

From partner to carer

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DOI:

[10.12968/ijtr.2018.25.8.405](https://doi.org/10.12968/ijtr.2018.25.8.405)

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Document Version

Peer reviewed version

Citation for published version (Harvard):

Killner, L & Soundy, A 2018, 'From partner to carer: motivation and experiences of role transition in spousal caregivers of people with multiple sclerosis - a thematic synthesis', *International Journal of Therapy and Rehabilitation*, vol. 25, no. 8, pp. 405-413. <https://doi.org/10.12968/ijtr.2018.25.8.405>

[Link to publication on Research at Birmingham portal](#)

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Checked for eligibility: 28/02/2018

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International Journal of Therapy and Rehabilitation

From partner to carer: motivation and experiences of role transition in spousal caregivers of people with multiple sclerosis - a thematic synthesis --Manuscript Draft--

Manuscript Number:	ijtr.2016.0020R1
Full Title:	From partner to carer: motivation and experiences of role transition in spousal caregivers of people with multiple sclerosis - a thematic synthesis
Article Type:	Critical review
Keywords:	Multiple Sclerosis, Caregiver, Qualitative, Review
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Abstract:	<p>Background: Review-based research is required to understand the spousal experiences and role transitions needed when care giving for patients with multiple sclerosis. The aim of the current study was to meet this need by undertaking a synthesis of qualitative research from the experiences of patients with MS.</p> <p>Methods: A qualitative thematic synthesis was undertaken in 3 stages: (1) systematic search for literature, (2) critical appraisal of included studies and (3) synthesis of data using an a-priori framework.</p> <p>Findings: A total of 10 studies with 120 spousal caregivers were included. Three major themes were identified: (1) motivation for care, (2) role transition and (3) relationship changes.</p> <p>Conclusions: The findings present a variety of motivations amongst spousal caregivers, and report both positive and negative experiences of transition and relationship change. These findings have important implications for healthcare professionals, who work closely with caregivers in practice.</p>

Title Page

From partner to carer: motivation and experiences of role transition in spousal caregivers of people with multiple sclerosis – a thematic synthesis

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Word Count: 3463

Abstract

Background: Review-based research is required to understand the spousal experiences and role transitions needed when care giving for patients with multiple sclerosis (MS). The aim of the current study was to meet this need by undertaking a synthesis of qualitative research from the experiences of spouses of people with MS.

Methods: A qualitative thematic synthesis was undertaken in 3 stages: (1) systematic search for literature, (2) critical appraisal of included studies and (3) synthesis of data using an a-priori framework.

Findings: A total of 10 studies with 120 spousal caregivers were included. Three major themes were identified: (1) motivation for care, (2) role transition and (3) relationship changes.

Conclusions: The findings present a variety of motivations amongst spousal caregivers, and report both positive and negative experiences of transition and relationship change. These findings have important implications for healthcare professionals, who work closely with caregivers in practice.

Key words: multiple sclerosis, thematic synthesis, spousal caregivers, motivation, role transition, and experiences

1. Introduction

In the UK there are over 6.5 million caregivers (Carers UK, 2015), contributing an estimated £119 billion of care per year (NHS England, 2014). Around 30% of people with Multiple Sclerosis (MS) need informal care, most frequently (upto 78% of individuals with MS) this is provided by the spouse and 80% is provided by unpaid caregivers (Hillman, 2013). Informal care to individuals with an EDSS score of 7-9 can cost over 20, 000 € per patient per year in some studies, equalling the highest costs of care (Kobelt et al., 2017). A caregiver, is someone who provides unpaid, voluntary support to an ill, older or disabled friend or relative, in order to assist them with their daily activities (Department of Health, 2013). As a result, caregivers can relieve pressure and financial burden on the nation's healthcare services, however there is a high caregiver burden associated with this (Corry and While, 2009), including significant deterioration in mental well-being (high personal distress, more negative feelings) (Bayen et al., 2015) and higher medication use for anxiety, stress and mood disorders (McKenzie et al., 2015). Deterioration of the spouse's mental well-being is more significant when the partner with MS has a greater level of disability and/or worse mental well-being (Figved et al., 2007). This is true of caregivers who support patients with MS, notably at later more debilitating stages of the disease or during relapses (McKeown et al, 2003).

Spousal caregivers are uniquely, and arguably most significantly, affected by the responsibility of giving care (McKeown et al., 2004; Corry and While, 2009; Pakenham and Samios, 2013). Spousal caregivers experience significantly higher levels of distress and poorer quality of life compared to all other groups of caregivers

(Figved et al., 2007). It is important that health care professionals understand, what motivates the caregivers engagements with patients, what the perceived pressures on caregivers' are and what change in relationships can occur following the onset of MS (Curry et al., 2009).

Qualitative based review evidence has provided a useful way to access an indepth understanding of this information (McKeown et al., 2003; Corry and While, 2009; Topcu et al., 2016). Only the most recent review (Topcu et al., 2016) has provided an idea of the factors which influence the carers motivation including; (a) a sense of duty (varying from those willing to those who felt obliged), (b) the need to maintain some degree of 'normality', although this could be restricted because of limited sources of support, and (c) benefits were identified by some caregivers such as achievements gained from the role. However, further details about the factors that motivate spouses are needed and research is required that considers the transition to becoming a spousal caregiver. In particular motives can be considered by utilising past understanding. Notably, Schluz et al. (1989) proposed three main motives for caregiving: altruism, egoism and social norms. Altruistic motives have the goal of promoting the welfare of others and are largely provoked by empathy. This is likely to be seen in close relationships, such as spouses, where there is genuine concern for the other person's well-being (Maner and Gailliot, 2007). In contrast, egoistic motivations are self-serving, often seeking reward or avoiding punishment (Schluz et al., 1989). Social norms (such as marital commitments for spouses' of patients with MS) may also influence a person's behaviour and bring an element of expectation to assume the role (Pakenham and Samios, 2013).

Given the above, the aim of the current study is to undertake a qualitative review that extends past understanding on the spousal caregivers

experiences, motives and challenges as they transition to the role. This will focus on understanding the factors and processes that influence their motivation for the role.

Methods

A subtle-realist paradigmatic position was assumed. A thematic synthesis using a three-stage approach was selected (Thomas and Harden, 2008); (a) systematic search, (b) critical appraisal of research and (c) synthesis of results from included studies.

2.1 Electronic Search

An electronic database search was conducted from inception of databases until January 2016 including; CINAHL, Medline, Embase, ProQuest Nursing and Allied Health Source, PsycINFO and Scopus databases. Search terms related to design (qualitative, mixed methods), sample (multiple sclerosis, MS, spouse, couples, carer, caregiver) and phenomenon of interest (motivation, motivation for care, experience, role, role transition) were used. Standard Boolean operators were used and qualitative filters were applied where available (Noyes et al., 2011). Other search strategies included citation chasing and consideration of key authors' e-profiles.

2.2 Eligibility Criteria

Studies that satisfied all domains of the following 'SPIDER' criteria (Cooke, Smith and Booth, 2012) below:

S – Sample

To be included, studies had to focus on spouses who provide care to their partner with MS. Studies including other caregivers, for example parents, siblings or children, were excluded.

PI – Phenomenon of interest

Studies were included if they considered the caregivers' experiences of transition from partner to caregiver, including either role, motivation, motivation for care, relationship or occupational changes. Studies reporting on an intervention for a couple were only included if findings related to experiences outside the intervention.

D – Design

Any type of qualitative design was considered. Mixed method studies were included if a synthesis of the qualitative findings was clearly reported. Studies using quantitative methods, case studies and all literature reviews were excluded.

E – Evaluation

Studies were included where interviews or focus groups were used to explore and document the motivations or role transitional experiences of spousal caregivers.

R – Result Type

Studies were required to report qualitative results and were only included if they were published in English. Where studies reported the same results across multiple publications only the first study was included.

2.3 Consolidated Criteria for Reporting Qualitative Studies (COREQ)

A modified 13-item COREQ tool (Soundy, et al., 2016a) was used to appraise the methodological quality of the eligible studies. Three domains (research team and reflexivity, study design, and analysis and findings) were assessed to establish the integrity and transparency of the studies, and consequently imply the trustworthiness of their findings. A total score of 13 could be obtained and a score of less than 7 was further critiqued by both authors with two questions: Are the findings unbelievable or questionable (e.g., do the verbatim quotes link with the text?, is there very limited

description of themes or explanation of minor units? And is there any reason to exclude this article, if so, how do these weaknesses impact on the findings? Articles were excluded after this, if they were considered independently as fatally flawed¹. Disagreements were arbitrated by a third author. No disagreements occurred. The critical appraisal was used as a way to exclude studies and to establish confidence in findings of individuals studies. The purpose of the synthesis was not to claim a 'truth' or a single reality where quality of the individual studies moderates the results, rather the aim was to establish a common reality which others can relate to based on consistency of results. It is important to note that many aspects which assess quality e.g., if someone has not reported reflexivity is less important to this process (considering the selected paradigmatic position) than it would be to assessing bias within a quantitative based review. It is also important to note that reporting in qualitative studies may also be limited by the word limits of journals.

