Caring for each other: A rapid review of how mutual dependency is challenged by advanced illness.

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Abstract:

Objectives: This review explores factors sustaining and threatening couple's relationships when both have advanced illness.

Methods: Qualitative studies exploring relationships between two people in a marriage/partnership with advanced illness were included.

Results: Twelve papers were included. Internal enabling factors, external enabling factors and threatening factors are identified.

Significance of results: There is limited evidence internationally on factors sustaining these relationships, and crisis factors. Little is known about the impact of crises on the couple and the process of change from mutual dependency to carer and cared for. Shifts by Services towards holistic care focussed on the couple's needs is indicated.

Keywords: Mutual dependency, care, advanced illness, caring for each other.

Introduction

Health and social care services in the global north can be characterised as being organised around the idea of an individual patient or carer. Much research has been designed around this dichotomised model. It is increasingly the case however, particularly given the ageing population, that both members of a couple (two people living together as partners or as spouses) are living with serious conditions (Nimmon et al, 2018; Radcliffe et al, 2013; Torge, 2014). We describe these as 'caring couples': people who live together, mutually supporting each other and fulfilling complementary roles which may vary from day to day in response to fluctuations in their state of health. This review explores what is known about the experiences of caring couples and about the potential challenges to service provision faced in health and social care systems when attempting to support mutually caring couples.

The topic is important because rising demand for care services is linked to ageing populations. It is known that 11% of the world's population is now aged 60 years old or older; this figure is expected to increase to 22% by 2050 (Kanasi et al, 2016). Longer life expectancy has resulted in increasing numbers of people living with long term conditions and frailty. In the UK, for example, 58% of people aged over 60 have at least one long term condition, compared to just 14% of people aged under 40 (The Kings Fund, 2019). Frailty arises as a consequence of decline in physiological systems as a result of the ageing process and involves multiple body systems gradually losing their in-built reserves; in the UK around 10 per cent of people aged over 65 years have frailty, rising to between a quarter and a half of those aged over 85 (Age UK, 2020). Increasing numbers of older people live at home, encouraged by policies on 'Aging in Place', a scheme in the US providing often paid-for services (such as personal care, household chores, meals, money management and healthcare) to allow older people to access the support they need to stay living at home (National Institute of Aging, 2020). This emphasis on remaining at home places an increasing expectation that family members will undertake caring tasks and responsibilities.

For spouses or partners, often of similar age, each living with their own long term conditions, this may be challenging for both members of the couple, leading to situations in which one or both members of the dyad neglect their own health needs due to prioritising the needs of their partner (Gysels and Higginson, 2009; Kitko, 2010). Caring for older family members is associated with increased stress (Tamdee et al, 2019) and a recent study found that 58.6% of primary carers of frail older people experienced sadness, anger or depression (Lopez Hartmann et al, 2019).

Given the role caring couples play in maintaining each other's independence and wellbeing (Ahn and Kim, 2007; Torge, 2014), and thus also in preventing pressure on health and social care systems (Torge, 2014), it is important to understand how such relationships function and can best be supported by health and social care professionals. Relevant questions include: 'How are roles and tasks balanced within the caring couple's relationship?'; 'What interacting factors enable such couples to retain their independence?' [internal processes and external elements that interact to influence experience] (Nanton, 2015); and 'What are the critical points or situations that disrupt the stability of such relationships?'.

The aim of this review is to explore: the experiences of couples where both partners live with advanced progressive illness; the *internal factors* (such as psychological resources) and *external enabling factors* (such as social and practical resources) that make this possible; and the *critical events* that lead to a crisis situation developing. Illness can vary substantially in severity and duration, and may include periods of illness that are short-term or temporary; illnesses that ultimately result in the end of life; or (for example in the context of a disability) long-term or chronic illness, or multiple illnesses. In this review, we are interested in '*advanced progressive illness'*, by which we mean life-threatening illnesses (where treatment may be possible but can fail and may lead to end of life), or a life-limiting condition (where there is no reasonable hope of cure) or those which are associated with a disability (Zwakman et al, 2018). The focus is on advanced progressive illness, as this is a context in which caring needs are likely to be substantial, and where the likelihood

of one or both members of the couple experiencing an exacerbation or worsening of their own health problems is high, potentially making their mutual caring relationship precarious.

Research question

How do advanced progressive illnesses affect the ways that mutually dependent couples sustain mutual caring?

Method

A rapid systematic review was conducted; this type of review employs a methodology similar to that for a systematic review, retaining systematic methodology in obtaining and synthesising literature to address the given research question in a similarly effective way, but within a shorter timeframe (Arksey and O'Malley 2005; Grant and Booth, 2009; Khangura et al, 2012). The review protocol was registered on PROSPERO, the international prospective register of systematic reviews and was conducted and reported in line with the PRISMA checklist (Moher et al, 2009).

