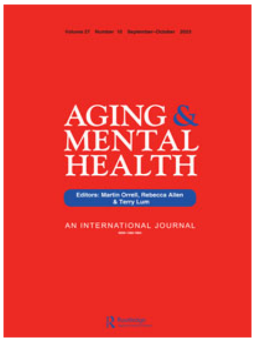

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Iris Hochgraeber, Kerstin Köhler, Hannah Stöcker & Bernhard Holle

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The dyadic relationship of family carers and people living with dementia – an umbrella review

Iris Hochgraeber[a,b], Kerstin Köhler[a,b], Hannah Stöcker[c] and Bernhard Holle[a,b]

[a]Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE), Witten, Germany; [b]Faculty of Health, School of Nursing Science, Witten/Herdecke University, Witten, Germany; [c]Faculty of Health, School of Psychology, Witten/Herdecke University, Witten, Germany

ABSTRACT

Objectives: The dyadic relationship of people living with dementia and their family carers is highly relevant when considering the stability of home-based care arrangements. There is a solid body of research that covers issues related to dyadic relationships. However, a synthesis of qualitative research is missing. Therefore, the aim of this review is to give an overview of the dyadic relationship, with the leading research question of what influences the dyadic relationship and how it can be maintained during the trajectory of the disease.

Methods: We performed an umbrella review of qualitative literature on the basis of thematic synthesis and used the SoCA-Dem theory as a theoretical framework. Literature searches in the databases PubMed (MEDLINE), CINAHL, Scopus, and PsycInfo were performed from July to September 2020, additional papers were included until September 2022. We searched without timeframe restrictions and considered publications in English or German.

Results: After a systematic database search, resulting in 1325 records, we included 12 reviews. Five analytical themes and 11 subthemes were identified. The analytical themes were 'change in the relationship', 'activities to maintain the relationship', 'continued togetherness', 'home as a place for enacting relationship', and 'influencing factors'.

Conclusion: The dyadic relationship is a complex and multifaceted phenomenon. It is characterized by family carers' attempts to continue togetherness using different strategies and is mainly influenced by the quality of the premorbid relationship and the mindset of the family carer.

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Informal caregiver; stability of care arrangements; interpersonal relations; meta-review; review-of-review; qualitative research

Introduction

Worldwide, there are over 55 million people living with dementia, and this number is expected to reach 78 million by 2030 (Gauthier et al., 2021). Most people with dementia live at home (Rothgang et al., 2010; World Health Organization, 2012) and desire to stay in their familiar environments for as long as possible (von Kutzleben et al., 2012). 'Ageing in place' is related to a sense of autonomy, connectedness to people and places and social inclusion; all of this is associated with a higher quality of life (O'Rourke et al., 2015; Pinkert et al., 2021; Wiles et al., 2012). Driven by the motivation to assist their loved-ones to stay at home, over the course of dementia mainly family members assume the often challenging carer role. They provide emotional support, practical supervision and care, serve as gate keepers between the informal and formal support systems, and manage care arrangements that are often complex (Nolan et al., 1996; Zigante, 2018). Family carers strive to 'keep things in balance' (Esandi et al., 2018) while they adjust to ongoing changes and changing needs (Quinn et al., 2015). In these dynamic processes, giving care does not necessarily have to be associated with negative consequences such as burden and depression (Etters et al., 2008; Miller et al., 2020) but can also be perceived as positive and rewarding (Cheng et al., 2016; Yu et al., 2018). Most family carers are the spouse or a child of the person with dementia, hence they often perceive care responsibilities as a natural continuation of their long-standing dyadic relationship with the person with dementia (Etters et al., 2008; Miller et al., 2020; Cheng et al., 2016; Yu et al., 2018). The 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem) theory provides a framework for family carers' strategies to create stable home-based care arrangements, and one of the key concepts that influence stability is the dyadic relationship (Köhler et al., 2021). According to the SoCA-Dem theory the kinship relation, the living situation and in particular the quality of the dyadic relationship—which is associated with a strong commitment to the carer role—have an impact on the stability of a home-based care arrangement. Relationship quality depends on whether the family caregiver and the person with dementia succeed to negotiate role changes and power shifts throughout the care trajectory and to maintain reciprocity and affection over the course of dementia (Köhler et al., 2022; Köhler et al., 2021). Depending on the prior history of the two care partners—between loving affection and possible conflicts—the carer role can range from a relatively uninvolved care manager to a primary carer providing hands-on care (Fletcher, 2021). Therefore, the premorbid relationship quality seems to be an important aspect when assessing the current relationship (e.g. Clark et al., 2019; Steadman et al., 2007). Relationship quality plays an important role regarding diverse aspects of giving care,

CONTACT Kerstin Köhler kerstin.koehler@dzne.de

including the management of behavioural and psychological symptoms of dementia (Luiu et al., 2020).

In a first search concerning dyadic relationship, it turned out that there are many studies on this topic, both single studies and literature reviews. Therefore, the aim of this umbrella review is to synthesize the qualitative literature about the dyadic relationship between family carers and people with dementia; the main focus is on what influences the dyadic relationship and how the relationship and relationship quality can be maintained throughout the disease trajectory.

