

## REVIEW ARTICLE

# The quality of life of older carers and the people they support: An international scoping review

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## Abstract

Older carers, aged 65 or over, may find it difficult to balance caring while maintaining their own health and quality of life (QoL). For older carers, especially, established approaches to separately identifying, assessing and addressing carers' and care-recipients' needs, may not fully consider the interwoven nature of caregiving relationships and the ways in which community-based social care services may impact the QoL of both parties. The purpose of this scoping review is to identify and synthesise what is already known about the QoL of older carers and care-recipients, considered together, which we refer to as 'dyadic QoL'; both in general, and with regard to the impact of community-based social care. We searched 16 electronic databases and grey literature in October and November 2020. A total 822 items were identified and reviewed based on the inclusion criteria: focusing on older carers and care-recipients from a dyadic perspective and their QoL or well-being, published since 2000 and in English. Fourteen papers were thematically analysed, and the findings were presented under two themes. First, the value of applying an overarching conceptual framework of 'interdependence theory' in understanding dyadic QoL, including two broad approaches: dyadic data analysis and the dynamics of caring relationships. Second, a number of papers highlighted the role of support from family, friends and neighbours and community-based social care services in promoting QoL outcomes of caring dyads. This review emphasised that considering the QoL of carers and care-recipients, together, would potentially improve the understanding of care needs, provision of care services and QoL outcomes. However, there is limited and fragmentary evidence about dyadic QoL or the impact of social care services on dyadic QoL outcomes. Future work is required to explore and evaluate the use of a dyadic approach in social care practice and research.

## KEYWORDS

carer, care-recipient, dyad, long-term care, quality of life, social care

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## 1 | INTRODUCTION

Internationally, unpaid care provided by family and friends (known as carers) is a critical dimension of the care of adults with long-term health problems and disabilities (Brimblecombe et al., 2018; Henwood et al., 2018). While there remains limited recognition of carers' needs, especially the risk of compromising their health and well-being, there has been a variety of policy responses to support carers in a number of countries. These include care leave entitlements for working-age carers, financial assistance and benefits, assessments of need and access to care services (e.g. counselling, education or training, support groups; Brimblecombe et al., 2018; Henwood et al., 2018). It is recognised that carers can benefit from good quality and responsive social care support for the people they care for, for example home care, day activities and other community-based interventions (Brimblecombe et al., 2018; Rand et al., 2020).

In England, there has been a long-standing policy commitment to protecting carers' health and well-being, facilitating access to support, training and employment, and for carers to be enabled to 'live a life outside caring' (Department of Health and Social Care, 2010, 2014, 2018a; NHS England, 2016). The most recent policy initiative, the 2014 Care Act, offers carers statutory parity with adults with support needs, in terms of esteem, the right to a needs assessment and support to address eligible needs that arise because of their caring responsibilities to an adult (Social Care Institute for Excellence, 2020). There is emphasis placed on the needs and outcomes of *both* service users and carers. The outcomes of social care and the needs of people who access care, whether service users or carers, are broadly defined in terms of social care-related aspects of quality of life (QoL), including social relationships, independence and control, accessing work, education or leisure activities and managing and maintaining nutrition, the home environment and personal hygiene (Social Care Institute for Excellence, 2020). Guidance promotes a whole-family approach to practice, whereby the views, needs and QoL of the family unit or household are considered in assessing needs and planning support for the person who needs it (Department of Health and Social Care et al., 2015).

Despite this whole family emphasis, the Care Act, and associated guidance, tends to present 'adults with care and support needs' and 'carers with support needs' as separate groups. This may partly reflect a historical tendency to subsume, or conflate, the carer's needs with those of the adult with support needs. It also reflects organisational practices in the social care sector (also, known as long-term care), which has, historically, tended to separate support 'for carers', including needs assessment, from 'adults with support needs'. This tendency has been amplified by the market-based approach to adult social care in England, whereby statutory public services are commissioned, rather than directly provided by, local authorities. This has resulted in the development of a fragmented network of care providers, which includes third sector organisations, known as 'carers' organisations', who provide specialist carer support. In some

### What is known about this topic

- Although older carers, aged 65 or over, are increasing in number, their needs are often overlooked in research, policy and practice.
- While tools have been developed to understand and evaluate the quality of life outcomes of community-based social care support, they tend to focus on individuals, whether carers or adults with support needs, separately.
- Care practice and service commissioning and delivery also tend to adopt an individualised model.

### What this paper adds

- Identifies the need for the adoption of a dyadic approach in social care practice, policy and research.
- Highlights a paucity of evidence on understanding and assessing the quality of life of older carers and the people they support together.
- Little work has been done to develop—or adapt existing—tools or approaches to evaluate dyadic quality of life.

areas, they are commissioned to provide the statutory assessments of need for carers. They have no responsibility for assessing or meeting the needs of the adult with support needs; if the person is eligible for publicly funded support, they would access care via local authority needs assessment. This market-based pattern of provision not only contributes to atomised and inconsistent care and support, but also tends to overlook the intertwined nature of carers and care-recipients' lives and experiences and the interdependencies that often characterise their relationship (Brooks et al., 2017; Mitchell et al., 2015).