Search Strategy

Existing literature was searched to find all studies of couples living together and caring for each other in a mutually dependent way in the face of advanced progressive illness. Searches were conducted in July 2019, across the following bibliographical databases: CINAHL, Pubmed, Medline, Scopus and Web of Science. Database searches used the following search terms: 'caring couples', 'mutually dependent', 'caring spouses', caring partners', 'mutual care', 'caring dyads', co-dependent couples,' 'advanced progressive illness', 'life-limiting illness', 'palliative care', 'long-term conditions'. The Boolean operators of 'OR' and 'AND' were used to capture all relevant search results. Grey literature was searched for any unpublished theses eligible for inclusion, and reference sections of included articles were screened for any other potentially eligible paper.

Inclusion and exclusion criteria

A set of inclusion and exclusion criteria was determined prior to searches. Inclusion and exclusion criteria are presented in Table 1. The search did not include date limitations or restrictions on the countries where studies were conducted (to ensure an international perspective), and only included studies published in English.

Table 1 here

Screening

Following the initial search, duplicates were removed, and then the titles and abstracts of these were screened for eligibility. The full texts of these papers were read and considered for inclusion. Papers were eligible if they reported qualitative studies published in English that examined two people living together as a couple, who were both ill (and where at least one of the couple was experiencing advanced progressive illness), and who were providing mutual care. The full texts of included studies were assessed for eligibility by VN, with no discrepancies found. The references cited in all included papers were also screened for any additional papers eligible to be included in the review.

Extraction of data

Data were extracted by one author (JP) from each paper included in the review, using a predefined extraction spreadsheet. Data was also extracted from a sub-set of papers by another author (VN) to ensure accuracy. The information extracted from each paper was: author and year of publication; country of study; setting of study; dynamics of the relationship between couples; living situation, relationship, age, and health conditions / illnesses of study participants; internal and external enabling factors; and factors likely to cause crisis situations.

Critical appraisal

The quality, trustworthiness and relevance of included studies were assessed using the Critical Appraisal Skills Programme (CASP) qualitative checklist (CASP, 2018). CASP includes questions to

assess whether results of included studies are valid, what the results are and whether the results will help locally (CASP, 2018). Critical appraisal of papers was conducted by one author (JP), and a sub-set of papers was independently critically appraised by another author (VN) to check for accuracy and consistency. A high level of consistency, and no discrepancy was found between the two appraisals. All studies passed the first two screening questions of the CASP tool and were subject to the remainder of the critical appraisal. Studies were rated as either satisfying the CASP criteria ('yes'), not satisfying it ('no') or not providing enough information to make a judgement ('can't tell'). The final question 'How valuable is the research?' was rated as valuable ('yes') or not valuable ('no').

Data synthesis

As only qualitative studies were included in the review, a thematic synthesis was conducted (Grant and Booth, 2009). This involved identifying common themes across the results of the included studies that were relevant to the aims of the research. Themes were identified by coding the result sections of the included papers, comparing these codes across papers and defining topics that contributed to an increased understanding of the relationships of mutually dependent couples facing advanced progressive illness. All authors were involved in the synthesis of the results.

Results

Eligible literature

The initial search produced 1,115 results. After duplicates were removed, 1,051 results were screened. Following screening of the titles and abstracts for eligibility, the full texts of 42 papers were read and considered for inclusion. This resulted in 11 papers being included, and following screening of their references an additional paper was identified giving a total of twelve papers. A PRISMA diagram of the screening process is provided in Figure 1.

Figure 1 here

Characteristics of included papers

The twelve papers included in the review explored the relationship of mutually dependent couples living with advanced progressive illnesses; all were published between 2002 and 2019. Six of the studies were conducted in the UK (Greenwood et al, 2019a, 2019b; Gysels and Higginson, 2009; Radcliffe et al, 2013; Ray, 2006; Turner et al, 2016) and two in Canada (Nimmon et al, 2018; Racher, 2002). The remaining studies were conducted in South Korea (Ahn and Kim, 2007), Australia (Grimmer et al, 2004), the USA (Kitko, 2010) and Sweden (Torge, 2014). Of the 12 studies, four involved one-to-one interviews (Grimmer et al, 2004; Gysels and Higginson, 2009; Kitko, 2010; Turner et al, 2016); six involved joint interviews with a couple involved in a mutually caring relationship (Ahn and Kim, 2007; Nimmon et al, 2018; Racher, 2002; Radcliffe et al, 2013; Ray, 2006; Torge, 2014); and two used focus groups (Greenwood et al, 2019a, 2019b). One study recruited health professionals to gather their views on the experiences of older spouses living together with illness (Greenwood et al, 2019b).

