

# Marriage after the transition to stroke: a systematic review

SHARON ANDERSON\* and NORAH KEATING†

## **ABSTRACT**

In health and chronic illness, satisfying marriages promote wellbeing and life satisfaction, yet stroke research has focused on either the stroke survivor as the patient or the spouse as a care-giver. Using Pope, Mays and Popay's framework for synthesising 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 characterise the evolution of marriage after stroke: chaos in the marriage, work to re-establish the marriage and evolution of the marriages. While both the stroke condition itself and the survivors' 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 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.

**KEY WORDS**—marriage, stroke, review, interpersonal relations.

## **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).

\* Department of Human Ecology, University of Alberta, Edmonton, Canada.

† College of Human Sciences & Health Sciences, Swansea University, UK.

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 health-care 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 per cent (Feigin *et al.* 2014). Over 85 per cent of people now survive stroke; and of those, the vast majority (85%) are discharged to their pre-stroke residence (Hall *et al.* 2015; Krueger *et al.* 2015). Yet only 15 per cent 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 care-givers (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 that 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's 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 *et al.* 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 recognised 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 hypothesised 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 *et al.* 2015). This support is lacking in unhappy marriages or in cases in which marital partners are overwhelmed with their own or a spouses' 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 care-giver (McCarthy, Lyons and Powers 2011; Ostwald 2008).

Systematic reviews of the experiences of stroke survivors (Salter *et al.* 2008; Satink *et al.* 2013) and care-givers (Gaugler 2010; Salter *et al.* 2010) exist, but we found no reviews focusing 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 *et al.* 2015), which recognise 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 synthesised 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 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-methods reviews draw on the meaning of constructs found in qualitative methodologies and the magnitude and frequency of concepts in the quantitative studies to produce a contextual understanding (Pearson *et al.* 2015). In addition to producing an integrated analysis of extant knowledge on the topic, synthesising 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 involves identifying relevant articles and making decisions about article inclusion, appraising article quality and analysing 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; we then show how the related quantitative studies support, contradict or complement the qualitative data about the element 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: (a) written in English, (b) peer-reviewed, (c) participants were married or in a similar partnered relationship, (d) published 1995–2015, and (d) the marital relationship was a key theme or variable. Care-giving articles were excluded if other family members or friends were included as partners (care-givers), 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. Figure 1 shows 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