There is a tension between practice approaches that accommodate the wider family and informal support networks and those that focus on individual-level needs and outcomes. This tension is especially evident where the care and support needs of carers and care-recipients are treated separately, rather than engaging with the carer and care-recipient together. While it could be argued that the process of formally recognising and addressing carers' needs requires a distinctive focus on carers, there is a related tendency to overlook the relational nature of needs embedded in an, often, long-term relationship (Henwood et al., 2017; Larkin et al., 2019, 2020). This is a particularly prominent feature of later life-caring relationships (Milne & Hatzidimitriadou, 2003). Older carers, aged 65 years and over, represent at least 20% of all carers in the United Kingdom (UK), with estimates as high as 30% (Age UK, 2017; Holzhausen, 2016; NHS Digital, 2010). They tend to be co-resident with the person they support and are, typically, caring for a spouse or partner, although they may also be caring for an adult son or

daughter with disabilities or ageing parent(s)/in law (Henwood et al., 2018).

Recognising caring as an embedded relational activity is likely to offer a more holistic perspective that takes account of the lived experiences of carers and the relatives they support (Breheny et al., 2020). Although it is possible to conceptualise care-related needs and QoL outcomes, individually (as is routine, in policy, legislation and care practice), this perspective risks overlooking the intersecting nature of caring (Rand, 2020). It is particularly unhelpful in relation to lifelong spousal/partner relationships, as noted above (Anderson et al., 2017). It has been argued that a dyadic perspective, where the QoL of carers and the adult with care needs are considered together, may be beneficial, especially for older carers (Rand, 2020). Such an approach allows for consideration of the *individual influences* (e.g. health or disability), *shared environmental influences* on QoL (e.g. sharing a home, a similar/shared financial situation), and the role of the relationship between the carer and adult with support needs in (mutually) influencing QoL. This perspective, which we refer to as *dyadic QoL*, could be (and, in some cases, already is) adopted at various levels in long-term care systems from assessment of needs, care planning and review to the commissioning, planning and delivery of services (Rand, 2020).

In this paper, we discuss the findings of a scoping review of the international literature as it relates to the QoL outcomes of older carers and the people they support. The overarching research question is: *What is known about the dyadic QoL of older carers and people they support; both, in general, and with regard to the impact of community-based social care?* We focussed on QoL, broadly defined, rather than health-related QoL or psychological well-being, as social care services are intended to support people's QoL 'beyond health', for example they aim to promote inclusion and social engagement (Department of Health and Social Care, 2018b; Netten et al., 2012). By dyadic QoL, we refer to a perspective that considers the QoL of adults with support needs and their carer(s), together.

## 2 | METHODS

We conducted a scoping review, following the five-stage methodological framework developed by Arksey and O'Malley (2005). First, the research question and terminology (see Table 1) that underpin this review were developed and refined based on discussions by the project team and Advisory Group members; the Group includes representatives from local authorities, carers organisations and public and patient involvement research advisors, with experience of social care and/or caring.

Second, the search strategy was developed through pilot searches in Scopus, which was adapted for each database (see Table 2). We searched 16 electronic databases with international evidence, including Scopus, Web of Science, PubMed, Social Policy and Practice, Social Care Online, Cochrane Library, EBSCO Abstracts in Social Gerontology, EBSCO Open Dissertations, CINAHL Plus with Full Text, APA PsycInfo, PROSPERO, ProQuest, JSTOR, International Bibliography of the Social Sciences, DART-Europe, Open access theses and dissertations. This was supplemented by grey literature searches to identify policy and practice-related materials, and reports from the following databases or websites: Open Grey, Community Care Inform-Adults, Gov UK official documents, UK Parliamentary papers, Carer Research and Knowledge Exchange Network (CAREN), Social Care Institute for Excellence (SCIE), School for Social Care Research (SSCR), Carers UK and Carers Trust. This was further supplemented by reports or other documents identified by members of the Advisory Group. All searches were limited to literature published since 2000 to search dates (October/November 2020) and in English.

The study selection (stage 3, see Figure 1) was conducted by one researcher (WZ). Studies were screened by title and abstract based on the inclusion and exclusion criteria (Table 3). 10% of papers were screened in parallel by another researcher (SR). When there was a discrepancy, this was discussed until consensus was reached. All papers considered to be 'highly' or 'possibly' relevant from this

Term	Definition
Older carer	Adults who are aged 65 or older, and provide (unpaid) care to a family member or a friend
Quality of life (QoL)	This review focussed on studies of the QoL of older carers and care-recipients. This included qualitative and quantitative studies of aspects/measures/experience of care/care-related QoL, which is the target of social care interventions. Meanwhile, as this review considered QoL beyond health, we excluded studies related <i>only</i> to health-related QoL and/or clinical psychological measures and/or <i>only</i> to carer burden, stress or strain. In addition to studies on the measurement of QoL, this review also included qualitative studies discussing QoL of older carers and care-recipients, such as well-being or satisfaction with life
Community-based social care services	Community-based social care services included services or support used by care-recipients and carers in people's own home or local community. Services were included regardless how they were funded (i.e. included publicly-funded, voluntary/third sector or privately purchased care or support)

TABLE 1 Terminology

TABLE 2 Key concepts and search terms

Older carers	Care-recipient	Dyadic	QoL
(carer OR caregiver OR partner OR spous* OR parent OR sibling OR famil* OR relative OR couple) AND (Older OR elder* OR senior OR aged OR geriatric OR pensioner) AND	("care recipient" OR care-recipient OR care-receiver OR "care receiver" OR "service user" OR "end user" OR end-user OR client) AND	(dyad OR dyadic OR joint OR combined) AND	("quality of life" OR well-being OR "satisfaction of life" OR wellbeing OR "well being")

