the caregiver's well-being. For example, Cameron et al.'s (2014) "Timing it Right" intervention assumes that caregivers' educational needs and types of care tasks will change from acute care (preparation) through discharge home (implementation) and 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 points to the importance of dynamics of the relationship as sources of spousal caregivers' distress (Gaugler, 2010; McCarthy et al., 2011; Quinn, Murray & Malone, 2014b). Quinn et al. (2014b), for example, in a study of younger couples post-stroke found that spouses' distress was based on relational factors, like being troubled by changes to the husband or wife they loved and married; feeling like they were living with a stranger; as well as missing mutual conversations; sharing problems with, and receiving validation from, the survivor. Spouses perceived that survivors were no longer able to support them, but still felt a relational obligation to 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 have specifically considered spouses' and survivors' views of their marital relationships. The main findings in these studies point to post-stroke: emergence of roles akin to parent/child; disturbances of marital equity; decrease 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 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 et al. (2014b) and Banks & Pearson (2004) both characterized relationships as separate careers with spouses focused on caregiving and survivors on impairments. Although knowledge of the negative impacts of stroke on relationships is useful, gaps remain in our understanding of potential variation in relationships and the ways in which couples maintain, adjust, or adapt their relationships in light of impairments and the need for care.

A small number of studies measuring relationship quality found post-stroke stability. Godwin et al. (2013) and Ostwald, Godwin, & Cron (2009) found that spouses' relationship satisfaction declined longitudinally, but overall both survivors' and spouses' means remained high. Others have highlighted 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 per cent dissatisfied, and the remainder discordant (Achten, Visser-Meily, Post, & Schepers, 2012; Carlsson, Forsberg- Warleby, Moller, & Blomstrand, 2007). Forsberg-Warleby, Moller, and Blomstrand (2004) added a longitudinal dimension to the examination of relationship satisfaction by studying satisfaction trajectories one year poststroke. 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 per cent and decreased for 27 per cent over that time (Forsberg-Warleby et al., 2004). Significantly higher proportions of survivors compared to spouses were satisfied with their relationships, leading the authors to speculate that survivors were considering support from their spouse whereas some spouses had difficulty separating their caregiving from their spousal roles (Achten et al., 2012; Carlsson et al., 2007).

Evidence from Other Chronic Conditions

Couple-based research in other chronic conditions has also been theorized around the assumption that transitions such as the impairment and 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 the couple manages chronic diseases 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 such as 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's disease, cancer, heart disease, and older adults' discharge from intensive care adds to our understanding of how couples rearrange their relationships (Agard et al., 2015; Buck et al., 2015; Martin, 2016; Miller & Caughlin, 2013). Agard et al. (2015) portrayed the process of leaving the caregiving role and resuming the marriage as primarily under the spouse's control. In a study of spouses' perspectives only, they found that the survivor's re-engagement in marriage depended on the extent to which spouses assisted and coached them. In contrast, Martin (2016) examined couples' perspectives of their relationship after the diagnosis of Parkinson's disease. She found the potential for both the person with Parkinson's and their spouse to undermine or support their partner's role performances. It was difficult for people with Parkinson's to refuse the individual illness role or care-receiver roles

without their spouse's support. Also it was difficult for spouses to refuse the caregiving role when the person with Parkinson's regarded themselves as a patient. Further, relationship closeness influenced whether spousal support was perceived as in one's best interests or as over-supportive or paternalistic.

In their developmental contextual relationship model, Berg and Upchurch (2007) hypothesized that across time, chronic illnesses influence relationship development and that, in turn, relationships influence the course of the illness. Stroke researchers have investigated spousal caregiving and care receiving, but scant attention has been paid to joint perspectives or how marriages develop in the context of caregiving and the survivors' impairments and dependence (McCarthy et al., 2011; Green & King, 2010). With the current study, we sought to create knowledge towards addressing 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 through time (Elder, 1985; Alwin, 2012), whereas symbolic interaction is valuable for understanding how husbands and wives shape each other's roles (Charon, 2010; Turner, 2011).

The concept of transitions has been 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, pp. 31–32), although, more recently Alwin (2012) has argued that adjustment to transitions occurs 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), whereas the ways in which disability and marriage are understood likely evolve with time. Older survivors often have other chronic illnesses, but still find that even mild physical and cognitive impairment from stroke profoundly changes how they perceive themselves and 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.