Eleven studies recruited one or both members of a caring couple; the twelfth recruited professionals and volunteers working with older carers (Greenwood et al, 2019b). One study recruited participants aged 40- 72 years (Gysels and Higginson, 2009); all the others involved couples aged over 60. The illnesses of participants in the studies included those that can be classified as age-related (Ahn and Kim, 2007; Racher, 2002; Ray, 2006); illnesses that lead to end of life (Grimmer et al, 2004; Kitko, 2010; Nimmon et al, 2018; and Turner et al, 2016); and long-term chronic or multiple illnesses (Greenwood et al, 2019a; Greenwood et al, 2019b; Gysels and Higginson, 2009; Radcliffe et al, 2013; and Torge, 2014). Participants' health conditions included stroke (Radcliffe et al, 2013), heart failure (Kitko, 2010; Nimmon et al, 2018), cancer, COPD, cardiac failure and motor neurone disease (Gysels and Higginson, 2009). Full characteristics of each included study are shown in Table 2.

Table 2 here

Critical Appraisal

All included studies were critically appraised using CASP (CASP, 2018). Overall, the studies were rated positively on the CASP, with 11 of the 12 rated favourably on seven or more questions (Ahn and Kim (2007) was rated as positive on six of the questions), and ten of the twelve studies were rated favourably for eight or nine out of ten. All 12 of the included studies were rated 'no' or 'can't tell' to the question, 'Has the relationship between researcher and participants been adequately considered?' suggesting that this is an area that would benefit from clearer reporting to ensure the relationship between the researcher and participants is reflexively accounted for. Critical appraisal of included studies (including the questions assessed for each included study) can be found in Table 3.

Table 3 here

Thematic synthesis

Five main descriptive themes were identified in the included studies: positive emotions associated with caring for an unwell spouse; caring for a spouse as a natural part of a marriage / partnership; The whole being stronger than its parts; the availability of external sources of help; disruption in the face of advanced progressive illness; and individual health problems that affected the stability of the relationship. A matrix of themes is provided in Table 4 and each is discussed in turn.

Categorisation of themes

Several themes related to factors that enable a couple to continue living together independently, mutually relying on each other and able (most of the time) to preserve their ability to cope with their health problems. These were predominately internal enabling factors, although some external factors were also important. Other themes related to factors likely to disrupt the stability of the relationship, and push its resilience to a crisis, where additional support is required for one or both of members of the couple to receive adequate care. These themes are discussed below, and an overview of their categorisation is presented in Table 5.

Table 5 here

Theme 1: Internal enabling factors

Sub-theme 1.1: Positive emotions associated with caring for an unwell spouse

Six studies described caring for a spouse or partner as a positive experience, for example because the support that living together provided was appreciated (Ahn and Kim, 2007; Racher, 2002). For some, caring responsibilities were affected by the love couples felt for each other, enabling them to overcome some of the challenges they faced, either individually or as a couple (Greenwood et al, 2019a). Caring for each other also provided the opportunity to enjoy each other's company (Torge, 2014).

Sub-theme 1.2: Caring for a spouse is a natural part of marriage/ partnership

A prominent theme in five studies was that caring for one's spouse was a natural part of the contract of marriage (Greenwood et al, 2019b; Grimmer et al, 2004; Ray, 2006; Turner et al, 2016). It was part of what the couple felt they had 'signed up for', and thus was a commitment, even if their own health problems made it difficult (Turner et al, 2016). It was both expected of them and undertaken out of love. Some felt that caring for an unwell spouse was something that should happen, and attached a strong moral obligation to it (Torge, 2014).

Sub-theme 1.3: The whole being stronger than its parts

Some participants said that being part of a couple made it easier for them to remain independent than if they were alone. Participants in three of the papers discussed the feeling that a couple was a stronger unit than two separate individuals. The reciprocal nature of the relationship, and mutual dependency within it, allowed the couple to support each other, despite each having their own health problems (Racher, 2002). These couples presented themselves as an interdependent unit and as a team, reliant on each other; not as a carer and a patient (Radcliffe et al, 2013; Ray, 2006).

Six papers reported that some mutually dependent couples were able to remain independent, and in a stable situation, by sharing the responsibility of caring and day-to-day tasks and working together to accomplish things that needed doing (Racher, 2002; Torge, 2014). These adaptive relationships involved day-to-day balancing of tasks, with each taking on a larger share of these when required to allow the stability of the relationship to continue (Radcliffe et al, 2013; Torge, 2014; Ray, 2006). One study reported that being able to coordinate activities, and to reflect and adapt, preserved the couple's ability to remain independent (Nimmon et al, 2018).