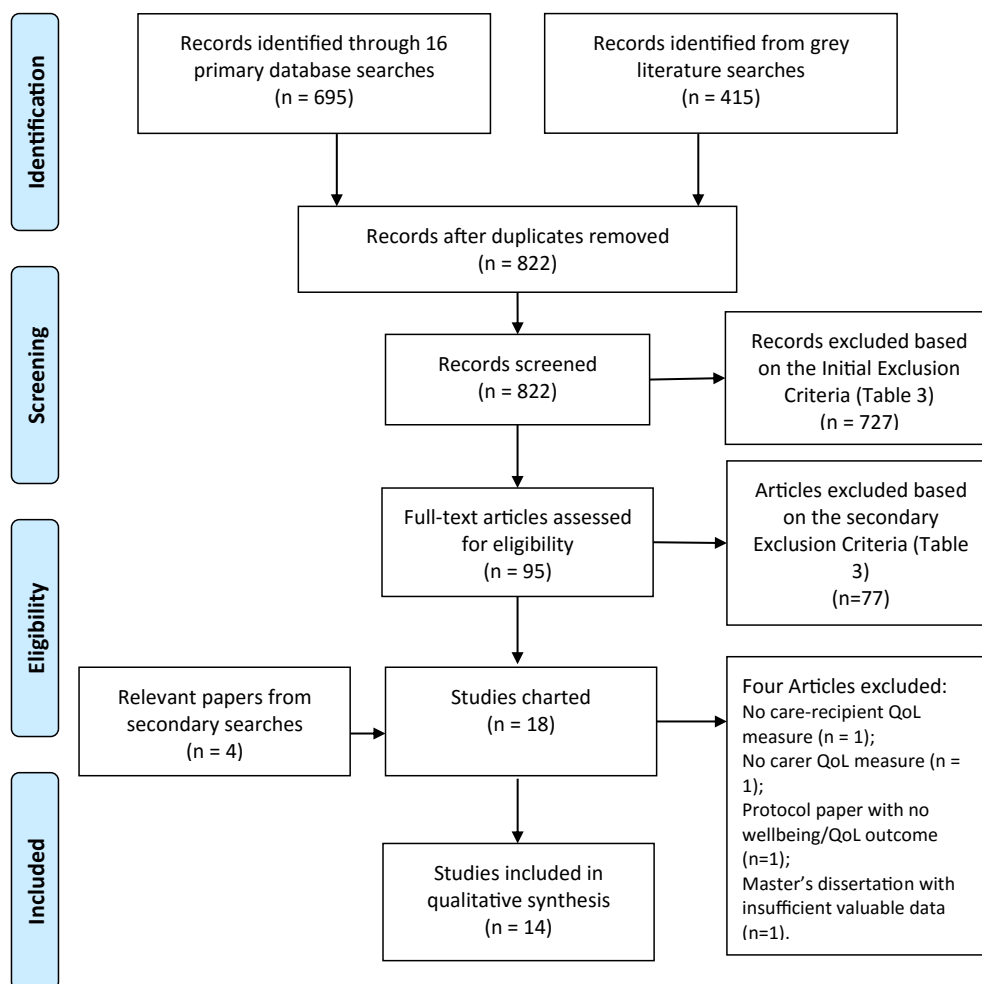


FIGURE 1 Search and review flow diagram

screening process were independently reviewed by title and abstract by two researchers (SR and GC).

Fourth, the selected papers ( $n = 14$ ) were summarised in a data extraction form with the following fields: Author (Year), Country, Title, Study type, Aims, Methods, Sample size, QoL measure(s). Finally, the selected papers were analysed thematically in NVivo by two researchers (WZ and GC) using an agreed codebook, which was finalised after coding six of the papers, and also reviewed by a third researcher (SR). Two overarching themes were identified: (1) understanding dyadic QoL, using (i) dyadic data analysis and/or (ii) theories related to relationship dynamics, and (2) support from family, friends

and neighbours and community-based social care services that influence dyadic QoL.

### 3 | RESULTS

Table 4 presents the main characteristics of the included literature. Two papers (Forrester-Jones, 2019; Hill, 2007) exclusively investigated the dyadic QoL of older carers and people they support. The other 12 items included both older carers and carers in other age groups. The papers spanned three countries (6 were from the UK,

TABLE 3 Inclusion/exclusion criteria

Primary inclusion criteria
<ul style="list-style-type: none"> <li>• Older carers</li> <li>• Published 2000 onwards</li> <li>• International literature—no restriction on countries or regions</li> <li>• Related to quality of life of carers and care-recipients (dyadic QoL)</li> </ul>
Initial exclusion criteria
<ul style="list-style-type: none"> <li>• Non-English literature</li> <li>• Published before 2000</li> <li>• Relates <b>Only</b> to carers who do <i>not co-resident</i> with care-recipients</li> <li>• Relates <b>Only</b> to carers who are younger adults (18–64 years)</li> <li>• Relates <b>Only</b> to 'paid' carers—care workers</li> <li>• Relates <b>Only</b> to <i>health-related</i> quality of life or <i>clinical psychological measures</i> or <i>care strain</i> or <i>burden</i></li> <li>• Relates <b>Only</b> to care in <i>institutional settings</i> (e.g. <i>hospital, care home</i>)</li> </ul>
Secondary exclusion criteria
<ul style="list-style-type: none"> <li>• Relates <b>Only</b> to healthcare intervention</li> <li>• Relates <b>Only</b> to outcomes on physical health</li> <li>• <b>Not dyadic</b> QoL outcomes (i.e. QoL only for the carer or only for the care-recipient)</li> <li>• <b>No</b> dyadic outcomes in findings but <b>Only</b> as suggestions for future research</li> <li>• Conference abstract with <b>No</b> full paper available</li> </ul>

3 were from the United States [US] and 1 was from China); in addition, other four literature review papers considering international studies. The papers represent a variety of study designs included (5 quantitative studies, 5 literature reviews, 3 qualitative studies and 1 mixed-methods study). Half of the papers presented the findings of studies with primary data collection.