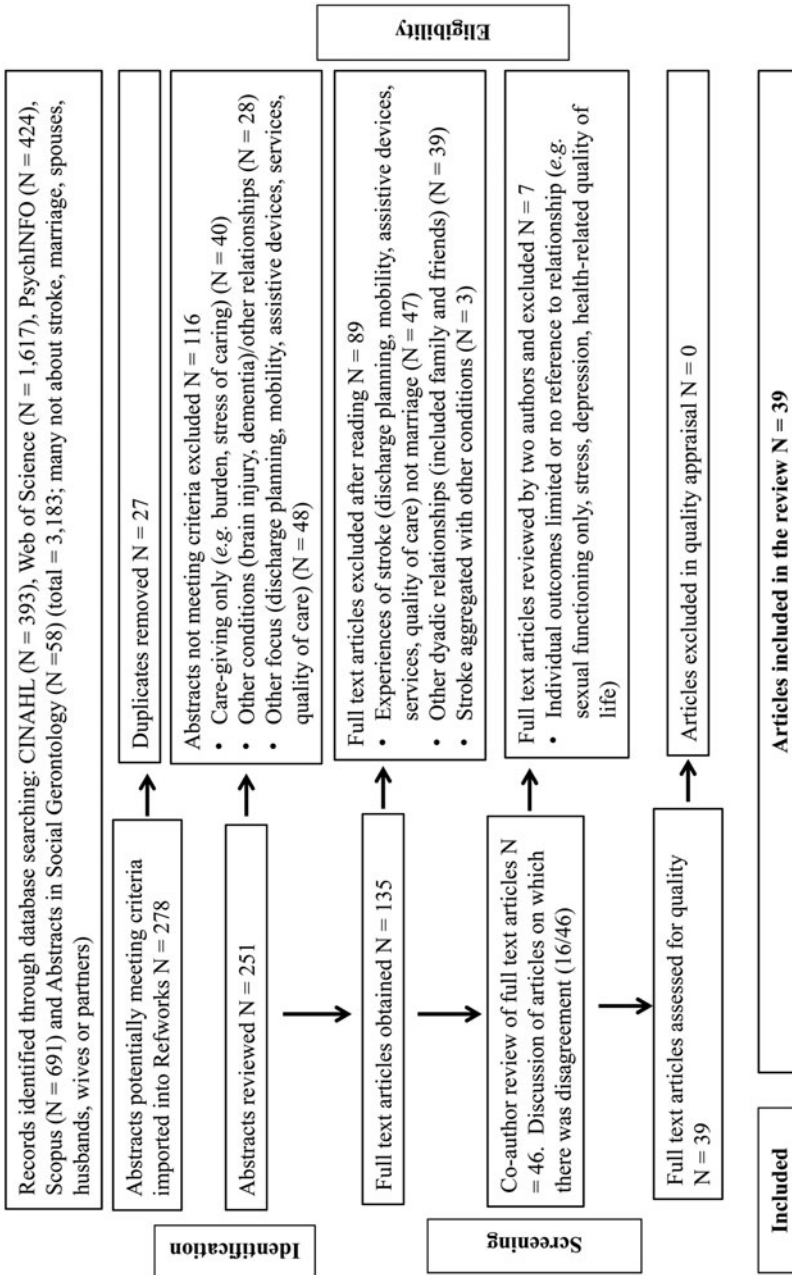


Figure 1. Literature search.

278 abstracts. We imported the 278 abstracts into the reference manager EndNote, and 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=47); 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 care-giving or sexual intercourse, 35 articles about stroke which measured relationship quality (as 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 consider methodological quality rigorously while sensitising us to the applicability of the results to our question. MMAT is a validated tool that uses different criteria to assess varying 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 the first column of Table 1. Articles included to this stage of the research had acceptable quality.

TABLE 1. *Description of studies: participants, methodology, recruitment, theoretical framework and findings*

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	<i>Participants</i> Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
Achten <i>et al.</i> <a href="#">2012</a> MMAT**** CASP 11/12	<i>Couples</i> Patients with stroke N = 78 (59; NR) Spouses N = 78 (55; NR) Same cohort as Visser-Meilly <i>et al.</i> <a href="#">2009</a>	Quantitative, cross- sectional (3 years)	In-patient rehabilitation, The Netherlands	Compare couples' life satisfaction (life satisfaction as rehabilitation outcome)	Associations between survivors' and spouses' satisfaction with relationship were not signifi- cant. Satisfied with partnered relationship: Survivors 92%; spouses 64%.
Visser-Meilly <i>et al.</i> <a href="#">2009</a> MMAT**** CASP 11/12	<i>Couples</i> Patients with stroke N = 121 (56; NR) Spouses N = 121 (54; NR) Same cohort as Achten <i>et al.</i> <a href="#">2012</a>	Quantitative, longitudinal (in rehabilitation, 2 months, 1 and 3 years)	Rehabilitation cohort, The Netherlands	Predictors of the course of spouses' psycho-social functioning (stress and coping)	Harmony in relationships decreased significantly at each measurement. Patient mental and cognitive functioning improved to one year. Care- giver burden decreased. Better marital relations (spouses only assessed) asso- ciated with male spouse, not having young children, more support seeking and less passive coping.

TABLE 1. (Cont.)