Data Collection

We used Charmaz's (2006) approach to grounded theory which evolved from symbolic interactionism, to inform participant recruitment, data collection, and 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 survivors and 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 were asked to contact the researcher. The first author phoned all those who made contact, provided them with information about the study, and screened for eligibility. Inclusion criteria were (1) a physician’s diagnosis of stroke, (2) discharge home six months or more prior to the study, (3) both partners consent to and participate in interviews, and (4) married or in a committed relationship for 5 or more years pre-stroke. This final criterion allowed us to target 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 had turned a conflictual post-stroke relationship around.

Interviews

A semi-structured interview guide was designed based on the literature review and 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 couple’s 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 on the survivors’ arrival 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 on age, education, number, and type of chronic conditions, length of marriage, and time since 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 home. 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 maintaining confidentiality. In individual interviews, participants were assured that the interviewer would not disclose any information from their interview to their spouse, nor use any information from that 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 are a joint relational account and an appropriate approach for a study of marriage requiring 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 accounts. The content of the dialogue and the couples' interactions are both data in joint interviews.

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

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, and 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

The 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 contexts (circumstances, situations), interactions (actions, responses), and consequences (outcomes), rather than to test an explicit hypothesis (Charmaz, 2006). As such, 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 (1) why this behaviour was present, (2) what they might be expecting of their partner, and (3) what they might have been thinking as they responded. Within actions, we looked for "identifying moments" when participants regarded themselves or their 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, the themes of *marriage submerged by survivors' need for care* and then *couples striving to return to marriage* emerged. 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, dispensing 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 – comparing couples who claimed they were comfortable with relationships with those 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 (2 [Couple 7], 3 [Couple 15], and 6 [Couple 16] years after the stroke). They were recruited through community stroke groups, secondary stroke prevention clinics, and rehabilitation clinics. Survivors were 45 to 91 years of age (mean: 62.6) and spouses 35 to 91 years of age (mean: 62.3). Seven survivors were female and 11 were males. All survivors had returned home to their partner. Married couples ($n = 15$) had been together for an average of 35.6 years (range: 11 to 72) and those in common-law relationships ($n = 3$) for an average of 15 years (range: 9–25) 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–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 from stroke including four who had been in a coma (one week to three months); 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 and had separated from their spouse, said they could not have functioned at home without their spouse for some time (range: 1 month to 5 years). Both survivors and spouses thought survivors had made a significant recovery after discharge.

Four of the survivors' spouses had no chronic conditions and six had one (e.g., benign enlargement of the prostate, Crohn's, arthritis). The other eight 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 specified that arthritis or heart conditions limited the amount of physical support they could provide to the survivor.

Findings

The analysis of the interview transcripts revealed two themes related to the post-stroke

marriage development processes. Theme 1, *Working out care*, involved couples discovering and then addressing disruptions in previously taken-for-granted activities. Theme 2, *Rethinking marriage*, involved couples 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 the couple described survivors' homecoming as comforting, yet unnerving. Coming home was a milestone towards resuming life after stroke. However, once home, 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 would entail. "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 to the survivor, as well as how best to deliver that help. A spouse characterized the uncertainty that both partners feel around 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 impairment 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 able to do an activity or not. Uncertainty, fear, and frustration brought emotions close to 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. They had been diagnosed, received rehabilitation, and been told that they could expect some, but not complete, recovery. Spouses had been warned that survivors might be untrustworthy at decision making, unable to find their way home, and/or incapable of expressing emotions appropriately. Unlike those with mild stroke who were surprised by impairments, these survivors expected them. 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 & Spouse, Couple 1)

Spouses also had a separate set of challenges in determining the kinds of support that survivors needed. Although they had received some assistance and training to provide care, there were huge gaps. Task training such as wheelchair transfers was helpful, but there was little guidance on how to get the survivor to do 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). They were unsure whether to be sympathetic, to explain why the response was inappropriate, or to ignore the problems.

That was a pretty stressful period ... you know, very inflexible thinking was hard to deal with ... her doctor told her to take [vitamin] 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, 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 survivors could or should do weighed heavily on spouses: *“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 the balance. One approach was to assist survivors to increase their capacity through helping, encouraging, and challenging them.

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 themselves or were cautious about others’ safety. Others said doing things for survivors 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 arose when there was disagreement on roles. Some spouses were frustrated by the survivor’s apparent unwillingness to do more for themselves: “*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 need 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 because 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 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 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 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: reconfirmed around their pre-stroke marriage; recalibrated around care; and a parallel relationship, his and her marriage. Three couples divorced.