2.4 Synthesis

The synthesis was conducted in 3 phases: (1) key concepts that had been identified in previous literature reviews (McKeown et al., 2003; Corry and While, 2009; Quinn et al., 2010) were used to identify a broad a-priori framework to establish themes to group content into. (2) Idea webbing was used to explore the relationships between these concepts (Arai et al., 2007). (3) Line-by-line coding enabled direct quotes relating to the imported concepts to be extracted, and were presented in tabular format (Arai et al., 2007). An audit trail of this process is

¹ A term used to identify that a study has compromised findings and has been assessed as untrustworthy.

available from the primary author. In order to present the most common caregiver experiences, codes supported by two or more studies were reported in the results.

3. Results

3.1 Literature Search

The literature search yielded a total of 158 results of which 10 were included (Boeije et al., 2003; Boeije and Van Doorne-Huiskes, 2003; Bogosian et al., 2009; Boland et al., 2012; Cheung and Hocking, 2004; Courts et al., 2005; Heward et al., 2006; Mutch, 2010; Neate et al., 2018; Starks, et al., 2010). This included 120 spousal caregivers (mean age of caregivers was between 50 and 63 years; 4/10 studies), and the overall age range was 20 to 77 years (8/10). Two studies (Bogosian et al., 2009; Mutch, 2010), reported an average number of years as a spousal caregiver as a median of 29 and a mean of 9 years respectively (the range across studies was between 2-27 years). Most often studies were conducted in the UK (3/10) or USA (2/10). The PRISMA flow diagram (Moher et al., 2009) in Figure 1 represents the complete search process.

INSERT FIGURE 1 AROUND HERE

3.2 Critical Appraisal

A mean score of 7.4/13 (± 2.5) was identified across all studies. The within tool analysis identified Domain 1 (research team and reflexivity) as the weakest domain across all studies, scoring 2.1/5 (± 1.2) on average. Within this, only one study (Neate et al., 2018) reported pre-established relationships with participants, and reporting of participant knowledge of the researcher was rare (3/10). Domain 2 (study design) was an overall stronger domain, averaging 3.2/5 (± 1.1). Interview guides were not frequently reported (4/10) and only 4 studies (4/10) discussed. Domain 3 (analysis and findings) gained the highest scores across all studies, with an average of 2.3/3 (± 0.6). The reporting of minor themes and diverse cases were often not

acknowledged within the studies (2/10). The methodological quality of all the studies was found to be satisfactory and their findings trustworthy. A complete summary of COREQ scores can be obtained from the corresponding author.

3.3 Synthesis

Three themes are presented: (1) motivation for care, (2) role transitions and (3) relationship changes. A further version of the results with allocated references is available from author LK. Table 1 provides an overview of the thematic structure and verbatim quotes.

INSERT TABLE 1 AROUND HERE

3.3.1 Motivation for care

Many studies discussed the motivations of caregivers to provide care for their spouse. Five subthemes were incorporated in this theme.

Love

The love that caregivers felt towards their partner (4/10) was a motivator. Many wanted to continue having a long and happy life with their partner (3/10), and felt they could enable this by assuming the caregiving role. For these caregivers, it was clear there was no question as to whether they should provide care for their spouse; it was something they wanted to do out of love and marital loyalty.

Duty

Conversely, some spouses felt obligated to become caregivers to their partners (4/10). These spouses felt there was a sense of inevitability in the role, as they believed that the professional support they received did not adequately meet their partners' needs, and therefore they had no choice but to provide additional care

(3/10). Furthermore, they reported an element of social pressure and expectation which influenced their decision to become caregivers for their spouse (Boeije and Van Doorne-Huiskes, 2003). Some of the caregivers believed that this was reflected in their marriage vows and the loyalty that they pledged (2/10), and many felt that there was no escape from the promise to support their spouse in sickness and health (3/10).

Fear of institutionalisation

Fear of institutionalisation amongst people with MS was reported (3/10) and was thought to derive from negative media representation and previous experiences. As a result, many spouses were motivated to care for their partner in order to respect their wishes and prevent admission (2/10). Other fears were highlighted; for instance a fear of losing their partner and the life they shared together and a fear of failing their partner and the guilt associated with this (2/10).

Reciprocity

Another motivational factor for caregivers was the concept of reciprocity (3/10). Some caregivers were grateful for all the things their spouse had done in health, and felt they owed it to them to return the favour by caring for them during their illness. Similarly, the idea of 'virtual reciprocity' was identified (3/10), in other words caregivers felt they should act in a way their spouse would have, had the situation been reversed.

Other motivational factors

Finally, other caregivers had unique motivations that may resonate with caregivers outside of this review. Two spouses already knew their partners' diagnosis when they got married, but admitted some naivety of the future burden and losses

they were to experience (2/10). Others reported acting out of sympathy for their partner, or were motivated by the gratitude they showed. Another caregiver remained motivated to care for her spouse as long as she had planned respite for this patient that was a holiday each year by herself. One particularly diverse case was a lady who did not identify as a caregiver, despite carrying out multiple caregiving tasks for her spouse (Heward et al., 2006). In this incidence, she was happy to continue her role without identifying a factor that motivated her.

3.3.2 Role transition

This theme reports the experiences of spousal caregivers when assuming a new role and some of the challenges and decisions they faced as a consequence. Three sub-themes were identified:

New Roles

One of the greatest challenges for the spouses of people with MS is the transition to caregiving itself (10/10). Some caregivers felt it was a change that was imposed upon them to which they were simply expected to adjust (3/10). Others believed it was a more gradual transition, and the true extent of the change can only be appreciated in hindsight (3/10). For many, the demands of caregiving felt like a 'full-time job' (5/10) and soon became the main focus of their lives, with one caregiver stating she was on "*24 hour standby*".

Caregivers responded to their new role in different ways. Some caregivers thrived, feeling a sense of achievement and reward that they were able to assist their spouse through a difficult time (4/10). This was identified in working as a 'team' (Boland et al., 2013) and adopting coping strategies for instance; dealing with

problems as they arised, accepting the change that occurred or gaining access to specialist equipment.

Others found the role easier because of previous experiences of caregiving (Starks et al., 2010). In contrast, some caregivers appeared resentful of the role (2/10). For these caregivers, they felt limited by their partner's increasing and on-going care needs and the responsibilities that this entailed. One husband described caregiving as *"a nice name for a slave or dogsbody"* (Heward et al., 2006, p.193).

Alongside the transition to caregiver, came the shift of other responsibilities. Many studies discussed a 'role reversal' (5/10), for instance this could include taking on household and domestic tasks (4/10), parenting responsibilities (4/10) and financial management. It was reported that some caregivers were initially fearful of the role reversal and new responsibilities (2/10). The caregivers could be inhibited by a sense of feeling vulnerable or not knowing what to do with this change e.g., one lady stated she had always been a housewife supported by her partner (Cheung and Hocking, 2004). Others faced unique challenges secondary to the loss of a co-parent (4/10). Conversely, some caregivers were able to adapt to their new roles, and recognise their own personal development (3/10). These caregivers could have a more optimistic attitude towards their new roles and were proud of their achievements, despite their life trajectories falling short of expectation.

Employment

The addition of new and time-consuming roles inevitably encroaches on other responsibilities. Reducing or giving up employment altogether was the only option for some caregivers (4/10), who were struggling to maintain their caregiving responsibilities alongside their paid work. This sacrifice often came with further

losses, including loss of a stable income (2/10) and loss of social outlet (2/10). These caregivers would mourn the loss of their identity (3/10). Furthermore, they felt there was a stigma associated with unemployment. For others, they continued to juggle the demands of work and caregiving to sustain a meaningful life (2/10). However, this was not without hardship; some described a 'second-shift' (a reference to relationship as a job) on returning home (Boeije and Van Doorne-Huiskes, 2003). Some identified new opportunities as a result of caregiving (2/10); For example becoming involved with the MS society. Engagement with meaningful activities provided satisfaction, a sense of purpose; better prospects, motivation as well as self-confidence.