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	<i>Participants</i> Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
Backstrom, Asplund and Sundin 2010 MMAT*** CASP 9/10	<i>Spouses</i> Female spouses N = 4 (52; 40–58) Partner who suffered a stroke (52.25; 42–58)	Qualitative, longitudinal (1, 6 and 12 months)	In-patient rehabilitation, Sweden	Spouses' lived experience of the relationship (phenomenological)	Two months: care was para- mount; spouses did not feel they were married to the same person; six months: strived to move back to spousal rela- tionship; one year: irreversibly altered relationship and lack of reciprocity.
Banks and Pearson 2004 MMAT**** CASP 10/10	<i>Couples</i> Younger stroke survivors N = 38 (44; 20–49) Informal carers/ spouses N = 36 (NR)	Qualitative, longitudinal (3, 6–9 and 12–15 months)	Community stroke groups, UK	Impact of stroke on relationships	Lack of communication and miscommunication were common. Survivors took diffi- culties and frustrations out on spouses. Survivors reported that partners could not relate to their situation and partners felt survivors had changed; 12–15 months: parallel lives, spouses in caring and survi- vors in stroke.
Brann <i>et al.</i> 2010 MMAT**** CASP 10/10	<i>Spouses</i> Survivors (NR) Spouses N = 16 (NR; 19–93)	Qualitative, cross- sectional	Extended care and community stroke group, USA	Spousal care-givers experiences of stroke (dialectical tensions)	Roles and reciprocity altered. Spouses prioritised survivors' needs over theirs. Survivors unable to reciprocate emo- tional support. Spouses ashamed of ambivalent feel- ings to survivors.



Buschenfeld, Morris and Lockwood 2009 MMAT**** CASP 10/10	<i>Spouses</i> Partners N = 7 (NR; 47–60)	Qualitative, cross-sectional	Community stroke groups, UK	Experiences of partners (phenomenology)	Two themes: (a) loss of person to whom they were married/changed marital roles and relationship; (b) enduring: spouses committed to remaining married.
Carlsson <i>et al.</i> 2007 MMAT**** CASP 11/12	<i>Couples</i> Patients N = 56 (60; 38–74) Spouses/partners (59; 34–79) Same cohort as Forsberg-Warleby, Moller and Blomstrand 2004	Quantitative, longitudinal (1 week, 1 year)	Acute stroke admission cohort, Sweden	Compare couples' life satisfaction (life satisfaction as rehabilitation 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%) (population norm 86%).
Forsberg-Warleby, Moller and Blomstrand 2004 MMAT**** CASP 12/12	<i>Spouses</i> 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% and increased 10%. Spouses' mean satisfaction lower than Swedish population. Dissatisfaction in depression/cognitive impairments not functional impairment.
Coombs 2007 MMAT**** CASP 10/10	<i>Spouses</i> Partners and spousal care-givers N = 8 (65.5; 57–81)	Qualitative, cross-sectional	In-patient rehabilitation, Canada	Spousal care-givers' 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	<i>Spouses/care-giving role</i> N = 17 (62.5; 44–78)	Quantitative, longitudinal (in hospital and 1 week after discharge home)	In-patient rehabilitation, USA	Factors affecting husbands and wives adjustment to care-giving role (gendered roles)	Husbands' and wives' role responsibilities increased and role enjoyment, joint social activities and wives' personally meaningful activities decreased. Marital unhappiness increased.

TABLE 1. (Cont.)

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	Participants Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
Enterlante and Kern 1995 MMAT*** CASP 7/12	<i>Wives</i> Spouses N = 10 (NR; 48–70)	Quantitative, longitudinal (in hospital and 2 weeks post-discharge)	In-patient rehabilitation, USA	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	<i>Stroke survivors</i> of working age N = 9 (51.22; 45–61)	Qualitative, longitudinal (1, 3, 6 and 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 inte- gration and four sub-categor- ies: (a) not recognised as the person I am, (b) burden of burden, (c) inspiration and belonging through social interactions, and (d) reality adjustment through other's feedback.
Giaquinto <i>et al.</i> 2003 MMAT**** CASP 12/12	<i>Couples</i> 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 one year after stroke	Sexual decline was common. Only age and disability sig- nificant. Spouses and psycho- social aspects rather than medical account for decline. Spouses experienced fear of relapse, anguish, lack of exci- tation or even horror, which withheld them from encour- aging sexual activities.