Methods

This publication has been generated as a part of the eDEM-CONNECT project. As methodology, we chose an umbrella review to present the pooled literature results (Biondi-Zoccai, 2016; Hunt et al., 2018). We decided to focus on qualitative reviews because qualitative studies not only describe influencing factors related to dyadic relationships but also illuminate the complex processes in their formation and shed light on the meaning of relationship changes for the persons involved.

As mentioned in the introduction, the SoCA-Dem theory conceptualizes the dyadic relationship of the family carer and the person with dementia as a key concept in the attempt of family carers to create and maintain the stability of their care arrangement. Therefore, we chose the SoCA-Dem theory (Köhler et al., 2021) as a theoretical frame and starting point for the analytic procedures in this umbrella review .

Search strategy

The international scientific literature was searched from July to September 2020 using the following databases: PubMed (MEDLINE), CINAHL, Scopus, and PsycInfo. Afterwards, we installed search alerts for every database and continually screened for new publications up to September 2022. IH created three search clusters related to the research aim: 'dementia', 'relationship' and 'qualitative literature review' (see Table 1 as an example), which were adapted to the unique conditions for different databases. HS and KK checked the strategy for completeness. One term (spous*) was added.

Additionally, we scanned the reference lists of the identified reviews and other relevant papers.

Eligibility criteria and study selection

The literature search was conducted without timeframe restrictions. We included reviews of qualitative and mixed studies published in peer-reviewed journals. The content focus had to be on the dyadic relationship between family carers and people with dementia living at home. Reviews of inpatient or nursing home settings were excluded.

The search results were imported into EndNote X9®. After removing duplicates, titles and abstracts were screened by one author (IH). Because in the title and abstract screening the decisions regarding the inclusion or exclusion of records were very clear and without doubts, we decided not to involve an additional author. This is an approved option to save resources, for example in rapid reviews (Tricco et al., 2015).

Full texts were obtained for all reviews considered to potentially meet the inclusion criteria. Full texts were independently screened by IH and HS for eligibility using a quality appraisal tool developed by von Kutzleben et al. (2012). The tool checks the reviews' relevance to answer the research questions of this umbrella review, and it appraises the methodological quality of the reviews. Those reviews considered borderline and those that were the subject of disagreement were discussed until consensus was reached. No reviews were excluded because of quality deficiencies. The used quality checklist as well as the results of the appraisal can be obtained from the corresponding author.

Data extraction and synthesis

We extracted the following data: authors, year of publication, country, type of review, research aim/question, search strategy, number of included studies, theoretical frame, analysis methods, quality appraisal, perspective(s) investigated (dyad, family carer, person with dementia, combined), kinship relation and the results and conclusions connected to dyadic relationships.

To generate results and conclusions, we performed a three-stage thematic synthesis (Thomas & Harden, 2008). IH and HS independently analysed the included reviews. The SoCA-Dem theory (Köhler et al., 2021) served as a framework for the analysis. The first step, 'line-by-line coding', was executed with a deductive coding scheme based on selected concepts of the SoCA-Dem theory (change, balancing, carer roles, mental resources and their connection to dyadic relationship). These deductive codes were enriched with inductively produced codes. In mixed studies reviews, only the qualitative results were analysed. IH and HS discussed the results of the 'line-by-line coding', and the 'descriptive themes', and afterwards, the 'analytic themes' were discussed with researchers from the SoCA team and with researchers familiar with the topic of dyadic relationships. For all analyses we used the software tool MAXQDA 2020.

Results

The initial search identified 1325 records. After removing duplicates and after the screening processes, 11 reviews were initially

Table 1. PubMed Search.

#1 DEMENTIA Linked with OR	#2 RELATIONSHIP Linked with OR	#3 QUALITATIVE LITERATURE REVIEW Linked with OR
dementia [MeSH Terms]	Relation* [Title]	review [Title/Abstract]
dementia [Title]	connect* [Title]	Synthesis [Title/Abstract]
Alzheimer* [Title]	closeness [Title]	meta-study [Title/Abstract]
demented[1] [Title][1]	mutuality [Title]	meta-ethnography [Title/Abstract]
	reciproc* [Title]	
	intima* [Title]	
	couple* [Title]	
	"family dynamics"[Title]	
	partnership [Title]	
	spous* [Title]	
#1 AND #2 AND #3		

[1] Even though the term demented is seen as problematic, it was included so that older publications would not be excluded.

included (Figure 1). With the installed search alerts, we identified one additional publication (Albert et al., 2022) which was included in May 2022. In sum, twelve publications were included in the analysis.

Review characteristics

The characteristics of the included reviews are summarized in Table 2.