### 3.1 | Theme 1: Understanding dyadic QoL

Eight of the studies explicitly highlighted the importance of considering and understanding the QoL outcomes of adults with support needs and their carers (Bielsten & Hellström, 2019a, 2019b; Bonds et al., 2020; Braun et al., 2009; Forrester-Jones, 2019; Larkin et al., 2019; Lyons et al., 2002; Rand et al., 2017). Some studies employed an overarching theoretical or conceptual framework to achieve this; others adopted perspectives from different disciplines to help to understand the caring relationship and dyadic QoL, for example from psychology (psychological well-being, distress in caring spouses, family adaptability), gender studies (gendered roles and caring, carer identity) and social policy and social work (empowerment of service users and carers; Braun et al., 2009; Hill, 2007; Lyons et al., 2002).

In the papers that drew upon an overarching theoretical or conceptual framework, two broad approaches to understanding dyadic QoL characterise the literature: (1) dyadic data analysis and (2) the dynamics of caring relationships. Both of these are set within the framework of 'interdependence theory', which suggests that relationships are defined through interpersonal interdependence (i.e. people interacting socially influence one another's experiences,

emotional states, thoughts and attitudes and QoL outcomes). It highlights the mutuality and interdependence of people in relationships defined by one or more of the following features: close proximity, intimacy, affection and/or dependence (Kelley, 1984; Rusbult & Arriaga, 1997; Rusbult & Van Lange, 2008). In the literature identified in this review, it has been applied to relationships, where one person 'cares for' another, due to illness, disability or long-term health conditions.

#### 3.1.1 | Dyadic data analysis of QoL outcomes

Two identified studies applied dyadic data analysis to explore the interdependency and mutual influence between members of the dyad (Moon et al., 2017; Rand et al., 2017). This quantitative methodology allows the modelling of outcomes (e.g. QoL) for two individuals in a way that accounts for both individual *and* mutual influences on outcomes (Kenny et al., 2020).

In the two identified studies, dyadic data analysis was applied to explore the QoL outcomes of carers *and* care-recipients. Moon et al.'s (2017) study investigated the QoL of people with mild-to-moderate dementia and their carers. The researchers asked care-recipients to rate the value they placed on social relationships with family and friends, as well as their perceived involvement in decision-making. Their carers were also asked to rate their view of the care-recipient's valuing of social relationships and decision-making involvement. Greater incongruence between care-recipient and carer's report of the value of social relationships predicted lower QoL for both parties; discrepancy of decision-making involvement rated by carers and care-recipients was not a significant predictor of QoL. The study did not consider the effect of health and social care services, or specific interventions, on QoL outcomes. However, the authors argued that the findings may have relevance to, and inform, the development of psycho-social interventions designed to support people living with dementia and their carers.

The second study by Rand et al. (2017) applied the Actor Partner Interdependence Model (APIM; Cook & Kenny, 2005) to understand the care-related QoL outcomes of carers and adults with a diverse range of social care support needs. The APIM is a type of dyadic quantitative data analysis that models *actor effects* (individual variables that affect their own QoL) and *partner effects* (individual variables that affect the QoL of the other member in the dyad), as well as the direct mutual influence of each person on the other through the caring relationship (see Figure 2).

The analysis presented in this study drew on previous research on the effect of social care on individual outcomes for carers or care-recipients. This was informed by a framework that (broadly) conceptualises influences on QoL as belonging to a number of key categories: individual characteristics (e.g. age, health), contextual or environmental features (e.g. household finances, housing quality), caring context (hours of care per week, type of caring tasks) and social care-related variables (e.g. intensity or type of support, satisfaction with support). In Rand et al.'s (2017) study, the APIM

TABLE 4 Study characteristics

Variable	Numbers of studies	Studies
Study context—country		
United Kingdom	6	Hill (2007); McIntyre and Reynolds (2012); Rand et al. (2017); Larkin et al. (2019); Henwood et al. (2018); Forrester-Jones (2019)
United States	3	Lyons et al. (2002); Moon et al. (2017); Bonds et al. (2020)
China	1	Wang et al. (2017)
International	4	Braun et al. (2009); Moon and Adams (2013); Bielsten and Hellström (2019a, 2019b)
Reference type		
Journal article	11	Lyons et al. (2002); Braun et al. (2009); McIntyre and Reynolds (2012); Moon and Adams (2013); Moon et al. (2017); Rand et al. (2017); Wang et al. (2017); Larkin et al. (2019); Bielsten and Hellström (2019a, 2019b); Bonds et al. (2020)
PhD thesis	1	Hill (2007).
Report	2	Henwood et al. (2018); Forrester-Jones (2019)
Study design		
Quantitative	5	
Cross-sectional study	3	Moon et al. (2017); Rand et al. (2017); Wang et al. (2017)
Secondary analysis of longitudinal study	1	Bonds et al. (2020)
Secondary analysis of combined samples from two studies in one region	1	Lyons et al. (2002)
Literature review	5	Braun et al. (2009); Moon and Adams (2013); Larkin et al. (2019); Bielsten and Hellström (2019a, 2019b)
Qualitative	3	Hill (2007); McIntyre and Reynolds (2012); Forrester-Jones (2019)
Mixed methods	1	Henwood et al. (2018)
Type of data		
Primary data	7	Hill (2007); McIntyre and Reynolds (2012); Moon et al. (2017); Rand et al. (2017); Wang et al. (2017); Henwood et al. (2018); Forrester-Jones (2019)
Secondary data	7	Lyons et al. (2002); Braun et al. (2009); Moon and Adams (2013); Larkin et al. (2019); Bielsten and Hellström (2019a, 2019b); Bonds et al. (2020)
Caring dyads		
Dyads with older carers (exclusively)	2	Hill (2007); Forrester-Jones (2019)
Mixed dyads of spousal, parent/child, siblings, friends or others	2	Larkin et al. (2019); Rand et al. (2017).
Dyads with older care-recipients and their spouse/adult-childcarers	1	Lyons et al. (2002)
Mixed dyads with older carers & carers (of any age) of people with dementia	1	Henwood et al. (2018)
Spousal dementia dyads	2	Braun et al. (2009); Bielsten and Hellström (2019a)
Dementia dyads	5	Moon and Adams (2013); McIntyre and Reynolds (2012); Moon et al. (2017); Bielsten and Hellström (2019b); Bonds et al. (2020)
Disabled older people and carers dyads	1	Wang et al. (2017)
Subjective QoL or well-being measures		
Quality of life-Alzheimer's disease (QoL-AD; Logsdon et al., 1999, 2002)	4	Moon and Adams (2013); Moon et al. (2017); Bielsten and Hellström (2019b); Bonds et al. (2020)
Adult Social Care Outcomes Toolkit (ASCOT; Malley et al., 2012; Netten et al., 2012) and ASCOT-Carer (Rand et al., 2015)	1	Rand et al. (2017)