<p>Godwin <i>et al.</i> 2013a MMAT**** CASP 11/12</p>	<p><i>Couples</i> Stroke survivors N = 30 (70.8; NR) Spousal care-givers N = 30 (64.9; NR) Same cohort as Godwin <i>et al.</i> 2013b; Oswald, Godwin and Cron 2009; Oswald <i>et al.</i> 2009</p>	<p>Quantitative, longitudinal (1, 3 and 5 years)</p>	<p>(CARES Intervention Cohort), hospitals and rehabilitation centres, USA</p>	<p>Impact of stroke on survivor's and spouse's health-related quality of life</p>	<p>Spouses', but not survivors', mutuality decreases signifi- cantly over time although care-givers' burden and depression decreased.</p>
<p>Godwin <i>et al.</i> 2013b MMAT**** CASP 12/12</p>	<p><i>Couples</i> Stroke survivors N = 134 (66.4; NR) Spousal care-givers N = 134 (62.5; NR) Same cohort as Godwin <i>et al.</i> 2013a; Oswald, Godwin and Cron 2009; Oswald <i>et al.</i> 2009</p>	<p>Quantitative, longitudinal (baseline, 6 and 12 months)</p>	<p>As above</p>	<p>Effect of mutuality on stress</p>	<p>Care-givers' mutuality decreased their stress, but not survivors' stress. Survivors' stress affected spouses' stress, but spouses' stress did not affect survivors' stress.</p>
<p>Oswald <i>et al.</i> 2009 MMAT**** CASP 12/12</p>	<p><i>Couples</i> Stroke survivors N = 113 (66.9; 51–88.6) Spousal care-givers N = 113 (63; 41–87) Same cohort as Godwin <i>et al.</i> 2013a, 2013b; Oswald, Godwin and Cron 2009</p>	<p>Quantitative, longitudinal (12 and 24 months)</p>	<p>As above</p>	<p>Variables associated with life satisfaction (life satisfaction as rehabilitation outcome)</p>	<p>Survivors (3.3/0–4) and spouses (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 mutual- ity were most satisfied with their lives.</p>

TABLE 1. (Cont.)

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	Participants Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
Ostwald, Godwin and Cron 2009 MMAT**** CASP 12/12	<i>Couples</i> Stroke survivors N = 159 (66.4; NR) Spousal care-givers N = 159 (62.5; NR) Same cohort as Godwin <i>et al.</i> 2013a, 2013b; Oswald <i>et al.</i> 2009	Quantitative, longitudinal (baseline, 6 and 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 func- tion but mediated by a good relationship.
Green and King 2009 MMAT**** CASP 9/10	<i>Couples</i> Male stroke patients N = 26 (63.9; 33–83) Wife-care-givers N = 26 (58.5; 33–75) Same cohort as Green and King 2010, 2011	Qualitative, longitudinal (1, 2, 3, 6, 9 and 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 and over-protectiveness increased tension in the rela- tionship. Survivors’ masculine sense of self was threatened.
Green and King 2010 MMAT**** CASP 12/12	<i>Couples</i> As above Same cohort as Green and King 2009, 2011	Quantitative, longitudinal (discharge, 1, 2, 3 and 12 months)	As above	Recovery trajectory for male patients and wife-care-givers (effects of mild stroke impairments)	Worsening of depression and marital functioning for both the patients and wife-care- givers, although the wife-care- givers’ perceptions of care- giver strain improved. None of the measured variables were associated with marital functioning one year post- discharge.

Green and King 2011 MMAT*** CASP10/12	<i>Couples</i> As above Same cohort as Green and King 2009, 2010	Quantitative, longitudinal (discharge, 1, 2 and 3 months) (see above)	As above	Biophysical and psycho-social effects of stroke (stress and coping theory)	Poorer marital function was associated with poorer mental health and functional out- comes. Improvement in wives' mental health improved marital functioning.
Kitzmüller, Asplund and Haggstrom 2012 MMAT**** CASP 8/10	<i>Couples</i> Stroke survivors N = 23 (51; 32–68) Spouses N = 17 (51; 32–65) Same cohort as Kitzmüller <i>et al.</i> 2012; Kitzmüller and Ervik 2015	Qualitative, cross- sectional	Convenience sample, in-patient rehabilitation and community groups, Sweden	Illuminate the long-term experience of family life after stroke particularly regarding marital relationships (phenomenology, Van Manen and Heidegger)	Role and marital changes caused fear and insecurity. Some survivors were worried that spouses would abandon them because of bad temper, disengagement and burden. Spouses viewed survivors as child-like, even as strangers. Couples who remained together enjoyed their lives/ perceived that relationships improved.
Kitzmüller <i>et al.</i> 2012 MMAT**** CASP 8/10	As above	Qualitative, cross- sectional	As above	Existential meaning of couples' experiences of stroke (phenomenology, Van Manen and Heidegger)	Sudden onset exaggerated dev- astating impact on life. Stroke survivors felt stigmatised and dismissed. Dealing with post- stroke changes made couples reinterpret their life-world and gave couples a deeper appreciation for life.