Leisure

Experiences surrounding leisure followed a similar format to those of employment. Whilst some caregivers had to give up their hobbies and interests (5/10), others were able to adapt and accommodate for leisure activities (3/10) or engage in new ones (3/10). Those who were forced to give up their recreational activities felt they were bound to their homes and caregiving duties, and would worry if they were to leave their spouses alone (Mutch, 2010). Furthermore, some believed all spontaneity had been lost from their lives due to the unpredictable nature of the disease, and the restrictions it imposed (5/10). As a consequence, many activities that the couples once shared became increasingly difficult to do; couples were often forced to bring forward plans as MS allowed, however sometimes plans were lost all together (2/10). Many caregivers dreamed of going on holiday, but avoided making long-term plans as they were unsure of the progression of their spouses' condition (5/10). For other couples, they were still able to continue their leisure activities with some adjustment (4/10). For instance, one husband bought his wife an adapted van so she was able to continue driving. Similarly, new hobbies were also discovered

through the loss of old (3/10), for instance going to the cinema replaced reading when sight changes prevented it.

3.3.3 Relationship changes

This theme discusses the contrasting experiences of caregivers within their marital relationships. Two subthemes were identified:

Becoming closer

Many caregivers expressed a strong and loving commitment to their spouse (4/10). For these caregivers, they had a great desire to stay with their spouse for as long as possible (3/10), and this motivated them to face the challenges of MS with fierce determination. These couples were able to coordinate their efforts and adapt in order to overcome these challenges (6/10), and caregivers commonly reported that having open and honest discussions (often sharing fears and concerns) with their spouse was essential to allow this (3/10). Many caregivers believed that their relationship had become somewhat stronger as a consequence (3/10). The relationship may have been enhanced by putting the other's needs first and become resilient to the challenges presented by MS through admiration and respect for their spouse (Boland et al., 2009).

Two studies investigated the apparent attributes of couples whose relationship prospered in the face of adversity (Mutch, 2010; Starks et al., 2010). Both studies concluded that the most successful couples had often had a long marriage prior to the diagnosis of MS (2/10).

Challenges and loss

On the contrary, some caregivers felt that MS had taken a toll on their relationship (8/10). Many felt they had regressed to a care-based relationship (3/10) and had become more distant from their spouse (3/10), in some cases viewing them as a patient. For many, they believed they had lost the person they had married (3/10) and the equal partnership they once shared (2/10).

Some caregivers blamed a lack of open discussion about their problems for the distancing of their relationship (3/10). Some felt their partners simply avoided any serious conversations, whereas others felt it was more limited by their spouses' declining cognitive state (2/10). Furthermore, their spouses' negative behaviours (for example, criticism of their efforts, lack of gratitude and pessimistic attitude) led to resentment amongst caregivers (3/10) and increased tension and arguments (3/10).

Relationships were further burdened by financial problems, secondary to their loss of employment (2/10). Under this new strain, they were no longer able to do the activities they once did together (2/10) and previously complementary partnerships could become unbalanced, and couples were often unable to adapt and work together (2/10). This sometimes sparked doubts about the caregiver's ability to cope in their new role and raised questions about whether to remain in the marriage (3/10).

4. Discussion

This review has provided a unique synthesis of the experiences of spousal caregivers by focusing on role transition and the motivating factors that influence continued caregiving. The current findings suggested that caregiving motivated by love towards one's spouse was a factor which was as equally important to individuals as the perceived obligation and duty to provide care. Previous research has illustrated that love is the strongest motivator of all (Quinn et al., 2010). Whilst love is altruistically driven (Maner and Gailliot, 2007), egoistic motives such as duty, reciprocity and fear of institutionalisation were also found to be highly influential on the motivation and commitment of caregivers. Importantly, the motivations of spousal caregivers vary significantly on a case-to-case basis.

The sacrifices caregivers made were directly related to their own life and this was represented by losses of roles and assumed social identities. Past research supports these findings suggesting this experience is both negative and challenging (Buhse, 2008). However, In addition to this research has identified positive changes in social identities (Cheung and Hocking, 2004) and obtaining a sense of reward and satisfaction (Corry and While, 2009). This review highlighted changes in employment and leisure as two key losses relating to the caregivers identity. This perceived loss of identity could be associated with a fear regarding the individuals future prospects and resentment regarding the new role acquired. The current results suggested that the transition to caregiving requires a process of adjustment. Assessing a caregiver's adaptation and hope (Soundy et al., 2016b) may be key to understanding if further support for the caregiver is required.

Contrasting experiences were also evident within the marital relationships of caregivers. Whilst some relationships flourished, others appeared defeated by the challenges and strains that MS entailed. The most successful relationships were created when couples prioritised their commitment to each other, co-ordinated their efforts and actively adopted coping strategies. These factors appeared to assist in the transition to a caregiving role and may be more prevalent in couples who are married for longer and adapt because of their established partnership (D'Ardenne, 2004). Open and honest communication appears to be a critical factor in allowing their relationship to prosper (Gordon and Perrone, 2004). One reason for this is because it facilitates a mutual understanding between the spouses, encourages empathy and enables gratitude towards one another (Mutch, 2010). Caregivers in less successful marriages may not be able to adapt in this way. They reported a breakdown in communication, secondary to their spouse's cognitive decline or negation of their disease, and had difficulty dealing with their changed behaviours and roles. A lack of communication led to conflict between the spouses and raised questions about the sustainability of the marriage (Gordon and Perrone, 2004).

4.2 Limitations

Several limitations are noted: Studies that were not written in English were excluded. Further to this, the findings of the review are based upon a limited number of qualitative studies and limited by the interpretation of the authors and type of analysis used. The findings may be limited by the strict eligibility criteria and the paradigmatic position taken.

4.3 Implications for Practice

HCPs need to understand the unique motivations of spouses and be mindful that not all spouses are predominantly motivated by love. HCPs need to identify the value of spouses ensuring open conversations and sharing experiences. HCPs may require empathetic communication styles because of the loss and change experienced. HCPs may benefit from identifying the needs of caregivers. Marital success may be enhanced by adopting effective coping strategies during a caregiver's transition of to the role of carer. Honest communication appeared to allow couples to share their fears, problems and frustrations, and may be important in working as a team.

4.4 Conclusion

HCPs need to understand and support spousal caregivers' transitions in their role and understand factors that influence these experiences. Further research should aim to establish the relationship between these concepts, and how they may change over time.

Conflict of Interest: None

Funding: No funding was obtained.

Acknowledgements: None

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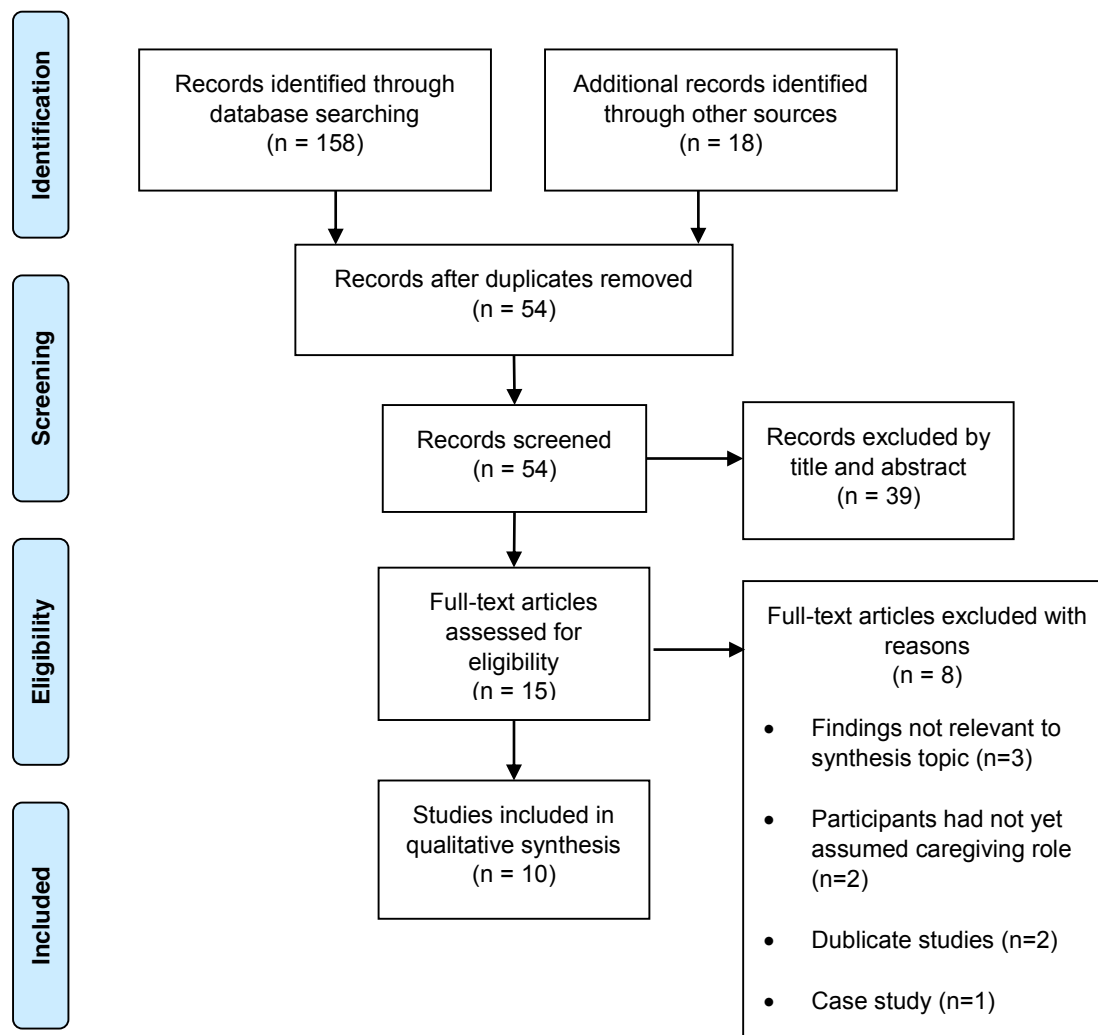