Reconfirmed Marriages

Some relationships were characterized by reaching new understandings of their husband and wife roles and on re-establishing 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 them 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 nutshell. 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 their new context of 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 points, and we've both learnt to live with each other's warts again. (Couple 8)

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

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 process associated with these reconfirmed marriage patterns involved working together, being able to resolve conflicts, and feeling that each mattered to their partner.

Re-calibrated Marriages

Some couples re-calibrated their relationship 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 survivors' changing and spouses' 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 their husband or wife'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 relationship: "*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 their marriage vows was the initial impetus to bring the 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 survivors’ preserved abilities and what they did in the relationship. Survivors agreed with their spouse about their situation and credited their spouse’s efforts for their autonomy and independence.

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; [I’d say], ‘You do it’, but I’ve had to be tough and I was never was before like that, never. (Couple 10)

Both survivors and spouses emphasized how they enjoyed their lives and continued to enjoy a range of activities in which 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. [They] go right to him. I watch”* (Survivor, Couple 14). Couples, however, stressed that re-defining their roles and relationship had been difficult at times, but that they had negotiated a relationship 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. Although 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 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 survivors’ 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 spouse’s 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 saw only 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 damned 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 partner 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 [being] watched"* (Survivor, Couple 9).

Spouses agreed that survivors' and their expectations were mismatched, but gave different reasons for the discrepancies than 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 their own needs: *"It was all about him. He would say, 'My days are hard. I need to go to bed at 9.' [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)

Another survivor, who separated six months after the interview, thought the lack of emotional connection would likely end their 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 to their partner:

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 to worry about not pleasing her. (Survivor, Couple 15)

In sum, the patterns associated with disconnected marriages were difficulty resolving divergent expectations, being unable to reach agreement on reciprocal roles, and finally the feeling that their partner 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.

Role of the Marriage Relationship in Caregiving

The committed relationship, married or common-law, between survivors and spouses was important in working out care. Spouses took on caregiving responsibilities because they were committed to the survivor or to marriage as a long-term commitment. All survivors, even those who had separated, credited their spouses for their current well-being. Both spouses and survivors, however, found that learning new caregiving and receiving roles presented a steep learning curve. They responded differently: taking a collaborative approach, with spouses doing activities with survivors who helped as they could; having spouses assume all responsibilities; or working through a volatile period of disagreements about conflicting expectations, but trusting that their partner 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 of our 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 in how we intervene in post-stroke relationships. Although stroke caregiving reviews often recommend augmenting spouses' caregiving skills or respite care to reduce spouses' burden of care, and the impact of survivors' characteristics (e.g., impairments, behaviour, depression) on spouses' well-being (Bakas et al., 2014; Quinn et al., 2014a), our findings highlight the importance of the relationship between survivors and spouses and the need to consider how relationship dynamics and quality influence both partners' well-being. This 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 survivors' recovery, spouses' burden of care, mortality, and quality of life as has been demonstrated in other chronic conditions (King & Reis, 2012; see also reviews: Badr & Krebs 2013; Falconier, Jackson, Hilpert, & Bodenmann, 2015; Martire, Schulz, Helgeson, Small, & Saghafi, 2010; Park & Schumacher,

2014; Robles et al., 2014).

Effects of Care on the Marriage Relationship

As 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, Bravo, Desrosier, St-Cyr Tribble, and Bourget (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. Our work, like research in other chronic conditions (Agard et al., 2015; Berg & Upchurch, 2007; Manne & Badr, 2008), 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/receiving and then a second to recalibrate the meaning of their relationship. Future research would benefit from differentiating the stress of care tasks, from stress related to changes to structure and functioning of relationships.

To date, 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. The elements of marriages precisely amenable to intervention were beyond the scope of this research, but couples suggested that communication and working together were crucial elements in managing stroke and improving their relationship. Reviews of couple interventions in chronic illness find those targeted to enhance couples' communication (express emotion, share concerns, communicate needs) had the largest effects on health and relationships (Badr & Krebs, 2013; Martire et al., 2010; Shields, Finley, Chawla, & Meadors, 2012).