Theme 2: External enabling factors

Sub theme 2.1: Availability of external sources of help

Six papers described the importance of external sources of support, particularly in times of crisis when the couple's mutually dependent balance was strained due to acute deterioration in the health of one or both partners (Nimmon et al, 2018; Turner et al, 2016). Participants often considered external support to be a last resort, when no other options were available, and when one partner was no longer able to meet the other's needs (Gysels and Higginson, 2009). Having a wider social network of support was found to take some of the pressure off the situation, and to reduce the feelings of isolation experienced by some spouses in these mutually dependent couples (Gysels and Higginson, 2009).

Despite the presence of external sources of support such as formal care services (e.g. care provided by a professional care company), some couples preferred to complete certain tasks (such as cleaning, showering or dressing) themselves, as this enabled them to retain some independence and to avoid reliance on external support. Nevertheless, in some cases, having formal care available allowed mutual care to continue, and the couple to remain as independent as possible (Ray, 2006; Torge, 2014).

The need for external support, however, was linked to feelings of frustration about waiting times and services that were insufficient to address the couple's needs (Greenwood et al, 2019a; Nimmon et al, 2018). This sometimes increased the challenges that the caring partner faced in accessing required care and support for their spouse when they could no longer fulfil this role.

Theme 3: Factors that may cause disruption of ability to provide mutual care

Sub-theme 3.1: Disruption in the face of advanced progressive illness

Deterioration in health – for one individual or both – within a couple was recognised as a destabilising factor that could prevent them from continuing to coordinate their caring activities. This theme was present in all the included papers, and could lead to a point of crisis in which one member of the couple had to take on a substantially increased caring role (Ahn and Kim, 2007; Nimmon et al, 2018; Racher, 2002; Radcliffe et al, 2013; Ray, 2006). Physical difficulties, emotional struggles and fatigue were all factors that affected individuals' ability to care for their spouse, often leaving them unsure of their ability to continue in the caring role (Greenwood et al, 2019a, 2019b; Turner et al, 2016). Some participants in the studies reported that physical barriers caused by their own health conditions were challenges to caring for their spouse, and that these also put their own health at risk of deteriorating further (Grimmer et al, 2004). In such situations, particularly when inadequate external support was available for the couple, the couple's coping system could break down (Nimmon et al, 2018).

Discussion

To our knowledge, this is the first rapid systematic review to examine mutually dependent couples and their coping relationships. It summarises the evidence on how caring couples seek to maintain their independence and wellbeing in the face of advanced progressive illness, and describes a range of enabling factors and disruptive events and circumstances. There was a greater focus on internal

enabling factors than on external ones, with only a limited number of external factors identified in the twelve included studies. The studies described mutual caring relationships that included positive experiences and situations, in contrast to the emphasis on 'burden' often associated with discussion of carer and patient relationships. This was particularly evident for those caring for a spouse whose condition was related to ageing (as opposed to those experiencing illness linked to end of life or long-term disability-related illness).

The studies reviewed were undertaken in a range of different countries, using varied methods to recruit participants. Direct comparisons between these studies' findings were not possible, however, as the studies rarely reported contextual information, such as the setting (e.g. whether participants lived in rural or urban locations, which could affect the availability or accessibility of external or formal sources of care and support); how long members of the couple had been caring for each other; or what external support or formal care services they were receiving.

The twelve studies included showed that some couples were able to maintain balance and coordination in their relationship and in their household and caring tasks. This ultimately enabled them to continue living together, often without the need for external or formal care. This was often described as a positive experience, and as part of the 'natural' role of being married or in a partnership. This moral obligation, reported in many of the included studies, is consistent with findings in the broader literature about feelings of obligation to provide care within a marriage or partnership (Cash et al, 2018), which some studies find can be disrupted when one member of a couple experiences deteriorating health. In such cases, continued mutual care became more difficult, or impossible, often resulting in a transition from mutually dependence, to dependence on the other partner. When partners were unable to maintain this balance it affected the stability of the relationship, in some cases causing feelings of burden. This is the point at which external help was often required to allow the couple to retain some sense of independence, and continue living

together, or (in the absence of such help) when admission to hospital might become necessary (Ahn and Kim, 2007; Racher, 2002).

Strengths and limitations

The review presented here provides insights into the experiences of mutually dependent couples in the face of advanced progressive illness. The rapid systematic review design allowed in-depth exploration of factors that enable such relationships to continue, and addressed some of the factors that may disrupt the stability of such couples' relationships.