Figure 1. PRISMA flow diagram (Adapted from Moher et al., 2009)

Table 1 The thematic overview from results and example units

Theme	Sub-Theme	Example Units
Motivation for care	Love	<p>"Marriage longevity and its vows, along with attitude and outlook on life by both partner and spouse, were the major motivational factors in staying together." (Mutch, 2010)</p> <p>"Leaving him is out of the question, so I'm left with my back to the wall. I can only do all this because I love him" (Boeije et al., 2003)</p>
	Duty	<p>"Several spouses pointed out their belief in marriage and in the vows they have taken. They have promised to take care of each other and they support this notion." (Boeije and Van Doorne-Huiskes, 2003)</p> <p>"Acceptance was reflected in a factual way, in that it was a duty that had to be performed in order for the day to proceed for both of them" (Heward et al., 2006)</p>
	Fear of institutionalisation	<p>"People with disabilities as well as caregivers share the fear of institutionalisation. Throughout the caregiving process, caregivers have demonstrated a commitment to prevent such an admission" (Boeije et al., 2003)</p> <p>"I've always felt it a bit rewarding about the way that we have stayed together and that Jan hasn't been sort of left [in a nursing home]." (Cheung and Hocking, 2004)</p>
	Reciprocity	<p>"Reciprocity in the relationship is an important motivation for some to continue caregiving. Others are motivated by an idea of virtual reciprocity: if they had become ill, their partner would have taken care of them instead" (Boeije and Van Doorne-Huiskes, 2003)</p> <p>"there was a resignation at 'MS', due to the knowledge that either person could have got it" (Mutch, 2010)</p>
	Other motivating factors	<p>"A break away from care giving, no matter how short, was essential for the partners and motivated them to continue in their role." (Mutch, 2010)</p> <p>"People with disabilities... are grateful to their partners for keeping their promise and taking care of them. In turn, this motivates caregivers to go on." (Boeije et al., 2003)</p>
Role transitions	New Roles	<p>"Having taken over added responsibilities from their partner, some participants were amazed at what they could actually do and fit into 24 hours." (Cheung and Hocking, 2004)</p> <p>"You are thrown into a role, you learn it; it's a very healthy thing" (Courts et al., 2005)</p> <p>"I was the doer and the shaker and the mover in the relationship. When I became less able to do a lot of that, [Husband] had to do more stuff...All of a sudden he's more in charge of things that he used to be" (person with MS) (Starks et al., 2010)</p>
	Employment	<p>"What I find very hard is that when I stopped working altogether two years ago I lost contact with the world and social contact with colleagues and customers." (Boeije and Van Doorne-Huiskes, 2003)</p> <p>"At odd times I get a flash that somebody is regarding me in a lesser light because I don't work, [because] I don't have any sort of identity that they can respect, or relate to." (Cheung and Hocking, 2004)</p>
	Leisure	<p>"Over the case of their life with MS, they were generally able to recalibrate and continue to do things that were meaningful to them, including working their jobs and finding ways to have fun with their partner and families." (Starks et al., 2010)</p> <p>"The main frustration for all partners was that spontaneity had been taken out of their lives. No longer could they 'just nip out' to go somewhere without it becoming a major expedition" (Mutch, 2010)</p>
Relationship changes	Becoming closer	<p>"It was tough... but within 3 years, we as a couple had adapted" (Courts et al., 2006)</p> <p>Some couples show a strong commitment to overcoming the problems together." (Boeije et al., 2003)</p>

		<p>"The couples' experiences were analogous to a three-legged race in which they must coordinate their efforts to achieve their goals. Four couples appeared to be in-sync and appeared to be 'on the same foot', working together to actively move forward in the lives and relationships" (Starks et al., 2010)</p>
	Challenges and loss	<p>"our relationship has changed. It has become more distant I think. It is more a care-based relationship now. And that is quite a different thing" (Boeije, et al., 2003)</p> <p>"He gets very angry, and quite rightly he takes that out with me, because that's what you're there for to some extent, and sometimes it is difficult to remember that he's not angry with you, he's angry about being frustrated that he can't do what he used to be able to do etcetera. And you kind of learn to let that go ... but not always [laughs]" (Bogosian et al., 2009).</p> <p>"Mrs T's relationship is burdened by all these difficulties. She takes her husband's reaction personally and is negatively affected by it. She cannot remember an occasion of intimacy and therefore feels she is his nurse rather than his wife" (Boeije and Van Doorne-Huiskes, 2003)</p>

Appendices

Appendix 1: Full-text excluded studies

Author	Reasons for exclusion
Blank and Finlayson (2007)	Does not address role transition, focuses on coping strategies employed by couples with MS
Bogosian et al. (2009)	Participants had not yet assumed caregiving role, as study investigates the early stages of MS.
Boland et al. (2012)	Does not address role transition, focuses on coping strategies. Caregiver experiences not clearly distinguishable from person with MS.
Cheung and Hocking (2004a)	Does not address role transition, focuses on caregiver burden and worry post-transition.
Strickland, Worth and Kennedy (2015)	Participants do not identify as caregivers, and did not specify spousal caregivers.

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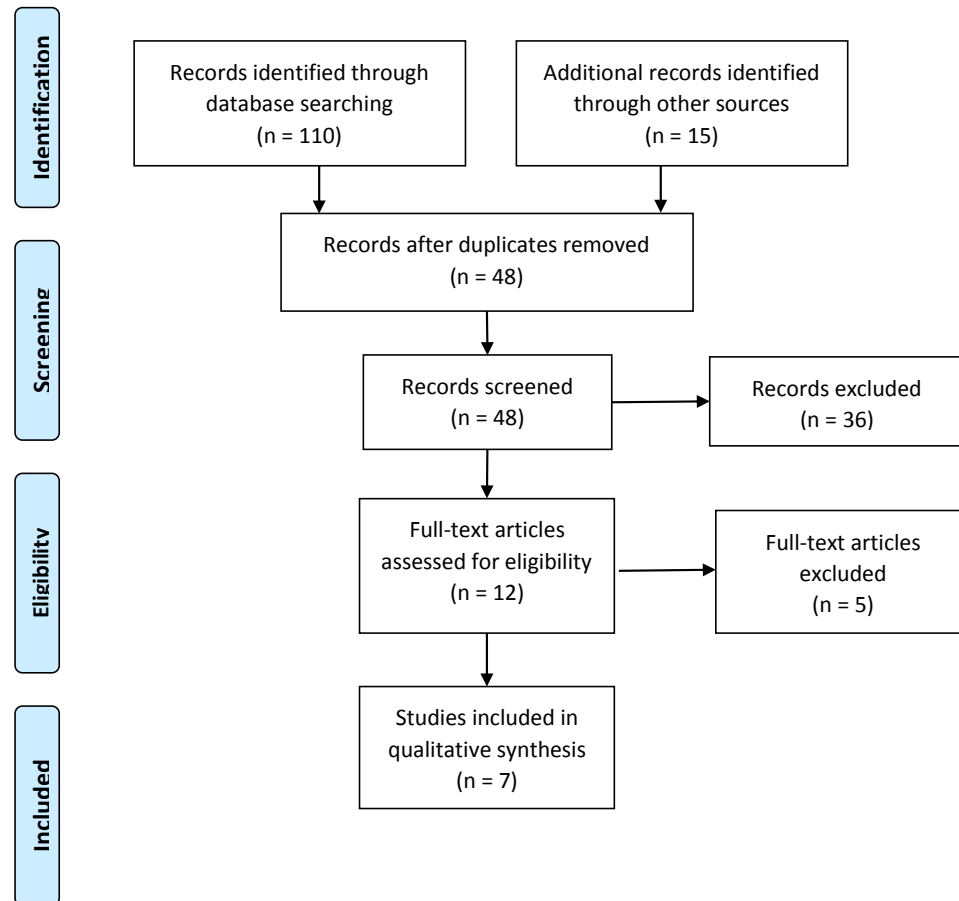
Appendix 2: Included study characteristics