TABLE 1. (Cont.)

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	Participants Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
Kitzmuller and Ervik 2015 MMAT**** CASP 8/10	<i>Spouses</i> Stroke-ridden partner (NR) Spouses N = 12 (52, 40–62) Same cohort as Kitzmuller, Asplund and Haggstrom 2012; Kitzmuller <i>et al.</i> 2012	Qualitative, cross- sectional	As above	Influence of stroke on female spouses' sexual relationship (phenomenology, Van Manen and Heidegger)	Four main themes: (a) married to a stranger, (b) the shift from partner to care-giver, (c) sexuality wrapped in silence, and (d) a void to live with.
Korpelainen, Nieminen and Myllyla 1999 MMAT**** CASP 12/12	<i>Stroke patients</i> N = 50 (53.5 32–65) Spouses N = 50 (NR)	Quantitative, longitudinal (2 and 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 (one-third), but mainly (two- thirds) to psycho-social factors.
Lapkiewicz <i>et al.</i> 2008 MMAT**** CASP 8/12	<i>Couples</i> 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 and 6 months)	In-patient rehabilitation, Poland	Impact of stroke on quality of marriage (ecological-marriage as context)	Overall, marriage quality, cohe- sion and satisfaction declined for couples dealing with stroke and aphasia, but more for aphasic survivors. Emotional expression declined in aphasia.

Lemieux, Cohen-Schneider and Holzapfel 2002 MMAT**** CASP 10/10	<i>Couples</i> 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 (half of survivors, two-thirds of spouses) and importance of sex reduced. Other sexual activities increased. Lack of communication was barrier to sex.
McCarthy, Lyons and Powers 2012 MMAT**** CASP 12/12	<i>Couples</i> Survivors N = 36 (60.03; 21–90) Spouses N = 36 (58.67; NR) Same cohort as McCarthy and Bauer 2015	Quantitative, cross-sectional	Convenience sample, in-patient rehabilitation and community groups, USA	Relational factors associated with depression (stress and coping, developmental-contextual model)	Partner protective buffering, perceived misunderstandings and perceptions that spouse's expectations unrealistic associated with survivor's depressive symptoms. Passive coping and survivor protective buffering associated with spouse's depressive symptoms.
McCarthy and Bauer 2015 MMAT**** CASP 10/10	As above Same cohort as McCarthy, Lyons and Powers 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	<i>Couples</i> Former inpatients/care recipients N = 57 (65.5; NR) Partner care-givers N = 57 (61.9; NR) Same cohort as McPherson <i>et al.</i> 2011	Quantitative, cross-sectional	In-patient rehabilitation, Canada	Impact of stroke on equity and survivors quality of life	Survivors highly satisfied with relationship <sup>5</sup> although self-perceived burden was higher in stroke (70%) than in advanced cancer (19–38%). Self-perceived burden moderately correlated with functional impairment ( $r = -.21$ ) and highly correlated with family roles ( $r = -0.61$ ).

TABLE 1. (Cont.)

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	<i>Participants</i> Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
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 care-giver burden	Spouses: 89.2% satisfied with marriage despite 60.7% doing more. Satisfaction with marital relationship and intrinsic care-giving rewards accounted for 24% of the positive reactions to care.
Quinn, Murray, and Malone 2014b MMAT**** CASP 10/10	<i>Couples</i> Survivors N = 8 (47; 36–61) Spouses N = 8 (45; 36–65)	Qualitative, cross- sectional (1–9 years post-stroke)	Two stroke associations and Facebook groups, UK	Experience of young survivors and partners (shared experiences)	All couples referred to shift in roles from partners to care- giving and cared for. Both partners had difficulty adapt- ing to reciprocal relationship roles. Spouses marital/care roles not congruent.
Radcliffe, Lowton and Morgan 2013 MMAT**** CASP 10/10	<i>Couples</i> Survivors N = 13 (NR; 75–85) Spouses N = 13 (NR; 59–85)	Qualitative, cross- sectional	Randomly selected from London Stroke Register, UK	Stroke survivors' and spouses' description of how stroke affected lives (narrative)	Emphasis on: 'United couples, normality as couple'; 'Positive caring couples, mutual-reli- ance managing care'; 'Frustrated couples, care and marriage hardships'.