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 indicating 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 those who were able to recalibrate their relationship 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 relationship (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 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 survivors and spouses perceived survivors were active participants in recreating their relationship. Similar to other research on chronic conditions, marital closeness contributed to survivors' and spouses' wellbeing above and beyond care (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 well-being after older adults' transition to chronic illness. Our findings support the idea that the way survivors and spouses respond to their marital partners' caregiving/receiving and husband/wife role-making efforts is an important factor in how couples (re)create closeness or increasingly feel separate from their marital partner. The relationship dynamics by which older couples develop positive caregiver, survivor, spouse, and/ or couple identities are worthy of further research. Although it is premature to suggest that group stroke interventions include relationship advice, the couples who received marital counselling recommended 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 diversity in ways in which couples recreate their marriages after stroke; 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 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 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 prestroke marital relationship might well be better understood through an intersectional theoretical framework and a larger and more diverse sample. For example, there is evidence women are less likely to be discharged home after stroke because they do not have someone prepared to care; and evidence that female spouses are more likely to bring disabled 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 referred to being natural caregivers or mothering. Parallel findings from the caregiving literature indicate that women provide more instrumental help than men and that women caregivers experience more stress, more depressive symptoms, and lower well-being and physical health (Gaugler, 2010; Pinquart & Sörensen, 2006). Similarly, marital researchers find that stress in the relationship affects wives' mental and physical health more than 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) argued that stressful environmental contexts such as poverty and lack of support are stronger contributors to marital conflict and marriage breakdown than individual-level interactions. 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 life course differences between younger and older couples.

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), when survivors become aware of themselves as partners. Notably, 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 survivors' recovery to being married and able to return home to a spouse. They recommended research on the impact of marriage on stroke recovery. By these participants' descriptions, survivors' recovery was remarkable. As reviews and meta-analysis 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., 2012), future studies should examine if marital quality impacts stroke recovery. Little causal research has been done 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 on a relationship that centred on care. They were in uncharted territory, as uncertain about how to relate 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 practice, married couples' needs and well-being should be assessed as individuals and a couple. It is important to determine if the post-stroke stress is related to caregiving tasks or the survivor/spouse relationship.

References

- Achten, D., Visser-Meily, J. M. A., Post, M. W. M., & Schepers, V. P. M. (2012). Life satisfaction of couples 3 years after stroke. *Disability and Rehabilitation*, *34*(17), 1468-1472.
- Adamit, T., Maeir, A., Ben Assayag, E., Bornstein, N. M., Korczyn, A. D. & Katz, N. (2015). Impact of first-ever mild stroke on participation at 3 and 6 month post-event: The TABASCO study. *Disability and Rehabilitation*, *37*, 667-673.
- Alwin, D.F. (2012). Integrating varieties of life course concepts. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, *67*(2), 206–220, doi:10.1093/geronb/gbr146.
- Agard, A. S., Egerod, I., Tonnesen, E., & Lomborg, K. (2015). From spouse to caregiver and back: a grounded theory study of post-intensive care unit spousal caregiving. *Journal of Advanced Nursing*, *71*(8), 1892-1903. doi:10.1111/jan.12657
- Backstrom, B., Asplund, K., & Sundin, K. (2010). The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first year postdischarge. *Nursing Inquiry*, *17*(3), 257-268. doi:10.1111/j.1440-1800.2010.00490.x
- Badr, H., & Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho-oncology*, *22*(8), 1688-1704. doi:10.1002/pon.3200
- Bakas, T., Clark, P. C., Kelly-Hayes, M., King, R. B., Lutz, B. J., & Miller, E. L. (2014). Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American Heart Association and American Stroke Association. *Stroke (00392499)*, *45*(9), 2836-2852. doi:10.1161/STR.0000000000000033
- Banks, P., & Pearson, C. (2004). Parallel lives: Younger stroke survivors and their partners coping with crisis. *Sexual and Relationship Therapy*, *19*(4), 413-429.
- Bates, B. E., Kwong, P. L., Xie, D., Valimahomed, A., Ripley, D. C., Kurichi, J. E., & Stineman, M. G. (2013). Factors influencing receipt of early rehabilitation after stroke. *Archives of Physical Medicine and Rehabilitation*, *94*(12), 2349-2356. doi:10.1016/j.apmr.2013.07.021
- Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, *133*(6), 920-954. doi:10.1037/0033-2909.133.6.920
- Buck, H. G., Harkness, K., Wion, R., Carroll, S. L., Cosman, T., Kaasalainen, S., . . . Arthur, H. M. (2015). Caregivers' contributions to heart failure self-care: A systematic review. *European Journal of Cardiovascular Nursing*, *14*(1), 79-89. doi:10.1177/1474515113518434
- Buehlman, K. T., Gottman, J. M., & Katz, L. F. (1992). How a couple views their past predicts their future: Predicting divorce from an oral history interview. *Journal of Family Psychology*, *5*(3-4), 295-318.
- Buschenfeld, K., Morris, R., & Lockwood, S. (2009). The experience of partners of young stroke survivors. *Disability and Rehabilitation*, *31*(20), 1643-1651. doi:10.1080/09638280902736338