The twelve studies included in the review are sufficient to explore internal and external factors that aid the sustainability of mutually dependent relationships, and to identify crisis situations that can trigger deterioration of the stability of the relationship. However, the review provided little information about how specific external factors (such as socio-economic factors, wider family networks and geographical locations) might help to sustain mutually dependent caring relationships. It also provided little insight into what happens when the health of one member of a couple deteriorates to the point that they are no longer providing mutual care, but have become dependent on their partner for support and care.

In addition, the review was limited to studies published in English, and so may have missed relevant literature, and none of the included studies focused on same-sex relationships. There is a need for research that studies the full range of mutually dependent couples, to enable fuller understanding of the dynamics that different relationships, as well as gender differences, may have on the sustainability of caring couples. Due to the specific aims of the review, no studies considered other types of couples who may have a mutually caring role; for example, co-habiting individuals who are not spouses or partners, or relationships that involve parents and their adult children who are providing mutual care.

As previously discussed, many of the studies provided little contextual information about external enabling factors of participants, such as whether or not formal or informal sources of care were present, whether any care or support was provided by friends or family, socio-economic factors or life-events that potentially disrupt the couple's situation. The role of both internal and external enabling factors is vital in understanding the needs and dynamics of mutually dependent couples, and the lack of which is therefore a limitation of included studies in this review.

The illnesses of participants within the reviewed studies varied. Some were experiencing ill health as a result of advanced age and frailty, while others were experiencing illness that was leading to end of life, or associated with long-term chronic, or multiple, illnesses. Different types of illness, and different durations of illness, may affect the support needed, both within the couple and from external sources (such as formal health and social care support, or support from friends or family). It was not possible to make this distinction in the review, and further literature is needed to allow such a comparison to take place.

Most of the studies reviewed focused on couples working together in a mutually dependent state, but paid little attention to events or situations that may contribute to a crisis emerging. The implications of such a crisis, for a previously mutually dependent couple, were not discussed in detail. Some studies in the review briefly discussed how the deterioration of one person can disrupt the ability of both individuals in a couple to remain independent, but this was not fully explored. From the studies, little can be learned about such couples' fears, worries and struggles, about the individuals within that couple, or about the impact of the deterioration in health of one on the other. It is unclear how individuals reliant on a mutually dependent relationship can be enabled to cope alone, and to manage tasks that they previously relied upon the other to undertake. A crisis in such relationships can lead to a breakdown in the remaining partner's own support network.

The studies reviewed paid only limited attention to the additional pressure on the carer / partner member of the couple (despite their own vulnerable condition), when the mutuality of the

relationship was transformed into one of dependency. Fears for the future if one partner's health deteriorates were identified in some papers, but there was no exploration of what happens should this occur.

As has been explained, the reviewed studies were conducted in several countries, encompassing varied health and social care systems and different cultural contexts. In Sweden, for example, where one study was conducted (Torge, 2014), the Government invests comparatively more in care of older people than is the case in as the UK or in Australia (Organisation for Economic Co-operation and Development, 2018). In South Korea, where the study by Ahn and Kim (2007) was conducted, cultural changes have left many older couples living alone without the help from their families that would previously have been the norm. Korea currently operates a universal long-term care insurance (LTCI) system for those over 65, paid via compulsory insurance premiums, general tax subsidies and co-payments, with the amount of funded care being determined by severity of the disability. This approach to care increases the proportion of older people outsourcing care (Peng and Yeandle 2017). Some countries have implemented policies that encourage older people to live at home as long as possible, rather than move into supported residential care. This may affect individuals' ability to choose how care is provided to their spouse or partner, potentially increasing the pressure to care for them at home despite their own ill health (National Institute of Aging, 2020). Furthermore, differences between expectations within a marriage or cohabiting relationship may exist between cultures and societies. Caring for a spouse or partner may be expected and presumed in some, whilst other couples may be in a mutually dependent situation due to an absence of other options, or an inability to fund external support. Further exploration of such differences is warranted.

Implications for practice

This review contains insights that can help inform policy and service provision for couples where both partners experience ill health. It draws attention to the challenges faced by those in mutually

dependent relationships that may otherwise go unrecognised. It also draws attention to the fact that being in a mutually caring relationship may mask the vulnerabilities of each partner. This is important, as individuals may not identify as carers, and interpret their situation simply as one in which they are carrying out their marital duties.