Study	Qualitative method	Participants	Sampling and setting	Data collection, study aims and analysis
Boeije, Duijnste and Grypdonck (2003)	Unstructured interviews	<p>17 spousal caregivers: 10 male and 7 female Age 39 to 77 years (mean: 58 years) Years caring for spouse: not specified</p> <p>17 people with MS: 7 male and 10 female Age 44 to 78 years (mean: 57 years) Time since diagnosis: 4 to 49 years (mean: 20 years)</p>	<p>Sampling: purposive</p> <p>Eligibility criteria: (a) people who lived at home, (b) were highly dependent as a result of their MS and (c) received care from their partner.</p> <p>Setting: all in participants homes, except one caregiver who was interviewed in his office at work. Participants were interviewed separately, however in 6/34 interviews the spouse was present (reasons provided).</p> <p>Study location: Netherlands and Belgium</p>	<p>Data collection tool: interview loosely structured around open questions dealing with a range of themes derived from the literature</p> <p>Study Aim: <i>“examine how commitment is established between people who have become dependent on care as a result of their MS and their spouses, and what their roles are in the maintenance of the caregiving role when total care is provided”</i> (page 243)</p> <p>Average interview time: 45 minutes Interview time range: 30 minutes – 1.5 hours</p> <p>Analysis: constant comparative analysis</p>
Boeije and Van Doorne-Huiskes (2003)	Semi-structured interviews	<p>13 spousal caregivers: 8 male and 5 female Age 48 to 75 years (mean: 60 years) Years caring for spouse: not specified</p> <p>13 people with MS: 5 male and 8 female Age 44 to 69 years (mean: 58 years) Time since diagnosis: males (mean: 25 years), females (mean: 13 years)</p>	<p>Sampling: purposive</p> <p>Eligibility criteria: researchers specified they wanted to include people who differed in various respects (e.g. perceived burden, years of ‘service’)</p> <p>Setting: not specified. Participants were interviewed separately. Interviews with person with MS were conducted <i>“with a view to obtain additional information on the perspectives of the caregivers”</i> (page 228)</p> <p>Study location: Netherlands and Belgium</p>	<p>Data collection tool: Topics derived from the literature. Participants asked how they saw their caregiving role and how caregiving had changed their lives.</p> <p>Study Aim: <i>“examine how spouses experience caregiving when predominantly motivated by a sense of duty and address whether any differences between female and male caregivers can be detected”</i> (page 223)</p> <p>Average interview time: 45 minutes Interview time range: 30 – 90 minutes</p> <p>Analysis: constant comparative analysis and interpretative methodology</p>
Cheung and Hocking (2004b)	Unstructured in-depth interviews	<p>10 spousal caregivers: 6 male and 4 female Age 40 to 60 years (mean: not specified)</p>	<p>Sampling: purposive</p> <p>Eligibility criteria: (a) speak English, (b) provide at least 1 hour of hands-on care for</p>	<p>Data collection tool: the leading question was “What is it like for you to be caring for (name)?”</p>

		Years caring for spouse: not specified, but years since diagnosis was 5< years	their partner per day and (c) their partner has been diagnosed with MS for at least 5 years Setting: participants homes Study location: Australia	Study Aim: <i>“to explore how spousal carers of people with MS interpreted their lived experience with their partner, the way in which they assigned meanings to their being in such a situation, and the skills and knowledge they have developed to live with their situation”</i> (page 154) Average interview time: not specified Interview time range: 1 – 2 hours Analysis: interpretative (hermeneutic) phenomenology
Courts, Newton and McNeal (2005)	Focus groups	8 male spousal caregivers: Age 31 to 67 years (mean: 50 years) Years caring for spouse: not specified, however time since diagnosis was 2 – 11 years (mean: 5.5 years) 4 female spousal caregivers: Age 50 to 65 years (mean: 55 years) Years caring for spouse: not specified, however time since diagnosis was 8 – 10 years (mean: 9 years)	Sampling: snowball Eligibility criteria: not specified Setting: not specified Study location: USA	Data collection tool: 2 focus groups (same sex group) where participants spoke freely about their experiences Study Aim: <i>“to investigate the experiences of persons whose spouses have MS”</i> (page 20) Average interview time: 1.75 hours Interview time range: 90 minutes – 2 hours Analysis: thematic analysis
Heward, Molineux and Gough (2006)	Semi-structured in-depth interviews	9 spousal caregivers: 5 male and 4 female Age range and mean: not specified Years caring for spouse: not specified, however time since diagnosis was 3 – 40 years (mean: 18 years)	Sampling: purposive Eligibility criteria: (a) relapsing/remitting or secondary progressive MS, (b) partner to have an intimate relationship with the individual diagnosed with MS before diagnosis, (c) partner to have no major health complaints and (d) individuals who are not going through a crisis situation Setting: place of participants choosing, but partner with MS was not present Study location: UK	Data collection tool: Interview schedule informed by the literature, guiding participants through their past, present and future occupational engagements. Study Aim: <i>“the way in which MS can affect family life, particularly exploring how it affects the occupations of the partner”</i> (page 188) Average interview time: not specified Interview time range: not specified Analysis: grounded theory analysis
Mutch	Semi-	8 spousal caregivers:	Sampling: homogenous	Data collection tool: interviews followed a

(2010)	structured interviews	4 male and 4 female Age 50 to 74 years (mean: 63 years) Years caring for spouse: 5 – 20 years (mean: 9 years)	Eligibility criteria: (a) living with a person with a confirmed diagnosis of MS (b) partners provided at least 2 hours hands-on care per 24 hours and (c) couples had not been in direct contact with the researcher in the past year Setting: not specified, however person with MS not present Study location: UK	semi-structured questionnaire covering: living with MS, support in the caring role, the impact of MS on the partners, motivation for caring and family/professional support Study Aim: “(a) understand the experience of partners’ role as they perceived it and (b) to explore strategies partners use to manage their caring role” (page 215) Average interview time: not specified Interview time range: 40 – 60 minutes Analysis: thematic analysis
Starks, et al. (2010)	Semi-structured interviews	8 spousal caregivers: 6 male and 2 female Age range and mean: not specified Years caring for spouse: not specified 8 people with MS: 2 male and 6 female Age 40 – 69 years (mean: 52 years) Time since diagnosis: 1 – 21 years (mean: not specified)	Sampling: purposive Eligibility criteria: (a) age 18 or older, (b) consent by both individuals, (c) residence within 50 miles of the university and (d) one partner diagnosed with MS Setting: University of Washington. The first two couples were interviewed separately, but the researchers found very similar content so interviewed the remaining six couples in joint interviews. Study location: USA	Data collection tool: interview guide that explored strengths and challenges in their relationship, role changes and support Study Aim: “to examine how couples adapt to the challenges of MS and to identify possible risk factors for relational stress” (page 196) Average interview time: not specified Interview time range: not specified Analysis: not specified. Description of coding and analysis given (case-by-case and based on concepts from interview guide)

Appendix 3: PRISMA flow diagram (Moher et al., 2009)



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Appendix 4: COREQ scores (Soundy et al., 2016)