Robinson- Smith and Mahoney 1995 MMAT**** CASP 10/10	<i>Couples</i> Survivors N = 7 (NR; 60–79) Spouses N = 7 (NR; 62–82)	Qualitative, cross-sectional	Rehabilitation and community group (6 months post-stroke), USA	Factors affecting marital equilibrium	Stroke had major impact. Survivors reported feeling useless, uncertain and frustrated about getting better. Spouses gave attention to survivors' needs, precluding their own. One couple in conflict but rest co-ordinated activities and were working out a new relationship balance.
Schmitz and Finkelstein 2010 MMAT**** CASP 10/10	<i>Couples</i> <sup>6</sup> Stroke survivors N = 15 (65; 29–85) Partners of stroke survivors N = 14 (65; 29–85)	Qualitative, cross-sectional	Opportunistic sample, USA	Experiences of sexual issues	Two stroke effects: physical and relationship changes. Dynamics of care-giving altered role identity and established interaction patterns which affect sexual confidence, desirability and interest.
Tellier, Rochette and Lefebvre 2011 MMAT**** CASP 10/10	<i>Spouses</i> N = 8 (56.9; 45–69)	Qualitative, cross-sectional (3 months after discharge)	Hospitalised 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 six of eight citing conflict over survivors' changed behaviour (passive, avoidant or conflictual).
Thompson and Ryan 2009 MMAT**** CASP 10/10	<i>Survivors</i> Survivors of stroke N = 16 (56; 33–78) Spouse (NR)	Qualitative, cross-sectional	Stroke Nurse specialist registrar, UK	Impact of stroke on spousal relationships (importance of survivor's perspective)	Unable to continue with traditional roles. Anger and agitation frequent. Blamed frustration on impairments and dependence.

TABLE 1. (Cont.)

Author Quality rating MMAT <sup>1</sup> CASP <sup>2</sup>	<i>Participants</i> Survivors and spouses <sup>3</sup> (mean age; range)	Methodology (data collection points)	Recruitment, country	Research aim (theoretical framework)	Findings
Trygged, Hedlund and Kåreholt 2011 MMAT**** CASP 12/12	People aged 18–64 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, Runge and Jonsson 2009 MMAT**** CASP 10/10	<i>Couple</i> Stroke survivor N = 1 (81) Partner N = 1 (84)	Qualitative case study, longitudinal (7 months to 3 years)	Selected from larger study, The Netherlands	Older couple's experience (occupation)	Couple acted as one entity/col- laborated. Made use of differ- ent strengths. Mutual relationship strengthened by stroke.
Yilmaz, Gumus and Yilmaz 2015 MMAT*** CASP 8/10 <sup>7</sup>	<i>Survivors</i> 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.

Notes: NR: not reported. UK: United Kingdom. USA: United States of America. 1. Mixed-methods appraisal tool assessment: scores varying from 25 per cent (\*; one criterion met) to 100 per cent (\*\*\*\*; all four criteria met). 2. Critical Skills Appraisal Programme: score/number of criteria (number of criteria vary by type: qualitative and quantitative cohort, comparison or randomised). 3. Terms used by authors to describe survivors and spouses are used. 4. Not all marital satisfaction scores reported. 5. Contacted author for Quality of the Marriage Index scores. 6. Husbands and wives, but not necessarily couples married to each other. 7. Demographics other than sex of survivors not reported.