The review presented here draws attention to questions about external support for caring couples. It has identified factors that may trigger crisis situations, which are often linked to a deterioration in health. This has implications for the role of healthcare providers in primary care settings, such as GPs or nurses. When one member of a caring couple becomes unwell, such professionals need to be aware of the implications this may have for the partner, and for the couple's ability to maintain their independence. It highlights the need for healthcare professionals to look beyond the individual "patient", and to view a mutually dependent couple as a unit whose combined healthcare needs should be considered as a whole. Especially at times when one or both members of a couple are ill, the couple may become physically and / or emotionally unable to continue caring roles. The provision of sufficient and appropriate support, and giving each member of the couple the opportunity to talk separately and independently about their experiences and expectations of caring for the other (Cash et al, 2018), may enable successful management of such situations and avoid a breakdown in the couple's living arrangement. Currently, many health and social care services are designed for relationships consisting of a patient and their carer, and around the needs of the individual person, rather than around the intertwined needs of a mutually caring couple.

This review also highlights gaps in the evidence base. Future research should explore the resources needed for mutually dependent couples to maintain their independence, and what happens when couples move from mutually dependent relationships to situations of dependency when one partner's health deteriorates to the point that they can no longer provide mutual care. Research is also needed to explore how the experiences of caring couples are affected by different models of health and social care provision in different socioeconomic and cultural contexts.

Conclusions

Internal enabling factors, supportive of independent mutual caring, include positive emotions associated with caring for an unwell spouse; caring for a spouse being considered a natural part of a marriage or partnership; and a couple being stronger together than as two separate individuals. A key external enabling factor was the availability of alternative sources of help. Factors that may disrupt the stability of mutual caring relationships included disruption as a result of advanced progressive illness. There is limited literature examining the external factors that influenced the stability of mutually dependent relationships, or triggers likely to cause a crisis point, as couples cope with advanced progressive illness. Further research into situations when the health of one member of the couple deteriorates and destabilises their mutual dependence, requiring a more traditional patient and carer relationship, is needed. Alternative models of health and social care support that incorporate a more dyadic perspective may be needed for those couples where a mutually dependent relationship exists.

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Conflict of Interest

The authors declare that there is no conflict of interest.

Author contributions

JP conducted the searches and screening, extraction, quality assessment and synthesis and writing of findings, and VN conducted second (independent) full text screening, partial quality assessment, synthesis and writing.

All authors were involved in the development of the protocol including defining the inclusion and exclusion criteria and search terms, and contributing to the analysis and interpretation of findings and the drafting of the paper.

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Table 1: Inclusion and exclusion criteria:

Inclusion criteria	Exclusion criteria
Studies examining two people living together, as a couple, providing mutual care	Studies examining one carer and one patient and the impact of caring on the carers' own health
Qualitative studies	Reviews of literature (systematic reviews, scoping reviews, literature reviews etc)
Studies published in English	Participants are living in residential care homes or are in hospital at the time of the study
Both members of the couple are ill, with at least one of them experiencing advanced illness	Two people living together not as a couple (either married or in a partnership)