(Continues)



TABLE 4 (Continued)

Variable	Numbers of studies	Studies
Life Satisfaction Index-B (LSI-B; Neugarten et al., 1961)	1	Wang et al. (2017)
World Health Organisation's Quality of Life Assessment (WHOQOL; WHO, 2012)	1	Bielsten and Hellström (2019b)
No scale used	8	Lyons et al. (2002); Hill (2007); Braun et al. (2009); McIntyre and Reynolds (2012); Larkin et al. (2019); Bielsten and Hellström (2019a); Henwood et al. (2018); Forrester-Jones (2019)

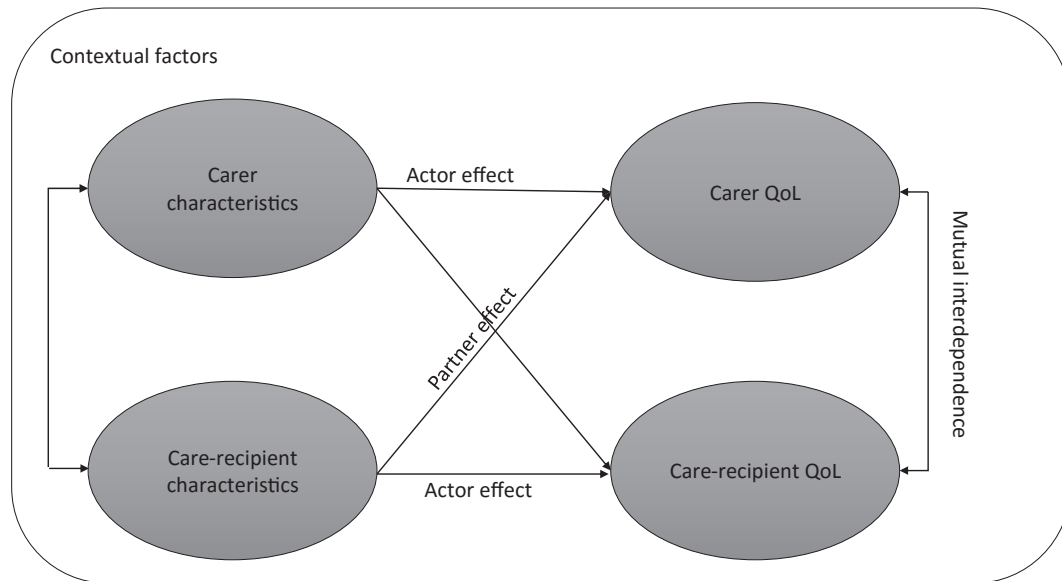


FIGURE 2 Actor-partner interdependence model, adapted based on Rand et al. (2017)

was applied to 298 caring dyads to consider, and control for, these individual, contextual and care-related variables, as well as to model the direct mutual influence on QoL through the caring relationship. The study found that there were *both* individual-level and dyad-level factors that were significantly related to three aspects of care-related QoL of care-recipients and their carers—*Social participation*, *Occupation* (meaningful activity), *Control over daily life*. However, mutual interdependence (see Figure 2) was found for only one of the three domains of QoL considered in the analysis (*Control over daily life*). This analysis demonstrates that there are dyadic influences on QoL, through both partner effects and mutual interdependence, and underscores the importance of understanding the impact on QoL of both people with support needs *and their carers*, whether in the assessment of need, the evaluation of interventions or in the development, commissioning or delivery of services.