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, analytical processes); and the trustworthiness of the results. Second, the second author ensured that 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 and 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, Mays and Popay 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](#)). Six research programmes reported on different elements of the same study populations in multiple articles (e.g. McCarthy – two; McPherson – three; Kitzmuller – three) (18 articles are identified with † in the reference list). 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 US 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 of America (USA), Canada, United Kingdom, The 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 aged-matched population. Thirteen articles measured relationship satisfaction as a variable that could moderate the impact of stroke on depression, quality of life, care-giver 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 emphasised 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 the 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 organise 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 stroke survivors' dependence and need for care necessitated that spouses assume a care-giver 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 prioritising 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 care-giver roles (DeLaune and Brown 2001; Enterlante and Kern 1995).

Decision-making power shifted to spouses, but the changes to the established relationship standards were characterised as stressful for both spouses and stroke survivors. A common finding (ten studies: eight qualitative, two 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 (nine 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 recognise 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 over-protection increased the 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, 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 (four 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 care-giver 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 (six studies). Psycho-social relational problems such as: uncertainty about having sexual intercourse given stroke impairments, difficulty communicating about the relationship, and the stroke survivor no longer feeling desirable as a partner or 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.* 2009). Nine studies found care-giving 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 recognising 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 current post-stroke marriage and adjust daily interactions and long-term relationship goals to their 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 realise that a return to the hoped for meaningful marriage would not be possible (Brann *et al.* 2010; Kitzmuller and Ervik 2015; Kitzmüller *et al.* 2012).

Eight qualitative studies denoted that realisation 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, authors described two ways by which 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 (Kitzmüller 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 (Kitzmüller, 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 marriages*

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 care-giving/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 towards 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 their development pre-stroke. Authors described two forms in which relationships evolved. The most common evolution was towards a care-giving/receiving relationship, with a smaller proportion of relationships evolving as marriages. Quinn,

Murray and Malone (2014a), for example, categorised seven of eight relationships as care-giving because the power in the relationship was similar to the parental/child care dynamic. There was one exception to the care-giving/receiving marital relationship. One spouse valued the stroke survivors' ability to reciprocate emotional support, so the relationship was deemed typical of emotional reciprocity within marriages. Kitzmuller and Ervik (2015) characterised 12 of 16 relationships as care-giving/receiving based on how spouses spoke about sexuality and equity. In contrast to the majority of studies in the literature which depicted significantly more care-giving/receiving relationships than marital relationships, the proportions of care-giving/receiving and marriage relationships were almost equal in two studies (Radcliffe, Lowton and Morgan 2013; Robinson-Smith and Mahoney 1995). Radcliffe, Lowton and Morgan (2013) classified seven relationships as care-giving 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.

*Care-giving/receiving relationships.* Some marriages became care-giving/receiving in the transition to stroke and remained focused on care-giving despite the stroke survivors' recovery. Like Radcliffe, Lowton and Morgan (2013), a few other authors portrayed care-giving/receiving relationships as satisfying (Robinson-Smith and Mahoney 1995; Van Nes, Runge and Jonsson 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, Cohen-Schneider and Holzapfel 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 care-giving/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, Morris and Lockwood (2009) also found that five of seven spouses of stroke survivors referred mainly to their roles as 'care-givers'. They felt their lives were devalued and meaningless beyond their care-giving role.

*Marriages with new meaning.* In contrast to the loss of emotional qualities in care-giving/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.* 2013a) 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.* 2013a) 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 care-giving task load and because of relationship inequity. Spouses' perceptions of the care-giving role overload and being isolated at home intensified perceptions of being trapped in a care-giving role and because of an overall deterioration in the relationship (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 care-giver (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 care-giving or impairments *per se*. Backstrom, Asplund and Sundin (2010), for example, reported that spouses had care-giving procedures in place, but by six months love had changed to embarrassment and pity. Brann *et al.* (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, American and Belgian spouses' dissatisfaction with the marriage seemed to be tied to relational factors rather than to care-giving 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 care-giving 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, Moller and Blomstrand 2004; Godwin *et al.* 2013a, 2013b; Green and King 2010, 2011; Ostwald, Godwin and Cron 2009; Ostwald *et al.* 2009; Visser-Meily *et al.* 2009) and cross-sectional (McCarthy, Lyons and Powers 2012; McPherson *et al.* 2010, 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.*

2009). Similarly, American (McCarthy, Lyons and Powers 2012) and Canadian (McPherson *et al.* 2010, 2011) cross-sectional studies found that stroke survivors and spouses rated relationships as satisfying. When asked to rate marital happiness on a scale from 1 to 10, most Canadian spouses (89.2%) and stroke survivors (94%) rated happiness between 6 (happy) and 10 (perfectly happy).