Study	Research team and reflexivity	Study design	Analysis and findings	Overall score
Boeije, Duijnste and Grypdonck (2003)	2/5	4/5	2/3	8/13
Boeije and Van Doorne-Huiskes (2003)	3/5	4/5	3/3	10/13
Cheung and Hocking (2004b)	2/5	4/5	2/3	8/13
Courts, Newton and McNeal (2005)	3/5	2/5	2/3	7/13
Heward, Molineux and Gough (2006)	3/5	5/5	3/3	11/13
Mutch (2010)	3/5	3/5	2/3	8/13
Starks, et al. (2010)	2/5	3/5	2/3	7/13

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Appendix 5: Thematic synthesis (stage 1) – Motivation for care

Study	Quotes	Comments	Subthemes
Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> They have gone along with giving help without fully realising the consequences and they have underestimated what they were giving up. 'Just get on with it' and 'don't give up' are expressions often used. MS is something that will never go away. As a consequence, dealing with it is felt to be inevitable. The couples believe that professional home care is in no way capable of providing all the care that is needed. Healthcare professionals are only able to come at certain times of the day, whereas some of the people with disabilities need help unexpectedly, others need help the whole day through and most of them even need help at night. The spouses are inevitably called on in the situations, often feeling there is no alternative. Several caregivers refer to the vows of marriage and the promise to take care of each other till 'death us do part': I am married to her, and I still take that very seriously. When you give your marriage vows, and marriage is forever, forever and a day, well, stick to them. But I know some men whose wives had MS and they got divorced, and I understand them and I can't say that they are wrong. But I suppose they were younger when they got married. I was somewhat older and I knew what I was doing. (Mr 13, caregiver) Although most caregivers refer to marital loyalty, they can act upon this concept in different ways. For some caregivers, giving care is the only option because they love their partners. Loyalty comes with love: Leaving him is out of the question, so I'm left with my back to the wall. I can only do all this because I love him. And I strongly believe that he's better off with me caring for him. (Mrs 4, caregiver) Others use almost no expressions of love and affection. They do whatever is necessary in response to the situation, and they are loyal to their partners despite relationships which are sometimes characterised by disagreement. They act out of a sense of obligation, often based on the marriage vows. People with disabilities... are grateful to their partners for keeping their promise and taking care of them. In turn, this motivates caregivers to go on. Caregiving soon becomes an obligation and the caregiver can easily feel manipulated. In these cases, loyalty turns into a duty. Marital loyalty is a powerful explanation for the caregivers' willingness to go on providing care while feeling burdened by it. The feeling of a shared misfortune is partly dictated by the arbitrariness of the disease. Since it could have happened to the caregivers instead, there is an implication that the give and take would have been the other way around. This virtual reciprocity, or hypothetical exchange, motivates several caregivers to go on: when something like this hits you, you expect the other party to do right by you. Imagine, it could be you sitting in that wheelchair and it afflicts you, it could just as well have been you. (Mr 6, caregiver) Although not ill themselves, they suffer because the person with disabilities has lost so much as a consequence of the illness and want to help as much as they can. People with disabilities as well as caregivers share the fear of institutionalisation. Throughout the caregiving process, caregivers have demonstrated a commitment to prevent such an admission. The fear of institutionalisation is based on television documentaries, the experience of friends and family, or their own experiences (e.g. on the occasion of respite admissions). Caregivers have agreed to support the desire to stay at home for as long as possible and to do whatever is necessary to avoid admission. Some couples want to stay together for as long as possible because they have a happy life together considering the 	<p>Naivety/innocence – unaware of future burden</p> <p>Inevitability – spouses don't have a choice, as there is not enough professional support to meet partner's needs.</p> <p>Vows – out of love and loyalty. Promise was made.</p> <p>Vows – duty/obligation. A promise they must keep even though love has gone.</p> <p>Grateful/thankful partners</p> <p>Reciprocity - situation could have been reversed and would have expected the same.</p> <p>Sympathy</p> <p>Fear of admission – love, respect their partner's wishes, avoid personal guilt/failure.</p> <p>Love</p>	<p>Love</p> <p>Duty/obligation</p> <p>Fear of institutionalisation</p> <p>Reciprocity</p> <p>Naivety</p> <p>Reward</p> <p>Sympathy</p>

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	circumstances.		
Boeije and Van Doorne-Huiskes (2003)	<ul style="list-style-type: none"> Some had taken on caregiving as a matter of course and had taken it for granted as part of their marriage. As some say 'It crosses your path' or 'I never had any doubt about it'. As Mr L says: 'Nobody asks whether you want to provide care or not. It is just something that is there. It has to be done and it was thrown upon me'. However, the families believe that professional home care is in no way capable of providing all the care that is needed. Their organizations allow professionals to come at certain times of the day, whereas some of the disabled persons need help unexpectedly, others need help the whole day through and most of them even at night. So that is where spouses inevitably come in, or so they feel. Several spouses pointed out their belief in marriage and in the vows they have taken. They have promised to take care of each other and they support this notion. They see their spouse's illness as something from which there is no escape and their caregiving is also perceived as inevitably caused by the promises made. 'Till death, well, that is the vow of marriage. And I intend to keep that promise although it is hard at times'. Another caregiver says that he is from a generation that keeps their promise, while he expects many young people to divorce should they meet what he has met. It is here that they come to speak of fulfilling a duty. As Mr S says: 'It is a duty, cause the love was soon gone'. Reciprocity in the relationship is an important motivation for some to continue caregiving. Others are motivated by an idea of virtual reciprocity: if they had become ill, their partner would have taken care of them instead. As Mr C expresses these general feelings: You have lived so many years together, done things together, worked together, and then to say when things are not going too well, look after yourself, that is something I think is frankly indecent. Obligation with a strong reference to the marriage vows. They consider the provision of total care as part of the deal since they took the vows. When his wife dies he will not feel regret or guilt because he will have done his best. Mr J has promised his wife to give care to her and they agreed that she does not have to live in a nursing home. I knew my husband was ill when we married. Only, I was twenty years old and I did not give it a thought. Nowadays I often think, if I had known I would not have done it Since illness can affect anybody, you cannot simply abandon someone who has met this misfortune as she calls it. She feels committed to the marriage and sees no alternative to going on. (Talking about preventing admission) She supported his decision because she was afraid that this kind of help would take away the only thing they still had in common, watching television in the evening. I would fall apart from feelings of guilt. If I can't cope physically, everyone will be able to see it and then no one will think that I just had him put away. That's a terrible thing to say, isn't it He continues to provide care because he promised to try to keep his wife from being institutionalised. 	<p>Inevitability as a spouse</p> <p>Vows – promises made/obligation</p> <p>Duty when love has gone</p> <p>Highly values promise</p> <p>Reciprocity – they would have done the same</p> <p>To avoid the guilt they would feel if admitted to nursing home</p> <p>Naivety about progression of disease</p> <p>Promise to avoid institutionalisation</p>	<p>Duty/obligation</p> <p>Fear of institutionalisation</p> <p>Reciprocity</p> <p>Naivety</p>
Cheung and Hocking (2004b)	No findings		
Courts, Newton and McNeal (2005)	No findings		

Heward, Molineux and Gough (2006)	<ul style="list-style-type: none"> Lifestyle changes followed inevitably. Acceptance was reflected in a factual way, in that it was a duty that had to be performed in order for the day to proceed for both of them. The transition to carer was tarnished with resentment and a sense of being forced into a role they do not want to fulfil. Although these may seem like the occupations of a carer, Carol did not describe herself as her husband's carer. The extent to which Carol accepts a carer identity is brought into question. It may illustrate someone who is in a transient state from being a partner to being a carer. 	<p>Inevitable and obligation as spouse</p> <p>Denial</p>	<p>Duty/obligation</p> <p>Denial</p>
Mutch (2010)	<ul style="list-style-type: none"> Overall, there was a resignation at 'MS', due to the knowledge that either person could have got it. A major motivating factor that kept all partners caring for their spouse was the commitment of marriage and the vows they made. Morally I've accepted to do it a long time ago, in sickness and in health, you know it's just the way it's going to be and I've accepted it. No, I love him. He is my husband. Marriage longevity and its vows, along with attitude and outlook on life by both partner and spouse, were the major motivational factors in staying together. A break away from care giving, no matter how short, was essential for the partners and motivated them to continue in their role. As long as I can have my holiday once a year, I don't mind but, at the thought of not having my holiday, as much as I love John, I feel that life wouldn't be very fair. I know I shouldn't say that but that is how I feel. Respite, such as holidays from the caring role was essential, despite the logistics required to organise them, as they were a great source of motivation. 	<p>Reciprocity</p> <p>Vows – duty</p> <p>Love and positive outlook on spending a long life together</p> <p>Value of break away from caregiving role</p>	<p>Love</p> <p>Reciprocity</p> <p>Duty/obligation</p> <p>Breaks</p>
Starks, et al. (2010)	No findings		