### 3.1.2 | The dynamics of caring relationships

Caring, which encompasses the giving and receiving of care and support (e.g. help with washing, dressing or eating, support with

mobility or transport, social and emotional support), takes place within a relationship between two people (the 'carer' and 'care-recipient'). It shapes the relationship; likewise, the experience of caring is shaped by the relationship (Bielsten & Hellström, 2019a, 2019b; Braun et al., 2009; Henwood et al., 2018; Hill, 2007; Lyons et al., 2002). Each relationship has its own dynamics with different strengths and weaknesses that affect the experience of caring and also QoL outcomes (Bielsten & Hellström, 2019a, 2019b; Braun et al., 2009). While some patterns may be shared across 'types' of care relationship (i.e. spousal care, parent care), individual features of the relationship are profoundly influential. Caring dyads commonly work to retain their pre-existing familial roles and sense of identity as 'spouse', 'son' or 'mum' (Bielsten & Hellström, 2019b; McIntyre & Reynolds, 2012). The terminology of 'carer' and 'care-recipient', which describe roles within the caring relationship and are useful terms for health and social care professionals or services, are typically less important to families than the pre-existing relational roles and identities (e.g. parent-child, husband-wife or partners; McIntyre & Reynolds, 2012). However, the reality is that intensive caring can sometimes eclipse pre-existing relationships (Lyons et al., 2002), substantially change relationship dynamics (Henwood et al., 2018)

and immerse carers in the tasks of caring with limited space left for engagement with other, more 'normal', aspects of the relationship (McIntyre & Reynolds, 2012).

While dyadic data analysis allows the modelling of different influences on QoL, including the mutual influence through the caring relationship (see Figure 2), it does not provide insight into the nature of caring relationships or their dynamics, which may mediate the interdependence of QoL through the relationship. Two conceptual frameworks that relate to caring relationship dynamics were identified in the review, as outlined below, may offer useful insights.

#### *Social exchange theory and equity theory*

Some studies referred to principles of social exchange theory and equity theory (Bielsten & Hellström, 2019a, 2019b; Braun et al., 2009; Henwood et al., 2018; Hill, 2007; Lyons et al., 2002). Social exchange theory proposes that people seek to maximise mutual rewards that arise in relationships or social interactions, and that the decision as to whether to sustain an interaction or relationship is based on cost-benefit analysis of risks and rewards (Dowd, 1980; Gergen & Gergen, 1986). Understanding the exchanges between two members in a long-term relationship over time, especially the quality and equality of their past relationship, Braun et al. (2009) suggest that social exchange theory may explain why some spousal carers provide care to their partner with dementia and report positive caring experiences. Equity Theory, which is closely linked to Social Exchange Theory, highlights the important role of equality and mutuality in dyadic relationships (Wright & Aquilino, 1998). While it is rare for equality (i.e. the balance between what is given and what is received in social exchanges, Gergen & Gergen, 1986) to exist in a caring relationship, the balance of exchanges tend to be conceptualised as existing over the length of the whole relationship (Braun et al., 2009; Hill, 2007). In other words, reciprocity has a status and meaning that transcends time; it is one of the embedded features of a long-term relationship referred to above. This is based on evidence that the caring relationship's quality is related to the quality of the pre-existing relationship, where caring arises due to the onset of illness or disability; in turn, this influences the experience of caring (Braun et al., 2009), dyadic needs and QoL outcomes (Bielsten & Hellström, 2019a, 2019b) and also predicts carers' capacity to continue caring (Henwood et al., 2018).

#### *Dyadic conflict and power in care relationships*

Some studies highlighted tensions within caring dyads (Hill, 2007; McIntyre & Reynolds, 2012), dyadic conflicts and incongruence in views, attitudes, needs and/or outcomes (Lyons et al., 2002; McIntyre & Reynolds, 2012; Moon et al., 2017). These take a number of forms. Adults with support needs often have limited power and feel obliged to relinquish control to their carer; carers may also 'take control' in ways that disenfranchise the cared-for person or make them feel uncomfortable. Care-recipients may push back against this, creating difficulties for the carer. Carers may also feel obliged to care; in these circumstances carers' QoL is often compromised

(McIntyre & Reynolds, 2012). These dynamics influence both the quality of the dyadic relationship and the personhood (self and identity) of care-recipients (McIntyre & Reynolds, 2012), as well as the QoL of both carers and care-recipients (Moon et al., 2017). Dyadic conflicts may arise from incongruences between goals or perspectives of carers and care-recipients, developmental discrepancies arising from different life stages (e.g. parent and adult child), or the history of the relationship (Lyons et al., 2002).

### 3.2 | Theme 2: Support from family, friends and neighbours and community-based social care services that influence QoL

A number of papers highlighted the role of support from family, friends and neighbours and formal services in promoting QoL outcomes of caring dyads (Bielsten & Hellström, 2019a, 2019b; Bonds et al., 2020; Forrester-Jones, 2019; Henwood et al., 2018; Hill, 2007; McIntyre & Reynolds, 2012; Rand et al., 2017).

#### 3.2.1 | Support from family, friends and neighbours

Beyond the relationship between the carer and the care-recipient, there is often a wider network of support from family, friends and neighbours that has the capacity to positively influence the QoL outcomes of the caring dyad. Hill (2007) outlines the vital contribution of families to older spousal caring dyads QoL; relatives provide assistance in both emergencies and everyday situations, offer regular hands-on help with care tasks and provide social and/or emotional support to both members of the dyad. Forrester-Jones (2019) echoes these findings in her work with people with learning disabilities and/or autism and their parent carer; siblings are especially an important source of support. There is, as might be expected, significant variation in the extent and type of support different families are able to provide; key factors that influence this include the health of (other) family members, how far away they live from the dyad, and paid work demands (Hill, 2007). Socio-demographical changes that threaten the capacity of the wider family to support care dyads include smaller and more disparate families and the growing number of people ageing without children (Larkin et al., 2019).