Figure 1: PRISMA flow

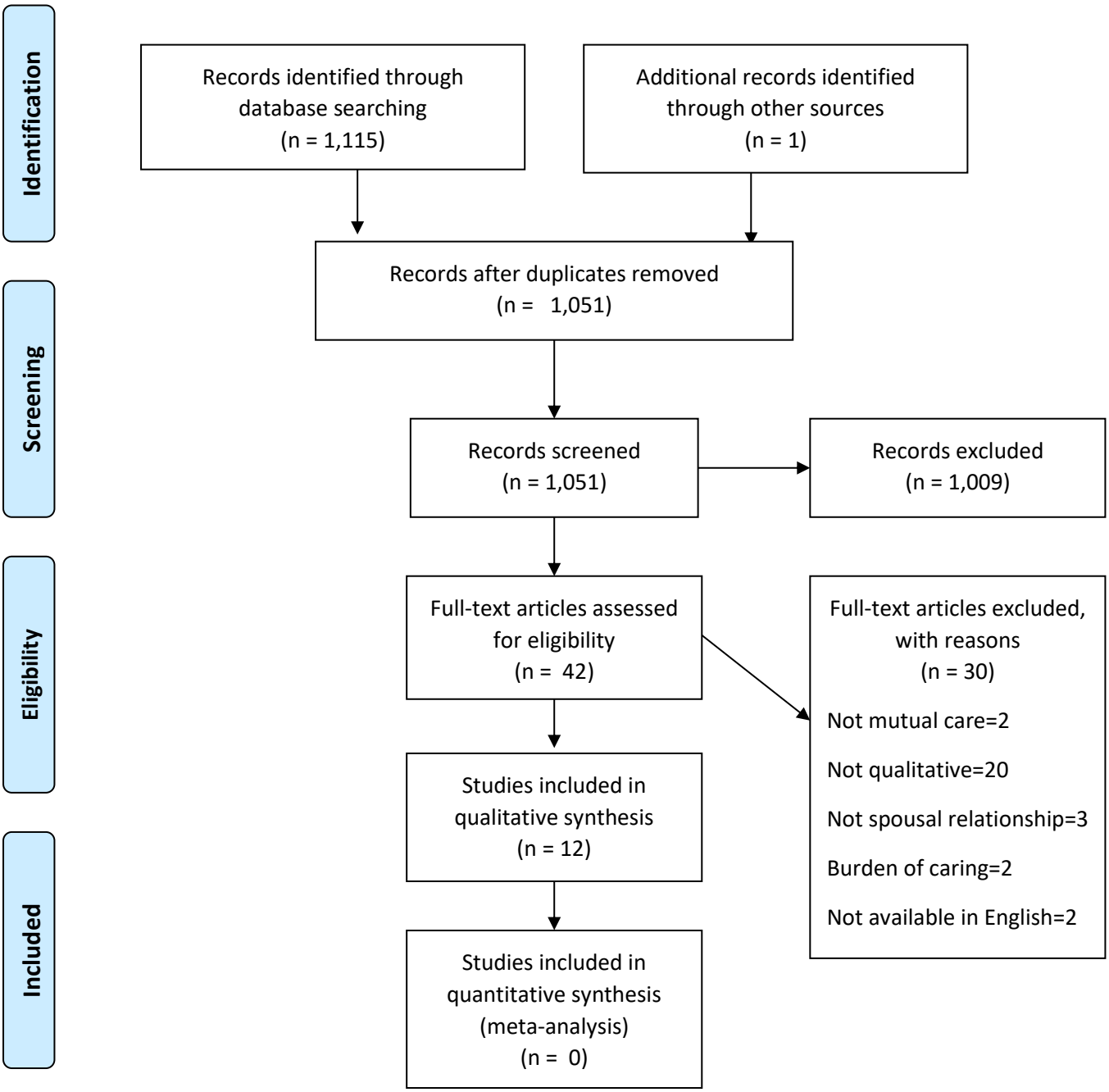

Table 2: Main characteristics of included studies

Author and year	**Country of study**	**Setting of study**	**Participants**	**Couple characteristics**	**Age group of participants**	**Health conditions/ illness of participants**
Ahn and Kim 2007	South Korea	Observed and interviewed in their own homes	10 elder couples (20 individuals)	Elder couples living together (living without their children).	Over 65 (between 65-84 years. Average age of 77 for males, and 72 for females).	Geriatric-related diseases
Greenwood et al. 2019 (a)	UK	Third-sector carer organisations	44 carers in Greater London	Majority of carers were spouses or dual carers, but 37% sample were parents or adult children.	70-87 years	Carers had declining physical and emotional health and strength. Care recipient's health condition included dementia, stroke, Parkinson's etc.).
Greenwood et al. 2019 (b)	UK	In the recruiting voluntary organisation	35 volunteers and professionals working with older carers.	Older carers with deteriorating health conditions, caring for someone with long-term advanced illness.	Mean age of participants 52.1.	Older carers with deteriorating health conditions, caring for someone with long-term advanced illness.

Grimmer et al. 2004	South Australia	Participants home or over the telephone (participant being at home)	24 primary carers of recently ill, elderly patients.	Majority of carers were spouses to older person, others were family or friends.	Mean age of 67.5 years for participants from the city, and mean age of 74.7 for participants from the country.	Carers had pre-existing medical conditions. Patients were discharged from an acute hospital admission marking a change in their future health prospects.
Gysels 2009	UK	Participants own home or at researchers office when requested by participant.	15 informal carers of patients with breathlessness.	Informal carers and patients with advanced progressive illness who suffer from breathlessness.	Age range 40-72	Patients had a diagnosis of an advanced progressive illness either cancer, COPD, cardiac failure or Motor Neuron Disease, experiencing breathlessness.
Kitko 2010	US	Participants home or private convenient location	20 spousal caregivers of heart failure patients	Spousal caregivers of heart failure patients, over 62.	Caregivers were 46-78 years (mean of 67 years).	Spouses had heart failure. Carers' illnesses not explicitly stated, just that their own health often was impacted by caring role.