Six reviews were carried out in European countries (4 UK, 1 Denmark, 1 Switzerland), five in Australia and one in Brazil. Ten reviews analysed solely qualitative studies, and two reviews, Ablitt et al. (2009) and Conway et al. (2018), included mixed studies. The number of single studies included in the reviews ranged from 9 to 31 and included a total of at least 127 different studies. Braun et al. (2009) did not report the exact number of studies included. Sixteen single studies were included in 3 or more of the reviews (Table 3). Thirteen single studies were included exactly 2 times. Ninety-eight single studies were included in only 1 of the reviews. The study most often included (8 times) is Hellström et al. (2016a).

The 12 reviews included in this umbrella review reported the sample sizes and sociodemographic data of the study participants almost exclusively in tabular form for the individual studies. With one exception (Pozzebon et al., 2016) there was no aggregated presentation at the review level. The type of dementia and the duration of the care trajectories were only mentioned in 8 of the included reviews, and these descriptions were very brief and heterogeneous. Overall, people with Alzheimer's dementia, vascular dementia, young onset dementia and other forms of dementia and in all stages of the disease were represented in the review samples.

The perspective investigated by the reviews was usually a dyadic one and almost exclusively an investigation of the relationship of couples or spouses. Only La Fontaine and Oyebode (2014) stated that they examined whole families, and Ablitt et al. (2009) examined parent-child relationships in addition to couple relationships.

Thematic analysis

From the synthesis of the content related to dyadic relationships, we identified 5 analytic themes and 11 subthemes (Table 4).

Change in the dyadic relationship

The first analytical theme is **change in the dyadic relationship**. Changes threatened the relationship and the sense of togetherness: 'The changes and losses that accompanied dementia impacted on the […] marital relationship in many different ways and challenged the partnership, closeness and togetherness that the couple shared.' (Evans & Lee, 2014, p. 346).

One subtheme, the **change in the person living with dementia**, was mostly caused by a reduction in capabilities (Conway et al., 2018; Holdsworth & McCabe, 2018a, 2018b; Pozzebon et al., 2016) and in behavioural changes (Ablitt et al., 2009; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018b; Pozzebon et al., 2016). From the perspective of the family carer, these changes resulted in the loss of partner (Conway et al., 2018; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018b; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016) because the identity of the person with dementia had changed. As one study noted, 'Some spouses were troubled by the changes caused by dementia, feeling that their partner was becoming a stranger to them.' (Evans & Lee, 2014, p. 341). The changes in the person with dementia were characterized as small in the beginning of dementia and larger in advanced stages (Egilstrod et al., 2019; Evans & Lee, 2014), with the diagnosis being an important inflection point with a negative impact (Ablitt et al., 2009;

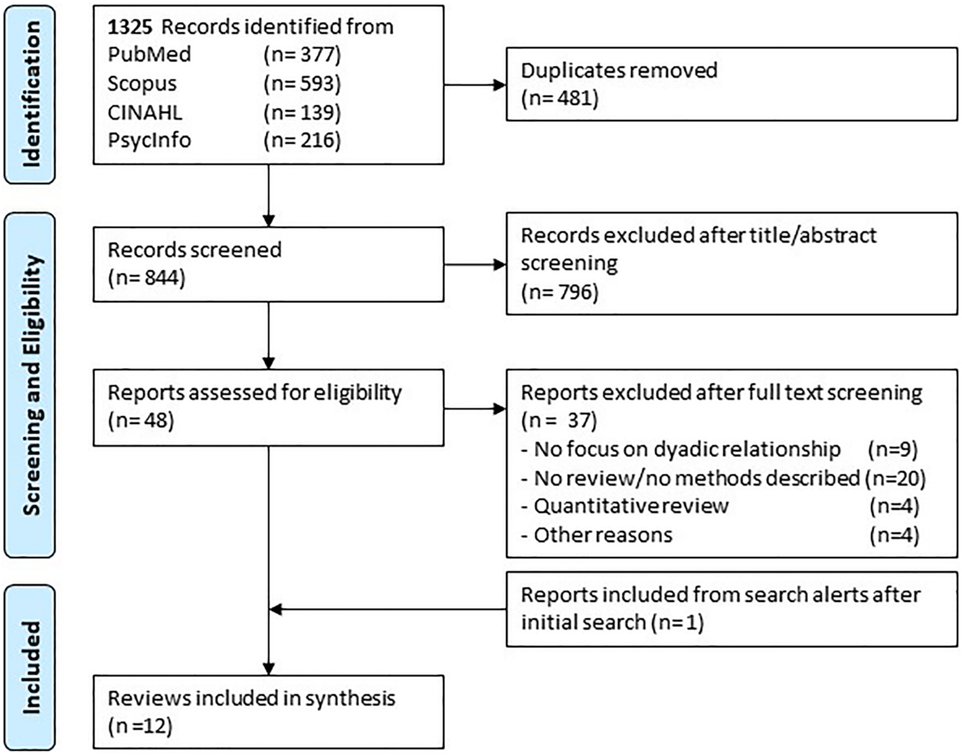

Figure 1. Flowchart of the identification, screening and inclusion of reviews.

Table 2. Characteristics of the included reviews.