Support from beyond the family, that is from friends and neighbours, is an important supplementary source of assistance for dyads (Forrester-Jones, 2019; Hill, 2007). More than a fifth of the older couples who participated in Hill's (2007) study had regular help from their neighbours. Evidence suggests that while neighbours and friends will help with instrumental care tasks, such as with shopping or transport to medical appointments, they are less willing to offer personal care or offer support with complex tasks, for example resolving medication issues (Crow et al., 2002; Hill, 2007). Older couples are often concerned not to 'take advantage' of friends and neighbours and worry about being indebted to them; this limits the range and number of demands they make (Hill, 2007).



### 3.2.2 | Community-based social care

In terms of the impact of community-based services on carers' and care-recipients' QoL, evidence is mixed; it is also limited as to which services, in which quantities, are most effective (Bielsten & Hellström, 2019a, 2019b; Forrester-Jones, 2019; Henwood et al., 2018; Hill, 2007; Larkin et al., 2019; Lyons et al., 2002; McIntyre & Reynolds, 2012; Rand et al., 2017). Bielsten and Hellström's (2019a, 2019b) review focussed on joint interventions (e.g. couples counselling, music therapy), which are designed to benefit the dyad, with evidence of positive impacts on the well-being of both carer and care-recipient. However, the majority of dyadic interventions did not take into account relationship factors and neglected interpersonal issues (e.g. communication between carer and care-recipient), and the care-recipients' views tended to be overlooked.

Other papers focussed on individual services, which target *either* the carer *or* care-recipient. Although these interventions may impact on the intended beneficiary, whether carer or care-recipient, they may also affect the other member of the caring dyad and/or both parties. For example respite care and short-term breaks have been consistently identified as services that positively influence dyadic QoL (Forrester-Jones, 2019; Henwood et al., 2018; Hill, 2007; Larkin et al., 2019; McIntyre & Reynolds, 2012). However, it is usually a combination of services that constitute 'effective support' for the dyad (Henwood et al., 2018). Irrespective of the source of support, older couples in Hill's (2007) study conceptualised effective care as support that helped them, both as individuals and as a dyad, to fulfil caring responsibilities, retain independence and stay socially connected to family, friends and the wider community.

Some social care practitioners and providers recognise the importance of adopting a dyadic approach to needs assessments, reviews and care planning (Forrester-Jones, 2019; Hill, 2007). Representatives of home care organisations who participated in Hill's (2007) study suggested that the most cost-effective, efficient and comprehensive approach to care service provision was to include both carers and care-recipients in review meetings. By involving, valuing and supporting carers, care providers felt more able to respond quickly and sensitively to changing needs and crises. Joint approaches were highly valued by the couples; it helped them to cope *together* with care issues and to protect the relationship (Hill, 2007; Larkin et al., 2019). Furthermore, a dyadic approach to understanding and addressing needs has been highlighted as important for future planning when the carer may become too ill or infirm to continue to provide care. This is a particularly important issue for older parents of adult children with learning disabilities, who want to have a plan in place for when they are no longer able to care (Forrester-Jones, 2019; Henwood et al., 2018).

## 4 | DISCUSSION

This scoping review identified what we know about the dyadic QoL of older carers and people they support, both, in general, and with

regard to the impact of community-based social care. Almost all studies included in our review emphasised that considering the QoL of carers and the people they support, together, would potentially improve the understanding of care needs, provision of care services and QoL outcomes. Despite this consensus, however, there is limited and fragmentary evidence on dyadic QoL or the impact of social care services on dyadic QoL outcomes.

Although limited in number, the focus of most dyadic work is dementia dyads (8 studies exclusively on dementia dyads). Only two of the 14 identified papers specifically investigated the QoL of older carers and people they support. The other 12 papers included *both* older carers and carers in other age groups. Although there is some recognition of the need to consider the ageing process and end-of life issues for older caring dyads (Forrester-Jones, 2019; Henwood et al., 2018), this is not well-developed and represents a gap in the evidence.

The majority of evidence comes from the UK (6 out of 10 country-specific papers), which partly reflects the policy emphasis on family-focused interventions and social care support in the UK (Department of Health and Social Care et al., 2015). In the literature, there is also growing interest in exploring interventions that improve the QoL of adults with support needs and their carers, together. However, few studies have adopted a dyadic perspective. This may be partly due to the ambiguous conceptual and actual status of carers. Are carers a free resource to be co-opted into caring, a part of the care workforce alongside paid care staff, or co-clients who have a right to needs assessment and support from services (Twigg, 1989)? This frame of reference matters as it influences whether the carer's QoL outcomes are considered (as co-clients), or not (as resources or co-workers; Rand & Malley, 2014). To consider the care dyad as a legitimate focus of research on QoL outcomes, carers need to be understood as co-clients or co-beneficiaries of interventions and support, even if those benefits are indirect (in which case, it is about capturing the 'wider effect' of care).

A second reason why dyadic QoL is so little explored is the methodological challenge of how to adequately account for, and capture, dyadic outcomes. Health and social care research has a long tradition of assessing and measuring concepts like 'effectiveness' and 'QoL', as they pertain to an individual (usually, the care-recipient). Whether, when and how to extend these concepts to include the carer and/or dyad, especially in terms of economic evaluation of healthcare interventions, is still being explored (Brouwer, 2019; Dixon & Round, 2019; Prosser & Wittenberg, 2019). Arguably, both the care-recipient and carer may benefit from social care support, as co-beneficiaries, rather than indirectly as 'spill over effects', so these concepts may be more straightforwardly applied than in relation to healthcare interventions (Rand et al., 2020). However, the methodological issues of how to adequately conceptualise and model dyadic QoL outcomes, so as to avoid double-counting, remain unresolved.