Nimmon et al. 2018	Canada	A location convenient for participants; typically their own homes.	13 patient-partner couples.	Patients with advanced heart failure and their partners with chronic illness.	Predominantly 60-90 years	Patient with advanced heart failure, and partner with chronic illness (including cancer, chronic pain, arthritis, cataracts).
Racher 2002	Canada	Not stated	19 rural couples	Spouses were 75 years or over, living in their own homes, or on nearby farms.	Age range 72-96.	Seven of the included couples were providing mutual care to each other.
Radcliffe et al. 2013	UK	Participant's homes	Community-dwelling stroke survivors aged 75-85. At least one year post stroke.	13 couples consisting of stroke survivor and their spouse.	Stroke survivors were 75-85 years, and spouses were 59-85 years.	Stroke survivors all had other health conditions in addition to stroke, and spouses had a number of health/ mobility conditions (including osteoporosis, heart conditions, diabetes).
Ray 2006	UK		13 couples married for 35 years or more.	13 elderly couples married for 35 years or more.		Both partners of long-term marriage are more likely to be experiencing significant health problems.

Torgé 2014	Sweden		9 couples who had lived for at least 12 years with a physical disability	Couples living together with physical disabilities.	Between 60-83 years old	At least 12 years with physical disabilities, although most had disabilities for 20 years + (including; stroke, polio, accidents etc)
Turner et al. 2016	UK		17 participants	older carers caring for a dying spouse at home	Aged 80 or over	Spouse suffered from variety of life-limiting illness, mostly cancer. Carer experiencing physical disability related to growing older.

Table 3: Critical appraisal of included studies using CASP tool (2018)

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
Ahn and Kim 2007	Yes	Yes	Yes	Can't tell	Yes	No	Can’t tell	Can’t tell	Yes	Valuable. Research contributes to learning about support systems Recommends future research to further strengthen the evidence.
Greenwood et al. 2019 (a)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable. Clear how the current study adds to current knowledge. Suggests new areas of research needed.

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
Greenwood et al. 2019 (b)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable. Implications of the research is discussed, in relation to supporting older carers. Recommendations for future research made regarding service provision.
Grimmer et al. 2004	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Valuable. Discussed contributions to the way carers identify themselves. Discusses implications of working with carers.

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
Gysels 2009	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable. Clear recommendations for practice made to help carers cope better with their caring role at home.
Kitko 2010	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable. Findings provide a theoretical explanation of the work providing care to a spouse with heart failure. Findings have implications for nursing by increasing the awareness of the needs associated with spousal caregiving for patients with heart failure.

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
Nimmon et al. 2018	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable. Discusses implications and recommendations for health professionals working with heart failure patients and their ill spouses.
Racher 2002	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable. Highlights the need to ask how couples living in mutually supportive relationships can be supported? And how to maintain the relationship.

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
Radcliffe et al. 2013	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable. Generated knowledge about how older couples experience interpersonal relationships with illness present. Implications in terms of addressing the needs of older spousal caregivers.
Ray 2006	Yes	Yes	Yes	Can't tell	Yes	No	Can't tell	Yes	Yes	Valuable. Knowledge generated about motivations to provide long-standing care and support. Makes recommendations for practice for how health professionals

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
										should support couples in maintaining important relationships, and managing change in the relationship.
Torgé 2014	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Valuable. The results provide useful knowledge about the relationship between formal and informal care. Discusses implications for care amongst older couples.

Included study	Included clear statement of research aims?	Qualitative methodology appropriate?	Research design appropriate to address aims of research?	Recruitment strategy appropriate to the aims of the research?	Data collected in a way that addressed research issue?	Relationship between researcher and participants adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Included clear statement of findings?	How valuable is the research? (valuable or not valuable and explanation)
Turner et al. 2016	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable. It clearly discusses the contribution that the paper makes to the knowledge about the needs of older carers. It makes clear recommendations for health professionals working with this population.

Table 4: Matrix of thematic themes

Author and year	**1.1 Positive emotions associated with caring for an unwell spouse**	**1.2. Caring for spouse is a natural part of marriage/ partnership**	**1.3. The whole being stronger than its parts**	**2.1.Availability of external sources of help**	**3.1.Disruption when one partner becomes ill**
Ahn and Kim 2007	X				x
Greenwood et al. 2019 (a)	X			X	X
Greenwood et al. 2019 (b)		x			X
Grimmer et al. 2004		x			X
Gysels 2009				X	X
Kitko 2010			X		X
Nimmon et al. 2018			X	X	X
Racher 2002	X		X		X
Radcliffe et al. 2013			X		X
Ray 2006	X	x	X	X	X
Torgé 2014	X	x	X	X	X
Turner et al. 2016	X	x		X	x

Table 5: Categorisation of themes

Categorisation of theme	**Sub-theme**
Theme 1: Internal enabling factors	1.1 Positive emotions associated with caring for an unwell spouse
	1.2 Caring for spouse is a natural part of marriage/ partnership
	1.3 The whole being stronger than its parts
Theme 2: External enabling factors	2.1 Availability of external sources of help
Theme 3: Factors that may cause crisis	3.1 Disruption when one partner becomes ill