Appendix 6: Thematic synthesis (stage 2) – Motivation for care

Subtheme	Studies	Quotes	Codes
Love	Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> Although most caregivers refer to marital loyalty, they can act upon this concept in different ways. For some caregivers, giving care is the only option because they love their partners. Loyalty comes with love: Leaving him is out of the question, so I'm left with my back to the wall. I can only do all this because I love him. And I strongly believe that he's better off with me caring for him. (Mrs 4, caregiver) Some couples want to stay together for as long as possible because they have a happy life together considering the circumstances. 	<p>Vows – out of love and loyalty</p> <p>Belief their partner is better off being cared for by them</p> <p>Want a long and happy life together</p>
	Mutch (2010)	<ul style="list-style-type: none"> No, I love him. He is my husband. Marriage longevity and its vows, along with attitude and outlook on life by both partner and spouse, were the major motivational factors in staying together. 	<p>There is no question – they must care because they love their spouse and made vows</p> <p>Positive outlook on spending a long life together</p>
Duty/obligation	Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> 'Just get on with it' and 'don't give up' are expressions often used. MS is something that will never go away. As a consequence, dealing with it is felt to be inevitable. The couples believe that professional home care is in no way capable of providing all the care that is needed. Healthcare professionals are only able to come at certain times of the day, whereas some of the people with disabilities need help unexpectedly, others need help the whole day through and most of them even need help at night. The spouses are inevitably called on in the situations, often feeling there is no alternative. Several caregivers refer to the vows of marriage and the promise to take care of each other till 'death us do part': I am married to her, and I still take that very seriously. When you give your marriage vows, and marriage is forever, forever and a day, well, stick to them. But I know some men whose wives had MS and they got divorced, and I understand them and I can't say that they are wrong. But I suppose they were younger when they got married. I was somewhat older and I knew what I was doing. (Mr 13, caregiver) Others use almost no expressions of love and affection. They do whatever is necessary in response to the situation, and they are loyal to their partners despite relationships which are sometimes characterised by disagreement. They act out of a sense of obligation, often based on the marriage vows. Caregiving soon becomes an obligation and the caregiver can easily feel manipulated. In these cases, loyalty turns into a duty. Marital loyalty is a powerful explanation for the caregivers' willingness to go on providing care while feeling burdened by it. 	<p>Inevitability – spouses don't have a choice, as there is not enough professional support to meet partner's needs. No alternative</p> <p>Vows – duty/obligation. A promise they must keep</p> <p>Loyalty even though love has gone. Obligated by marriage vows</p>
	Boeije and Van Doorne-Huiskes (2003)	<ul style="list-style-type: none"> Some had taken on caregiving as a matter of course and had taken it for granted as part of their marriage. As some say 'It crosses your path' or 'I never had any doubt about it'. As Mr L says: 'Nobody asks whether you want to provide care or not. It is just something that is there. It has to be done and it was thrown upon me'. However, the families believe that professional home care is in no way capable of providing all the care that is needed. Their organizations allow professionals to come at certain times of the day, whereas some of the disabled persons need help unexpectedly, others need help the whole day through and most of them even at night. So that is where spouses inevitably come in, or so they feel. Several spouses pointed out their belief in marriage and in the vows they have taken. They have promised to take care of each other and they support this notion. They see their spouse's illness as 	<p>Inevitable – expected as a spouse.</p> <p>There is not enough professional support to meet partner's needs. No alternative</p> <p>Vows – duty/obligation. A promise they must keep</p>

		<p>something from which there is no escape and their caregiving is also perceived as inevitably caused by the promises made.</p> <ul style="list-style-type: none"> • ‘Till death, well, that is the vow of marriage. And I intend to keep that promise although it is hard at times’. • Another caregiver says that he is from a generation that keeps their promise, while he expects many young people to divorce should they meet what he has met. It is here that they come to speak of fulfilling a duty. As Mr S says: ‘It is a duty, cause the love was soon gone’. • Obligation with a strong reference to the marriage vows. They consider the provision of total care as part of the deal since they took the vows. • Since illness can affect anybody, you cannot simply abandon someone who has met this misfortune as she calls it. She feels committed to the marriage and sees no alternative to going on • Lifestyle changes followed inevitably. 	
	Heward, Molineux and Gough (2006)	<ul style="list-style-type: none"> • Acceptance was reflected in a factual way, in that it was a duty that had to be performed in order for the day to proceed for both of them. • The transition to carer was tarnished with resentment and a sense of being forced into a role they do not want to fulfil. 	Inevitable – had to be done so their spouse was properly looked after
	Mutch (2010)	<ul style="list-style-type: none"> • A major motivating factor that kept all partners caring for their spouse was the commitment of marriage and the vows they made. • Morally I’ve accepted to do it a long time ago, in sickness and in health, you know it’s just the way it’s going to be and I’ve accepted it. 	Marriage vows – accepted it as their duty
Fear of institutionalisation	Boeije, Duijnsteek and Grypdonck (2003)	<ul style="list-style-type: none"> • People with disabilities as well as caregivers share the fear of institutionalisation. Throughout the caregiving process, caregivers have demonstrated a commitment to prevent such an admission. The fear of institutionalisation is based on television documentaries, the experience of friends and family, or their own experiences (e.g. on the occasion of respite admissions). • Caregivers have agreed to support the desire to stay at home for as long as possible and to do whatever is necessary to avoid admission. 	<p>Caregiver fear of admission due to TV documentary and past experiences</p> <p>Respecting spouses wishes</p>
	Boeije and Van Doorne-Huiskes (2003)	<ul style="list-style-type: none"> • When his wife dies he will not feel regret or guilt because he will have done his best. • Mr J has promised his wife to give care to her and they agreed that she does not have to live in a nursing home. • (Talking about preventing admission) She supported his decision because she was afraid that this kind of help would take away the only thing they still had in common, watching television in the evening. • I would fall apart from feelings of guilt. • If I can’t cope physically, everyone will be able to see it and then no one will think that I just had him put away. That’s a terrible thing to say, isn’t it • He continues to provide care because he promised to try to keep his wife from being institutionalised. 	<p>To avoid a sense of failure and guilt</p> <p>Respecting spouses wishes/made promise to them</p> <p>Wanting to continue living with their spouse and sharing remaining interests</p>
	Cheung and Hocking (2004b)	<ul style="list-style-type: none"> • I’ve always felt it a bit rewarding about the way that we have stayed together and that Jan hasn’t been sort of left [in a nursing home]. Generally, I’m quite happy with the way things are going. 	Continue living together and sharing a life together

Reciprocity	Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> The feeling of a shared misfortune is partly dictated by the arbitrariness of the disease. Since it could have happened to the caregivers instead, there is an implication that the give and take would have been the other way around. This virtual reciprocity, or hypothetical exchange, motivates several caregivers to go on: when something like this hits you, you expect the other party to do right by you. Imagine, it could be you sitting in that wheelchair and it afflicts you, it could just as well have been you. (Mr 6, caregiver) 	The arbitrariness of the disease means either person could have been affected, and in this situation they would have hoped the other person would look after them.
	Boeije and Van Doorne-Huiskes (2003)	<ul style="list-style-type: none"> Reciprocity in the relationship is an important motivation for some to continue caregiving. Others are motivated by an idea of virtual reciprocity: if they had become ill, their partner would have taken care of them instead. As Mr C expresses these general feelings: You have lived so many years together, done things together, worked together, and then to say when things are not going too well, look after yourself, that is something I think is frankly indecent. 	<p>Giving back for all the things their spouse has done during their life together e.g. raise children</p> <p>Either person could have been affected</p>
	Mutch (2010)	<ul style="list-style-type: none"> Overall, there was a resignation at 'MS', due to the knowledge that either person could have got it. 	Either person could have been affected
Naivety	Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> They have gone along with giving help without fully realising the consequences and they have underestimated what they were giving up. 	Unaware of future burden and loss
	Boeije and Van Doorne-Huiskes (2003)	<ul style="list-style-type: none"> I knew my husband was ill when we married. Only, I was twenty years old and I did not give it a thought. Nowadays I often think, if I had known I would not have done it 	Unaware the extent of the progression and losses they would experience
Reward	Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> People with disabilities... are grateful to their partners for keeping their promise and taking care of them. In turn, this motivates caregivers to go on. 	Gratitude from their spouse
Sympathy	Boeije, Duijnste and Grypdonck (2003)	<ul style="list-style-type: none"> Although not ill themselves, they suffer because the person with disabilities has lost so much as a consequence of the illness and want to help as much as they can. 	Acting out of sympathy because their spouse has suffered and lost so much to MS
Denial	Heward, Molineux and Gough (2006)	<ul style="list-style-type: none"> Although these may seem like the occupations of a carer, Carol did not describe herself as her husband's carer. The extent to which Carol accepts a carer identity is brought into question. It may illustrate someone who is in a transient state from being a partner to being a carer. 	Does not accept that they are a caregiver, therefore happy to continue with what they are doing. Elements of naivety here.
Breaks	Mutch (2010)	<ul style="list-style-type: none"> A break away from care giving, no matter how short, was essential for the partners and motivated them to continue in their role. As long as I can have my holiday once a year, I don't mind but, at the thought of not having my holiday, as much as I love John, I feel that life wouldn't be very fair. I know I shouldn't say that but that is how I feel. Respite, such as holidays from the caring role was essential, despite the logistics required to organise them, as they were a great source of motivation. 	Motivated knowing they have some respite from caregiving responsibilities e.g. holidays