The review identified two methodological approaches that may inform the question of how to conceptualise and account for dyadic QoL outcomes: (1) quantitative dyadic data analysis, especially the APIM, and (2) theories that relate to the dynamics of caring relationships, including social exchange and equity theory. Both of these are

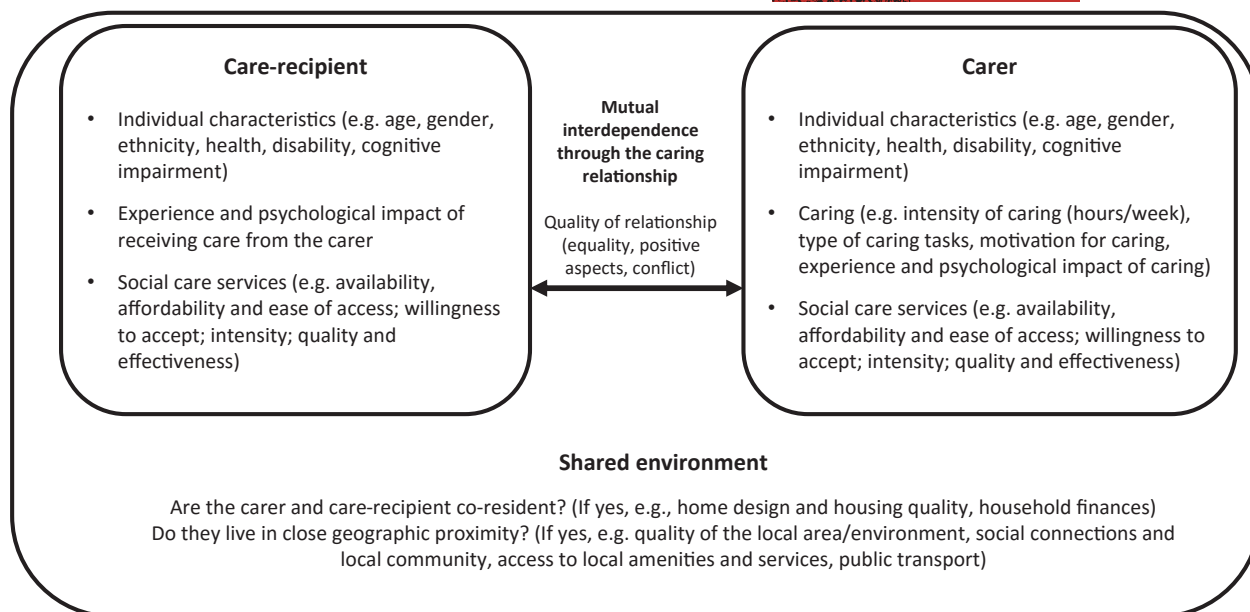


FIGURE 3 Influences on dyadic quality of life

situated under the conceptual umbrella of interdependence theory, as discussed above. We suggest that these could usefully contribute, along with insights from studies of individual QoL outcomes for people with support needs and carers (Forder et al., 2018; Rand & Malley, 2017; Rand et al., 2015; van Leeuwen et al., 2014), to the development of a framework for understanding and analysing dyadic QoL outcomes (see Figure 3). Such a framework could also help to capture dyadic social care outcomes as they relate to interventions for a 'care dyad'.

Aside from research evidence on dyadic QoL, and despite a broad search strategy which included a variety of grey literature sources, only two practice or policy-related papers were found to be relevant to our review questions (Henwood et al., 2017; Larkin & Milne, 2018). This absence reflects a number of issues. One is the policy contradiction relating to the 'importance of adopting a whole family, or relational, approach' to social care provision, while at the same time bolstering a social care system which promotes separate assessments of need for 'users' and 'carers' and commissions separate sets of services. A second tension relates to the claimed value of achieving positive outcomes for users and carers in contexts where practitioners are unable, or struggle to, deliver dyadic assessments of need or plan care that accommodates members' interdependency. That dyadic QoL issues are under-investigated in research compounds the challenge.

The study has a number of limitations. First, we exclusively included studies written in English; despite searching 16 electronic databases of international evidence, our grey literature search was limited to European countries (e.g. Open Grey) and predominantly in the UK. Second, given the paucity of literature on older caring dyads it not been possible to explore the *particular* care needs of older carers in different contexts, for example spousal carers, parent carers, filial carers; nor has it been possible to comment on issues arising from differences relating to race, ethnicity, gender, class, sexuality or disability.

## 5 | CONCLUSION

This review has identified a gap between the paucity of evidence about dyadic QoL and a broad consensus of support for a dyadic approach in social care practice and research. Recognising challenges in policy implementation and sustainability, this review emphasised that taking into account the QoL of carers and care-recipients, together, would potentially improve the understanding of care needs, provision of care services and QoL outcomes. Future work is required to explore and evaluate the use of a dyadic approach in social care practice and research. For example the next stages of the DYADic impact of Social care (DYADS) Study will explore the views and perspectives of social care practitioners and managers, as well as care-recipients and carers, to explore the potential benefits, challenges and barriers to applying a dyadic QoL outcome perspective in social care practice and services.

### AUTHOR CONTRIBUTIONS

SR, AM and WZ were involved in the study design. All authors reviewed and commented on the scoping review protocol. WZ and SR were involved in all stages of the literature review, including preparation of the manuscript. AM advised on all stages of the review and contributed to the draft of the manuscript. GC was involved in the item selection and extraction. All authors provided critical feedback on the draft manuscript, and approved the final manuscript.

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## CONFLICT OF INTEREST

None declared.

## DATA AVAILABILITY STATEMENT

Research data are available, upon reasonable request, from the corresponding author.

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