- Cameron, J. I., Naglie, G., Warner, G., Green, T., Gignac, M., Bayley, M., . . . Czerwonka, A. (2014). Randomized controlled trial of the timing of a right family support program. *Stroke*, *45*(12), E261-E261.
- Carlsson, G. E., Forsberg-Warleby, G., Moller, A., & Blomstrand, C. (2007). Comparison of life satisfaction within couples one year after a partner's stroke. *Journal of Rehabilitation Medicine*, *39*(3), 219-224. doi:10.2340/16501977-0048
- Calasanti, T., & King, N. (2015). Intersectionality and age. In J. Twigg & W. Martin (Eds.), *Routledge handbook of cultural gerontology* (pp. 193-200). London, UK: Routledge.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ, Rutgers University Press.
- Charon, J.M. (2010). *Symbolic interactionism: An introduction, an interpretation, an integration* (10th Ed.). New York: Prentice Hall.
- Daniel, K., Wolfe, C. D. A., Busch, M. A., & McKeivitt, C. (2009). What are the social consequences of stroke for working-aged adults?: a systematic review. *Stroke*, *40*(6), e431-e440. doi:10.1161/STROKEAHA.108.534487
- Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A. & Hearn, J. (2000). Investigating recovery from stroke: a qualitative study. *Journal of Clinical Nursing*, *9*, 507-515.
- Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, *20*(12), 1642-1655. doi:10.1177/1049732310376520.
- Elder, G. H. Jr. (Ed.). (1985). *Life course dynamics: Trajectories and transitions, 1968-1980*. (project of SSRC committee on the life course.). Ithaca, NY: Cornell University Press.
- Falconier, M. K., Jackson, J. B., Hilpert, P., & Bodenmann, G. (2015). Dyadic coping and relationship satisfaction: A meta-analysis. *Clinical Psychology Review*, *42*, 28-46. doi:10.1016/j.cpr.2015.07.002
- Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., . . . Grp, G. B. D. S. E. (2014). Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet*, *383*(9913), 245-255. doi:10.1016/S0140-6736(13)61953-4
- Forsberg-Warleby, G., Moller, A., & Blomstrand, C. (2004). Life satisfaction in spouses of patients with stroke during the first year after stroke. *Journal of Rehabilitation Medicine*, *36*(1), 4-11. doi:10.1080/16501970310015191
- Gaugler, J. E. (2010). The longitudinal ramifications of stroke caregiving: A systematic review. *Rehabilitation Psychology*, *55*(2), 108-125. doi:10.1037/a0019023
- Godwin, K. M., Ostwald, S. K., Cron, S. G., & Wasserman, J. (2013). Long-term health-related quality of life of stroke survivors and their spousal caregivers. *Journal of Neuroscience Nursing*, *45*(3), 147-154. doi:10.1097/JNN.0b013e31828a410b
- Gottman, J. M., & Notarius, C. I. (2002). Marital research in the 20th century and a research agenda for the 21st century. *Family Process*, *41*(2), 159-197. doi:10.1111/j.1545-5300.2002.41203.x
- Green, T. L., & King, K. M. (2010). Functional and Psychosocial Outcomes 1 year after Mild Stroke. *Journal of Stroke & Cerebrovascular Diseases*, *19*, 10-16.
- Grigorovich, A., Forde, S., Levinson, D., Bastawrous, M., Cheung, A. M., & Cameron, J. I. (2015). Restricted participation in stroke caregivers: Who is at risk? *Archives of Physical Medicine and Rehabilitation*, *96*(7), 1284-1290.