Appendix 7: Thematic synthesis (stage 3) – All themes

Theme	Subtheme	Code	Studies
Motivation for care	Love	Vows	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Mutch (2010)
		Continue spending life together	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Mutch (2010)
		Belief their partner is better off being cared by them	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003)
	Duty and obligation	Inevitability – not enough professional support	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003) Heward, Molineux and Gough (2006)
		Vows	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003) Mutch (2010)
		Social expectation	<ul style="list-style-type: none"> Boeije and Van Doorne-Huiskes (2003)
	Fear of institutionalisation	Respecting spouses wishes	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003)
		Negative media coverage or previous experiences	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003)
		Continue spending life together	<ul style="list-style-type: none"> Boeije and Van Doorne-Huiskes (2003) Cheung and Hocking (2004b)
		Avoidance of failure or guilt	<ul style="list-style-type: none"> Boeije and Van Doorne-Huiskes (2003)
	Reciprocity	Either person could have been affected	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003) Mutch (2010)
		Giving back to spouse	<ul style="list-style-type: none"> Boeije and Van Doorne-Huiskes (2003)
	Naivety	No consideration of future burden	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003)
	Reward	Gratitude from spouse	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003)
	Sympathy	Sympathetic to spouses suffering and loss	<ul style="list-style-type: none"> Boeije, Duijnste and Grypdonck (2003)
	Breaks	Respite from caregiving responsibilities	<ul style="list-style-type: none"> Mutch (2010)
	Denial	Denial of caregiving role	<ul style="list-style-type: none"> Heward, Molineux and Gough (2006)

Role transition	Employment	Reducing/giving up employment	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Boeije and Van Doorne-Huiskes (2003) • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Loss of socialisation	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Boeije and Van Doorne-Huiskes (2003)
		Loss of income	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Cheung and Hocking (2004b)
		Stigma of unemployment and loss of identity	<ul style="list-style-type: none"> • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Changing employment and new opportunities	<ul style="list-style-type: none"> • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Adjusting to remain in employment	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Starks, et al. (2010)
	Leisure	Giving up hobbies/interests	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Boeije and Van Doorne-Huiskes (2003) • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		MS restricts activities	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Boeije and Van Doorne-Huiskes (2003) • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006) • Mutch (2010)
		Loss of shared activities	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Heward, Molineux and Gough (2006)
		Loss of socialisation	<ul style="list-style-type: none"> • Heward, Molineux and Gough (2006)
		Realise dreams sooner	<ul style="list-style-type: none"> • Heward, Molineux and Gough (2006)
		New hobbies/interests	<ul style="list-style-type: none"> • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006) • Starks, et al. (2010)
		Adjusting to continue hobbies/interests	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Mutch (2010) • Starks, et al. (2010)
	New Roles	Caregiving role	<ul style="list-style-type: none"> • Boeije, Duijnste and Grypdonck (2003) • Boeije and Van Doorne-Huiskes (2003) • Cheung and Hocking (2004b) • Courts, Newton and McNeal (2005) • Heward, Molineux and Gough (2006)

			<ul style="list-style-type: none"> • Mutch (2010) • Starks, et al. (2010)
		Change ‘imposed’ on them – sudden	<ul style="list-style-type: none"> • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Gradual change and increase in responsibilities	<ul style="list-style-type: none"> • Boeije, Duijnstee and Grypdonck (2003) • Courts, Newton and McNeal (2005) • Starks, et al. (2010)
		Full-time job – constantly needed	<ul style="list-style-type: none"> • Boeije, Duijnstee and Grypdonck (2003) • Boeije and Van Doorne-Huiskes (2003) • Heward, Molineux and Gough (2006) • Mutch (2010)
		Responsibility shift and role reversal	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Cheung and Hocking (2004b) • Courts, Newton and McNeal (2005) • Heward, Molineux and Gough (2006) • Starks, et al. (2010)
		Domestic tasks	<ul style="list-style-type: none"> • Boeije, Duijnstee and Grypdonck (2003) • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Parenting and relationships with children	<ul style="list-style-type: none"> • Cheung and Hocking (2004b) • Courts, Newton and McNeal (2005) • Heward, Molineux and Gough (2006) • Starks, et al. (2010)
		Financial management	<ul style="list-style-type: none"> • Cheung and Hocking (2004b)
		Adapting - personal growth/development	<ul style="list-style-type: none"> • Boeije, Duijnstee and Grypdonck (2003) • Cheung and Hocking (2004b) • Courts, Newton and McNeal (2005)
		Boundaries of caregiving	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003)
		Fear of role transition	<ul style="list-style-type: none"> • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Previous caregiving experience	<ul style="list-style-type: none"> • Starks, et al. (2010)
		Planning	<ul style="list-style-type: none"> • Mutch (2010)
		Resentment of caregiving role	<ul style="list-style-type: none"> • Heward, Molineux and Gough (2006) • Mutch (2010)
		Caregiving is a rewarding role	<ul style="list-style-type: none"> • Boeije, Duijnstee and Grypdonck (2003) • Cheung and Hocking (2004b)

			<ul style="list-style-type: none"> Courts, Newton and McNeal (2005)
Relationship changes	Successful relationships	Adapting and working together to overcome challenges	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Courts, Newton and McNeal (2005) Mutch (2010) Starks, et al. (2010)
		Strong commitment and feelings of love	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Starks, et al. (2010)
		Openness and discussion	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003) Courts, Newton and McNeal (2005)
		Desire to stay together as long as possible	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003)
		Stronger relationship	<ul style="list-style-type: none"> Courts, Newton and McNeal (2005) Mutch (2010)
		Long marriage prior to MS	<ul style="list-style-type: none"> Mutch (2010) Starks, et al. (2010)
		Think of partner as the same person	<ul style="list-style-type: none"> Mutch (2010)
		Aware of MS on marriage	<ul style="list-style-type: none"> Starks, et al. (2010)
		Spouse also had chronic condition	<ul style="list-style-type: none"> Starks, et al. (2010)
	Challenges and loss	More distant relationship	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003) Cheung and Hocking (2004b)
		Care-based relationship	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003) Cheung and Hocking (2004b)
		Loss of love	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003)
		Resentment – person with MS does not recognise caregivers own suffering	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Courts, Newton and McNeal (2005) Heward, Molineux and Gough (2006)
		No open discussion – inability (cognition) or avoidance	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Boeije and Van Doorne-Huiskes (2003)
		Increased tension and arguments	<ul style="list-style-type: none"> Boeije, Duijnstee and Grypdonck (2003) Courts, Newton and McNeal (2005)
		No longer equals	<ul style="list-style-type: none"> Boeije and Van Doorne-Huiskes (2003) Heward, Molineux and Gough (2006)

		Loss of 'person they married'	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Cheung and Hocking (2004b) • Heward, Molineux and Gough (2006)
		Sexual problems and loss of intimacy	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003)
		Spouse negative behaviours – criticism, pressure, not accepting disability, no gratitude, pessimism	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) •
		Cognition	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Courts, Newton and McNeal (2005)
		Financial problems	<ul style="list-style-type: none"> • Courts, Newton and McNeal (2005) • Starks, et al. (2010)
		Unable to work together and adapt	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Starks, et al. (2010)
		Parenting problems	<ul style="list-style-type: none"> • Starks, et al. (2010)
		Decisions surrounding separation	<ul style="list-style-type: none"> • Boeije and Van Doorne-Huiskes (2003) • Courts, Newton and McNeal (2005)

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