Authors	Focus	Included studies	Perspectives stated by authors	Kinship relation	Main findings
Ablitt et al. (2009) UK	Influence of dementia on relationship and influence of prior relationship on present relationship	31	predominantly family carer, dyadic, person with dementia	predominantly couples, adult children, siblings	Dementia causes different declines in different aspects related to the relationship such as reciprocity. Some aspects, such as love, emotional warmth, closeness, and affection, can remain positive. The ability to maintain togetherness is crucial for the experience of both members. The authors propose a theoretical framework in which the quality of the prior relationship influences the relationship after dementia onset.
Albert et al. (2022) Brazil	sex and sexual intimacy in couple relationship	9	dyadic, family carer	couples	Sex is a part of the dyadic relationship between couples. Four key themes are identified: addressing dementia and sex; challenges to maintaining sexual intimacy; forms of sexual expression; and the desire to be seen as a sexual being.
Braun et al. (2009) Switzerland	Dyadic perception of relationship change caused by dementia	unknown	dyadic	couples	Different factors such as gender and affection in the prior relationship influence the relationship, the care and the wellbeing after the onset of dementia. The authors highlight that the dyadic perspective and the perspective of the person with dementia is often neglected.
Conway et al. (2018) Australia	Influencing factors on relationship quality	17	dyadic, family carer	couples, 1 adult child	The continuity of togetherness is based on a positive and strong prior relationship. Qualitative themes which influence the relationship positively or negatively include the following: connection to the carer role, identity of the person with dementia, current efforts to maintain the relationship connection, the dyad's response to dementia
Egilstrod et al. (2019) Denmark	Spouses experiences and changes	15	family carer	couples	The findings show how spouses struggle with everyday challenges and highlight strategies such as adapting to changes that are used from prediagnosis through the progression of dementia up to thoughts about the future.
Evans and Lee (2014) Australia	Impact of dementia on relationship	19	not explicitly stated	couples	Dementia causes a profound change on a marital relationship which induce couples to start a transformation process. The impact is subdivided in two major themes of 1) transition and loss and 2) effects at the level of the individual and of the couple. Traditional roles are challenged, and new roles have to be assumed. Communication, reciprocity and intimacy is also challenged and causes confusing feelings in the family carer, but they try to hold on for as long as they can.
Gopinath et al. (2018) UK	Interaction of couplehood, home and dementia	29	not explicitly stated	couples	Home has an important role in maintaining the habitus and the continuity of the relationship by locating and supporting the performance of (adapted) everyday relationships and domestic practices. Home actively constitutes a resource for the performance of normalcy and coupledom.
Holdsworth and McCabe (2018a) Australia	Influence of later onset dementia on relationship, intimacy and sex	13	dyadic, family carer, person with dementia	couples	Dementia has a significant impact on the dyadic relationship and the shared identity of the couple. The findings demonstrate that the family carer as well as the person with dementia work to maintain the identity and self-esteem of the person with dementia. Dementia impacts communication, reciprocity, affection, and sexual activities and leads to a feeling of losing the coupledom.
Holdsworth and McCabe (2018b) Australia	Influence of early onset dementia on relationship, intimacy and sex	11	dyadic, family carer, person with dementia	mixed (couples, adult children, siblings)	Themes with an influence on relationship, intimacy and sex include the following: changes in roles and responsibilities, declines in relationship quality (communication problems), changes in identity and self-esteem, increasing social isolation and loneliness, negative or positive change in intimacy and changes in sexual activities. The changes are complicated by delays in obtaining a diagnosis and the shortage of age-related information and support service for people with EOD.
La Fontaine and Oyebode (2014) UK	Reciprocal influences of family relationships and dementia	11	dyadic	family	Four superordinate themes are identified: 1) 'a shared history' 2) 'negotiating the impact of dementia upon the relationship' 3) 'openness and awareness' 4) 'shifting sands'.
Pozzebon et al. (2016) Australia	Experiences of partners of person with dementia with a focus on relationship	16	family carer	couples	Dementia is experienced by family carers in a relational context. Five descriptive themes are identified with the central theme of the loss of partner, including, among other things, the dyadic interaction and relationship quality. The others are acknowledging change, being in crisis, adapting and adjusting, and accepting and moving forwards
Wadham et al. (2016) UK	Experiences of partners of person with dementia with a focus on relationship	10	dyadic	couples	For couples with dementia, connection and attunement are important and supported their resilience and coping strategies. Their sense of shared coupledom is crucial. Four overarching themes emerged, which highlight couples' efforts to 1.) maintain the sense of togetherness 2.) manage shifts in balance and power within their relationship, which can impact both partners' sense of identity 3.) maintain the empathy and sensitive attunement between couples as they work to protect each other's sense of role and identity 4.) enhance the resilience couples demonstrate in the face of great fear, uncertainty and hopelessness.

Conway et al., 2018; Evans & Lee, 2014). As one study noted, 'In response to the dementia diagnosis (and the subsequent experience of fulfilling the carer role) carers perceived there to be an increase in responsibilities and demands […], and this contributed to feelings of burden and dependence (Quinn et al., 2008; Molyneaux et al., 2012; Conway et al., 2018, p. 1632)'. However, the impact of the diagnosis can also be perceived as positive, for example because it clarifies and finally names what the family is dealing with (Evans & Lee, 2014).