High relationship satisfaction means suggest that many couples were able to re-establish or maintain mutually satisfactory relationships. A Swedish study that analysed stability, positive change and negative change in spouses' satisfaction with their 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 per cent of spouses and decreased for 27 per cent of spouses.

The second conundrum relates to satisfaction with care-giving/receiving relationships. The qualitative studies portrayed the majority of marriages as care-giving/receiving and care-giving/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 they were 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 care-giving/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 well-being 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 survivors' 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.* 2009).

These findings raise questions about differences 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 characterise their marriage when one partner requires significant care and support. This is particularly important given that, 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.* 2009). Our review underscores the need to understand how marriages function in the context of a stroke survivors' 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 care-giver 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 care-giver burden (compared with the burdens of relative or friend care-givers), have been explained in terms of the amount of time care-giving requires and the difficulty of care-giving 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 the stroke survivor 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 care-givers (Cameron *et al.* 2013; Quinn, Murray and Malone 2014a).

Based on the assumption that care tasks are burdensome, stroke care-giving interventions have focused on training spouses in practical care tasks and in finding respite time (*e.g.* see reviews of spousal care-giving and couple interventions: Bakas *et al.* 2014; Quinn, Murray and Malone 2014a).

However, while reviews confirm that care-giver task training reduces stress and burden in the short term (three months), in the long term there have been few differences between care-givers who receive skills training and those who do not (Cameron *et al.* 2014; Gaugler 2010; Lutz and Young 2010). Indeed, in his review of longitudinal care-giving studies, Gaugler (2010) found that most stroke care-givers quickly learned care skills. He suggested the care-giver–receiver relationship had been overlooked as a source of strain. Our findings support that hypothesis. Researchers in the USA and Belgium found that when stroke survivors were discharged from hospital,

spouses were stressed by care tasks. Longitudinally, however, spouses' burden of care increased and their satisfaction with the marital relationship decreased at each time measurement (Godwin *et al.* 2013a; Ostwald *et al.* 2009; 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 care-giving and higher-quality marriages.

These findings suggest directions for further research. First, it would be useful to know how stroke survivors and spouses characterise their roles and relationships. Differentiating between care and spousal roles could help investigators determine whether care-giver 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 care-giving skills are not likely to reduce the strain in marriages in which the spouse is a competent care-giver, 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 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). The biological risk factors for cardiovascular disease and stroke are similar, so we hypothesise that marital quality would have similar effects on stroke outcomes 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 hypothesise 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's disease, which have similar effects 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 synthesise the studies presented in this review. The thematic synthesis adhered to the Preferred Reporting Items of Systematic Reviews and Meta-Analysis (PRISMA). 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-Meilly *et al.* 2009). A few articles mentioned that younger couples have stressors that older couples lack (*e.g.* young children, loss of employment, stigma of stroke at a younger age) (Kitzmuller *et al.* 2012; McCarthy and Bauer 2015; Quinn, Murray and Malone 2014b), but stressed that having to adapt to changes in their reciprocal relationship roles was the challenge for husbands and wives at younger and older ages (Kitzmuller *et al.* 2012; McCarthy and Bauer 2015; Quinn, Murray and Malone 2014b). Future research should specifically consider how age and gender may 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 for some couples, about two-thirds were able to retain or regain the closeness in their relationship. This finding is particularly important given that 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, and the qualities of, the relationship between stroke survivors and their spouses as husbands and wives, as well as care-givers and receivers. Future research could include a greater focus on qualitative or mixed-methods approaches to explore the processes by which marriages and stroke survivors' and spouses' interactions can impact both partners' outcomes.

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\*Indicates articles included in the review; † indicates multiple studies of the same population.

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Address for correspondence:

Sharon Anderson,  
Department of Human Ecology,  
University of Alberta,  
302 Human Ecology Building,  
Edmonton, AB Canada T6 G 2N1

E-mail: [sdanders@ualberta.ca](mailto:sdanders@ualberta.ca)