- Hall, R., Khan, F., O'Callaghan, C., Kapral, M.K., Cullen, A., Levi, J., Wu, J., Fang, J., Bayley, M. (2014). *Ontario stroke evaluation report 2014: On target for stroke prevention and care*. Retrieved from <http://www.ices.on.ca/Publications/Atlases-and-Reports/2014/Ontario-Stroke-Evaluation-Report-2014>
- Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine*, 7(7). doi:10.1371/journal.pmed.1000316
- King, K. B., & Reis, H. T. (2012). Marriage and long-term survival after coronary artery bypass grafting. *Health Psychology*, 31(1), 55-62. doi:10.1037/a0025061
- Krueger, H., Koot, J., Hall, R. E., O'Callaghan, C., Bayley, M., & Corbett, D. (2015). Prevalence of individuals experiencing the effects of stroke in Canada: Trends and projections. *Stroke; A Journal of Cerebral Circulation*, 46(8), 2226-2231. doi:10.1161/strokeaha.115.009616
- Kurichi, J. E., Xie, D., Bates, B. E., Ripley, D. C., Vogel, W. B., Kwong, P., & Stineman, M. G. (2014). Factors associated with home discharge among veterans with stroke. *Archives of Physical Medicine and Rehabilitation*, 95(7), 1277-1282.e1273. doi:10.1016/j.apmr.2014.03.008
- Mancini, A. D., & Bonanno, G. A. (2006). Marital closeness, functional disability, and adjustment in late life. *Psychology and Aging*, 21(3), 600-610. doi:10.1037/0882-7974.21.3.600
- Manne, S., & Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer*, 112(11 SUPPL.), 2541-2555. doi:10.1002/cncr.23450
- Martin, S. C. (2016). Relational issues within couples coping with Parkinson's Disease: implications and ideas for family-focused care. *Journal of Family Nursing*, 22(2), 224-251.
- Martire, L. M., Schulz, R., Helgeson, V. S., Small, B. J., & Saghafi, E. M. (2010). Review and Meta-analysis of Couple-Oriented Interventions for Chronic Illness. *Annals of Behavioral Medicine*, 40(3), 325-342. doi:10.1007/s12160-010-9216-2
- Mayo, N. E., Wood-Dauphinee, S., Carlton, R., Durcan, L., & Carlton, J. (2002). Activity, participation, and quality of life 6 months poststroke. *Archives of Physical Medicine and Rehabilitation*, 83(8), 1035-1042.
- McCarthy, M. J., Lyons, K. S., & Powers, L. E. (2011). Expanding poststroke depression research: Movement toward a dyadic perspective. *Topics In Stroke Rehabilitation*, 18(5), 450-460.
- Mees, M., Klein, J., Yperzeele, L., Vanacker, P. & Cras, P. (2016). Predicting discharge destination after stroke: A systematic review. *Clinical Neurology and Neurosurgery*, 142, 15-21.
- Mellor, R. M., Slaymaker, E., & Cleland, J. (2013). Recognizing and overcoming challenges of couple interview research. *Qualitative Health Research*, 23(10), 1399-1407. doi:10.1177/1049732313506963
- Miller, L. E., & Caughlin, J. P. (2013). "We're going to be survivors": Couples' identity challenges during and after cancer treatment. *Communication Monographs*, 80(1), 63-82. doi:10.1080/03637751.2012.739703
- Murray, S. L., & Holmes, J. G. (2011). *Interdependent minds: The dynamics of close relationships*. New York: The Guilford Press.