The changes in the person with dementia result in **role changes** where the family carer tries to compensate for deficits and the relationship converts from a partner to a caring relationship (Albert et al., 2022; Braun et al., 2009; Conway et al., 2018; Egilstrod et al., 2019; Evans & Lee, 2014; Gopinath et al.,

Table 3. Empirical studies most often included in the reviews identified in this umbrella analysis.

Included Reviews Empirical studies	Ablitt et al. (2009)	Albert et al. (2022)	Braun et al. (2009)	Conway et al. (2018)	Egilstrod et al. (2019)	Evans and Lee (2014)	Gopinath et al. (2018)	Holdsworth and McCabe (2018a)	Holdsworth and McCabe (2018b)	La Fontaine and Oyebode (2014)	Pozzebon et al. (2016)	Wadham et al. (2016)
Atta-Konadu et al. (2011)						X	X					X
Boylstein and Hayes (2012)				X	X						X	
Daniels et al. (2007)						X		X		X		X
Davies et al. (2010)		X							X		X	
Davies (2011)				X				X		X		X
Ducharme et al. (2013)					X				X		X	
Harris (2009)		X				X		X				
Hayes et al. (2009)		X		X		X						
Hellström et al. (2005)								X		X	X	
Hellström et al. (2016a)	X			X	X		X	X		X	X	X
Massimo et al. (2013)					X				X		X	
Molyneaux et al. (2012)				X				X		X	X	X
O'Shaughnessy et al. (2010)				X	X	X					X	
Robinson et al. (2005)								X		X		X
Svanström and Dahlberg (2004)						X	X	X		X		X
Vikström et al. (2008)					X		X					X

2018; Holdsworth & McCabe, 2018a, 2018b; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). This is linked to a shift to more responsibilities for the family carer (Wadham et al., 2016), which can eventually lead to the family carer's feeling of being trapped in their role (Conway et al., 2018; Holdsworth & McCabe, 2018b).

The last subtheme was **dyadic changes,** which are also mostly connected with negative consequences such as 'declines in reciprocity, communication, opportunities for shared activities and happiness in the relationship' (Ablitt et al., 2009, p. 499). The reduced reciprocity (Ablitt et al., 2009; Conway et al., 2018; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018a, 2018b; Pozzebon et al., 2016; Wadham et al., 2016) resulted in the carer feeling that they were 'becoming an "I" rather than a "we"'. (Wadham et al., 2016, p. 467). The shared identity is perceived as being lost, and the spousal carers no longer have the feeling of being in a marriage (Egilstrod et al., 2019; Evans & Lee, 2014; Holdsworth & McCabe, 2018b; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). Intimacy and sexual activity changed (Albert et al., 2022; Braun et al., 2009; Conway et al., 2018; Egilstrod et al., 2019; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018a, 2018b; Pozzebon et al., 2016) or the need for it was repressed (Albert et al., 2022). While most reviews report less intimacy and sexual activity, some report an increase in affection (Braun et al., 2009; Holdsworth & McCabe, 2018a; Wadham et al., 2016) and closer emotional bonds: 'Conversely, other familial carers […] showed a trend towards a closer emotional bond to the care recipient now than in the past' (Braun et al., 2009, p. 429). These changes are accompanied by or result in negative feelings in the family carer (Albert et al., 2022; Conway et al., 2018; Egilstrod et al., 2019; Gopinath et al., 2018; Holdsworth & McCabe, 2018a, 2018b; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016) and sometimes in the person with dementia (Wadham et al., 2016), such as sadness, anger or shame, and a feeling of hopelessness about their future life (Pozzebon et al., 2016).

Activities to maintain the dyadic relationship

The second analytical theme identified is **activities to maintain the dyadic relationship**. These activities are mostly performed by family carers. However, the **effort of the person with dementia** to protect and acknowledge their partner is also apparent (Evans & Lee, 2014; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Wadham et al., 2016): 'People with dementia wanted to protect their partner and avoid being a burden to them' (Wadham et al., 2016, p. 469). **Maintaining identity** is a further subtheme. The reviews showed 3 different categories of maintaining identity. The first category is the aim of the family carer to preserve the identity of the person with dementia (Albert et al., 2022; Conway et al., 2018; Gopinath et al., 2018; Holdsworth & McCabe, 2018a, 2018b). This seems to have a strong connection to relationship quality. The main strategy to support identity is to involve the person with dementia in daily activities or domestic routines (Ablitt et al., 2009; Conway et al., 2018; Egilstrod et al., 2019; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018a; Pozzebon et al., 2016). As one study noted, 'This was often demonstrated in attempts by partners to keep the PWD [person with dementia] involved in everyday tasks and previously enjoyed activities, as these were strong sources of identity (Hellström et al., 2005; Merrick et al., 2016; Molyneaux et al., 2012; Holdsworth & McCabe, 2018a, p. 12)'. The second category of maintaining identity is that the family carer struggled to keep their own identity by continuing their own activities and roles (Albert et al., 2022; Conway et al., 2018; Egilstrod et al., 2019; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018b; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). Holdsworth and McCabe (2018a) stated that family carers neglected their own identity by focusing solely on the person with dementia. In addition to the preservation of individual identities, the shared identity is also important for the dyadic relationship (Wadham et al., 2016). Examples of suggested activities for maintaining a shared identity are to stay involved with each other during common activities (Evans & Lee, 2014) and daily routines (Gopinath et al., 2018), but also to be mentally prepared by considering the disease as a part of ageing, to be prepared for changes (Holdsworth & McCabe, 2018a) and to remember positive experiences shared in the past (Pozzebon et al., 2016; Wadham et al., 2016). Most reviews highlight that time apart from each other focusing on their own identity is as important to keep the dyadic relationship as the time spent together.

Table 4. Summary of analytical themes and subthemes.

Analytical themes	Subthemes
Change in the dyadic relationship	Changes in the person living with dementia Role changes Dyadic changes
Activities to maintain the dyadic relationship	Efforts of the person with dementia Maintaining identity Reconstructing the dyadic relationship
Continued togetherness	Continued managing together Open communication Emotional connection
Home as a place for enacting relationship	
Influencing factors	Premorbid relationship Positive mindset

For maintaining the relationship, it is important for family carers to **reconstruct the dyadic relationship** and adapt to the ongoing changes (Albert et al., 2022; Egilstrod et al., 2019; Evans & Lee, 2014; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). As one study noted, 'They tried to sustain their marital relationship by letting their partner continue with social and household chores (Boylstein & Hayes, 2012), thereby distancing their marriage from the illness as a way of reconstructing their marriage (Hellström et al., 2016a)' (Egilstrod et al., 2019, p. 547). Similarly, a strategy to reconstruct the dyadic relationship was to externalise dementia (Conway et al., 2018; La Fontaine & Oyebode, 2014; Wadham et al., 2016), and that was closely connected to the dyad's standing together against 'the dementia' (Conway et al., 2018; Evans & Lee, 2014; Wadham et al., 2016). Another strategy for reconstructing the dyadic relationship was practicing balancing needs. Family carers balance different aspects, for example, their own needs and the needs of the person with dementia (Conway et al., 2018; Egilstrod et al., 2019), or safety and independence (Egilstrod et al., 2019; Gopinath et al., 2018; Wadham et al., 2016); they also may need to anticipate and avoid conflicts (Egilstrod et al., 2019; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016). Furthermore, another strategy is taking it day by day (Egilstrod et al., 2019; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014).

Continued togetherness

The third analytical theme is **continued togetherness**. If the maintenance of the relationship by the family carer is successful, a continued togetherness arises and can result in an increased wellbeing in both the family carer and the person with dementia (La Fontaine & Oyebode, 2014). Continued togetherness is shown in **managing together,** for example, managing dementia together (Conway et al., 2018; Egilstrod et al., 2019; Evans & Lee, 2014; La Fontaine & Oyebode, 2014) as conceptualized in a shared journey, indicating that the family carer and the person with dementia were travelling the dementia journey together (Evans & Lee, 2014; Pozzebon et al., 2016). This is accompanied by a feeling of continued reciprocity or mutuality (Ablitt et al., 2009; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Wadham et al., 2016), where the person with dementia is also an important player. Common activities such as shared routines enjoyed by both are another option to show and manage togetherness (Braun et al., 2009; Conway et al., 2018; Egilstrod et al., 2019; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018a, 2018b; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). The care partners framed the caring as a part of their continued relationship, and with some adaptations, they continued as normal for as long as possible (Braun et al., 2009; Conway et al., 2018; Evans & Lee, 2014; Gopinath et al., 2018; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014).

Open communication is, on the one hand, an indication of continued togetherness and, on the other hand, a prerequisite for it (Conway et al., 2018; Egilstrod et al., 2019; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016). As one study noted, 'Furthermore, open communication and managing things together was a feature of couple relationships reflected in their discussions about their lives together' (La Fontaine & Oyebode, 2014, p. 1258).

It is very important to maintain togetherness, and therefore, the relationship is an **emotional connection** or bond. It seems that some family carers succeed in maintaining the emotional connection and keep a close relationship (Ablitt et al., 2009; Conway et al., 2018; Gopinath et al., 2018; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016) because they share, for instance, activities and routines (Gopinath et al., 2018; Pozzebon et al., 2016; Wadham et al., 2016).

Home as a place for enacting relationship

The fourth analytical theme identified was **home as a place for enacting relationship**. The home (mainly of the person with dementia) is the place where people live, stay in contact with each other and enact their relationship. Therefore, the home is very important for maintaining continuity and normalcy in daily life (Gopinath et al., 2018). As one study noted, 'Our findings suggest that "home," as a context that locates couples' lives (Roseneil, 2006) is central to understanding how the couple and each partner may engage with and respond to gradual changes' (Gopinath et al., 2018, p. 31).