- Neff, L. A. & Karney, B. R. (2016). Acknowledging the elephant in the room: how stressful environmental contexts shape relationship dynamics. *Current Opinion in Psychology*, *13*, 107-110.
- Ostwald, S. K., Godwin, K. M., & Cron, S. G. (2009). Predictors of life satisfaction in stroke survivors and spousal caregivers after inpatient rehabilitation. *Rehabilitation Nursing*, *34*(4), 160-167+174.
- Park, E. O., & Schumacher, K. L. (2014). The state of the science of family caregiver-care receiver mutuality: a systematic review. *Nursing Inquiry*, *21*(2), 140-152. doi:10.1111/nin.12032
- Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *61*(1), P33-P45.
- Pretter, S., Raveis, V. H., Carrero, M., & Maurer, M. S. (2014). Couples living with cardiovascular disease: Effects on the marital relationship. *Journal of Family Social Work*, *17*(1), 21-36. doi:10.1080/10522158.2013.865288
- Quinn, K., Murray, C. D., & Malone, C. (2014a). The experience of couples when one partner has a stroke at a young age: an interpretative phenomenological analysis. *Disability and Rehabilitation*, *36*(20), 1670-1678. doi:10.3109/09638288.2013.866699
- Quinn, K., Murray, C.D., & Malone, C. (2014b). Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: A meta-synthesis of qualitative research. *Disability and Rehabilitation*, *36*(3), 185-198.
- Robles, T. F., Slatcher, R. B., Trombello, J. M., & McGinn, M. M. (2014). Marital quality and health: A meta-analytic review. *Psychological Bulletin*, *140*(1), 140-187. doi:10.1037/a0031859
- Robles, T. F. (2014). Marital quality and health: Implications for marriage in the 21st century. *Current Directions in Psychological Science*, *23*(6), 427-432. doi:10.1177/0963721414549043
- Rochette, A., Bravo, G., Desrosiers, J., St-Cyr Tribble, D., & Bourget, A. (2007). Adaptation process, participation and depression over six months in first-stroke individuals and spouses. *Clinical Rehabilitation*, *21*(6), 554-562. doi:10.1177/0269215507073490
- Rohrbaugh, M. J., & Shoham, V. (2012). Family consultation for couples coping with health problems: A social cybernetic approach in H.S. Friedman (Ed) *The Oxford Handbook of Health Psychology* (pp 477-498), Oxford, UK: Oxford University Press.
- Rottmann, N., Hansen, D. G., Larsen, P. V., Nicolaisen, A., Flyger, H., Johansen, C., & Hagedoorn, M. (2015). Dyadic coping within couples dealing with breast cancer: A longitudinal, population-based study. *Health Psychology*, *34*(5), 486-495. doi:10.1037/hea0000218
- Shields, C. G., Finley, M. A., Chawla, N., & Meadors, P. (2012). Couple and Family Interventions in Health Problems. *Journal of Marital and Family Therapy*, *38*(1), 265-280. doi:10.1111/j.1752-0606.2011.00269.
- Smurawska, L. T., Alexandrov, A. V., Blandin, C. F. & Norris, J. W. (1994). Cost of acute stroke care in Toronto, Canada. *Stroke*, *25*, 1628-1631.
- Tanwir, S., Montgomery, K., Chari, V., & Nesathurai, S. (2014). Stroke rehabilitation: availability of a family member as caregiver and discharge destination. *European journal of Physical and Rehabilitation Medicine*, *50*(3), 355-362.

- Taale, T. & Raheim, M. (2014). Life changed existentially: A qualitative study of experiences at 6-8 months after mild stroke. *Disability and Rehabilitation*, 36, 2107-2119.
- Teasell, R. W., Fernandez, M. M., McIntyre, A., & Mehta, S. (2014). Rethinking the continuum of stroke rehabilitation. *Archives of Physical Medicine and Rehabilitation*, 95(4), 595-596. doi:10.1016/j.apmr.2013.11.014.
- Thompson, H. S., & Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of Clinical Nursing*, 18(12), 1803-1811. doi:10.1111/j.1365-2702.2008.02694.x
- Traa, M. J., De Vries, J., Bodenmann, G., & Den Oudsten, B. L. (2015). Dyadic coping and relationship functioning in couples coping with cancer: A systematic review. *British Journal of Health Psychology*, 20(1), 85-114. doi:10.1111/bjhp.12094
- Trygged, S., Hedlund, E., & Kåreholt, I. (2011). Education and poststroke separation among couples with mutual children. *Journal of Divorce and Remarriage*, 52(6), 401-414. doi:10.1080/10502556.2011.592423
- Turner, J. H. (2011). Extending the symbolic interactionist theory of interaction processes: A conceptual outline. *Symbolic Interaction*, 34(3), 330-339. doi:10.1525/si.2011.34.3.330
- Uchino, B. N., Cawthon, R. M., Smith, T. W., Light, K. C., McKenzie, J., Carlisle, M., . . . Bowen, K. (2012). Social relationships and health: Is feeling positive, negative, or both (ambivalent) about your social ties related to telomeres? *Health Psychology*, 31(6), 789-796. doi:10.1037/a0026836
- Umberson, D., & Montez, J. K. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior*, 51, S54-S66. doi:10.1177/0022146510383501
- Visser-Meily, A., Post, M., Gorter, J. W., Berlekom, S. B. V., Van Den Bos, T., & Lindeman, E. (2006). Rehabilitation of stroke patients needs a family-centred approach. *Disability and Rehabilitation*, 28(24), 1557-1561.