Influencing factors

The fifth and final analytical theme is the set of **influencing factors** on how maintaining relationship can be successful: the premorbid relationship and a positive mindset in the family carer. The prior or **premorbid relationship** quality and the common history of both care partners determines the actual relationship quality (Ablitt et al., 2009; Braun et al., 2009; Conway et al., 2018; Holdsworth & McCabe, 2018a; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). In particular, dyads with a positive premorbid relationship and many mutual benefits see their current relationship as a continuation of a past commitment or an integral part of their long-term relationship (Braun et al., 2009; La Fontaine & Oyebode, 2014; Pozzebon et al., 2016; Wadham et al., 2016). Furthermore, where a negative shared history has shaped the past, dyads reflected on the difficulties evident in their current relationship (La Fontaine & Oyebode, 2014, p. 1257). The **positive mindset** of the family carer depends on both the premorbid and present relationship quality and on the positive motivation to care for the person with dementia (Ablitt et al., 2009; Wadham et al., 2016). Conversely, a positive mindset can strengthen the relationship. As one study noted, 'A positive mindset enabled them [the dyad] to focus on preserving whatever remaining aspects of shared companionship they had' (Pozzebon et al., 2016, p. 551).

Discussion

This umbrella review aimed to synthesize published evidence with regard to the dyadic relationship of people with dementia and their family carers. For this purpose, we integrated the results of 12 reviews. In the analysis, 5 analytic themes and 11 subthemes were identified. The results illustrate that changes in the dyadic relationship, such as role changes and reduced reciprocity, mainly caused by the declining abilities of the person with dementia, drive the family carer into activities to maintain the relationship. If the family carer succeeds, a sense of togetherness continues. The premorbid relationship and the mindset of the family carer substantially influence success. If the premorbid relationship was characterized by love and trust, then the motivation to take over care is more likely to be positive, as is the mindset of the family carer. The mindset can also be positive if somebody is already naturally inclined to be positive-minded and resilient. If the family carer is able to see the care and the changes over time as a continuation of the dyadic relationship and if he or she is able to integrate it into the normal daily routines, then the dyadic relationship stays positive and can be prolonged during the progression of dementia.

The results of this umbrella review support the SoCA-Dem theory (Köhler et al., 2021) and highlight the concept of dyadic relationship as fundamental to the stability of home-based care arrangements. Our results are in line with single studies not or not yet included in reviews. For example, Gallagher and Beard (2020) found that dementia is perceived by community-dwelling dyads as a common challenge with the aim of keeping roles and having shared outlooks, approaches and activities. The focus is more on the togetherness rather than on differences and deficits. In another paper, Gallagher and Rickenbach (2020) identified four major themes related to couplehood-changes: positive mindset, later life roles, transitions, and looking towards the future—which are similar to our results. A recent study by Köhler et al. (2022) also emphasized the importance of the premorbid relationship with regard to the perception and negotiation of roles and role changes in the current relationship. Shim et al. (2012) stated that family carers with a present negative relationship also described their past relationship with negative terms. These carers reported feeling a significant burden as well. Meanwhile, those family carers who described their past and their present relationship in loving terms expressed a satisfaction with caregiving and were not highly burdened. In a quantitative analysis, Steadman et al. (2007) show that premorbid relationship satisfaction is associated with perceptions of feeling burdened, reactions to the behaviour of the person with dementia and problem-solving skills. Therefore, premorbid relationship quality seems to have a significant influence on the current relationship and also on the stability of the care arrangement.

Another interesting point is that to succeed in continuing togetherness, not only the commonalities but also the separated activities of each member of the dyad are important to keep. Therefore, with separate hobbies, the identities of the person with dementia and of the family carer, as well as the common identity, contribute to the maintenance of a dyadic relationship. Popok et al. (2022) emphasized the unique experiences and views of both care partners and concluded that couple-based as well as individual psychosocial interventions are needed to support adaptation processes and well-being.

Even if most of the reviews included in this umbrella review stated that they researched a dyadic perspective, in fact, the perspective on the dyadic relationship was predominantly represented by the perspective of family carers, who were the informants for most primary studies. In a qualitative synthesis from 2020, the perspective of people with dementia on social connections in general was analysed (Birt et al., 2020). The findings show that people with dementia need help to present themselves and consequently also to maintain their identity.

Future research

The current research on dyadic relationships has primarily focused on couple relationships. However, intergenerational relationships such as adult-child (Chen et al., 2017; Ward-Griffin et al., 2007) or adult-grandchild (Venters & Jones, 2021) are also affected by dementia. Because the themes and subthemes presented in this umbrella review were generated from reviews that included studies on couples, it is conceivable that specific themes and subthemes are more relevant for couples than for other dyadic constellations. For example continuing togetherness may be more important for couples who lived intertwined lives for decades than for children who are the carers but not the life-partners of the person with dementia. Therefore, support for the dyadic relationship could have a greater impact on the stability of the care arrangement of couples than in adult-child relationships. Other research points out that the experiences of couples were different from that of children or others because caring for a parent may be perceived by the carer as just another responsibility among many others, such as caring for own children or doing a job (DeCaporale et al., 2013; Macdonald et al., 2020). For spouses, the caring role can be especially psychologically demanding (Clark et al., 2019). Consequently, future research on relationships should differentiate between couples and adult-child or other relationships. A further point is that people with dementia often have or need a network of people supporting them. Therefore, the classical dyad should be broadened to whole family networks (Esandi et al., 2021) who can have different typologies (Neubert et al., 2022) and who act in diverse cultural, societal and socio-economical contexts.

Regarding couples, there is a good body of knowledge on dyadic relationships and their meaning for the care situation. For future research, it is important to better involve the perspective of people with dementia, to better investigate other kinds of relationships and to broaden the focus on whole care networks with different strategies to respond to dementia.

Limitations

Due to time and resource restrictions but in line with rapid review methods (Tricco et al., 2015), title and abstract screening was conducted by just one author. By limiting our umbrella review to reviews of qualitative studies, aspects of the relationship explored in quantitative reviews might be overlooked, and the overall picture might have been different if we had included both review types. There is consensus that giving care and how the carer role is enacted is influenced by social and cultural context factors (McAllum et al., 2021; Roes et al., 2022). Most authors of the included reviews live in Western countries;

therefore, our results might be influenced by a Western perspective, and their validity in other social and cultural contexts is debatable.

Conclusion

This umbrella review provides a comprehensive synthesis of published qualitative evidence on dyadic relationships between family carers and people living with dementia. The findings highlighted the dyadic relationship as a multifaceted phenomenon that is significantly characterized by family carers' attempts to continue togetherness with the person with dementia through different strategies. The dyadic relationship is mainly influenced by the quality of the premorbid relationship and the mindset of the family carer. For dyadic interventions, it is crucial to understand the meaning and way family carers try to maintain the relationship. The focus of the included reviews is on couples' relationships from the perspective of the family carer. This aspect seems to be well researched. Other kinds of relationships, such as adult-child or friends, as well as the perspective of the person with dementia, need more attention in the future. Furthermore, the view should be broadened to the whole family and its dynamics.

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The authors report that there are no competing interests to declare.

Ethical approval

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ORCID

Iris Hochgraeber http://orcid.org/0000-0003-1425-5955
Kerstin Köhler http://orcid.org/0000-0002-8681-566X
Bernhard Holle http://orcid.org/0000-0003-2549-7765

References

Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health*, *13*(4), 497–511. https://doi.org/10.1080/13607860902774436

Albert, S. C., Eduardo Martinelli, J., & Costa Pessoa, M. S. (2022). Dementia and its impacts on the intimate, sexual couple relationship: A systematic review of qualitative research studies. *Dementia (London, England)*, *21*(4), 1449–1466. https://doi.org/10.1177/14713012211073205

Atta-Konadu, E., Keller, H. H., & Daly, K. (2011). The food-related role shift experiences of spousal male care partners and their wives with dementia. *Journal of Aging Studies*, *25*(3), 305–315. https://doi.org/10.1016/j.jaging.2010.11.002

Biondi-Zoccai, G. (2016). Umbrella reviews. Evidence synthesis with overviews of reviews and meta-epidemiologic studies. https://doi.org/10.1007/978-3-319-25655-9

Birt, L., Griffiths, R., Charlesworth, G., Higgs, P., Orrell, M., Leung, P., & Poland, F. (2020). Maintaining social connections in dementia: A qualitative synthesis. *Qualitative Health Research*, *30*(1), 23–42. https://doi.org/10.1177/1049732319874782

Boylstein, C., & Hayes, J. (2012). Reconstructing marital closeness while caring for a spouse with Alzheimer's. *Journal of Family Issues*, *33*(5), 584–612. https://doi.org/10.1177/0192513X11416449

Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective. *Aging & Mental Health*, *13*(3), 426–436. https://doi.org/10.1080/13607860902879441

Chen, C. K., Clayton, K., & Chodosh, J. (2017). The relationship between "what we believe" and "how we care" among daughters caring for a parent with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, *®*, *32*(2), 90–95. https://doi.org/10.1177/1533317517689875

Cheng, S. T., Mak, E. P., Lau, R. W., Ng, N. S., & Lam, L. C. (2016). Voices of Alzheimer caregivers on positive aspects of caregiving. *The Gerontologist*, *56*(3), 451–460. https://doi.org/10.1093/geront/gnu118

Clark, S., Prescott, T., & Murphy, G. (2019). The lived experiences of dementia in married couple relationships. *Dementia (London, England)*, *18*(5), 1727–1739. https://doi.org/10.1177/1471301217722034

Conway, E. R., Watson, B., Tatangelo, G., & McCabe, M. (2018). Is it all bleak? A systematic review of factors contributing to relationship change in dementia. *International Psychogeriatrics*, *30*(11), 1619–1637. https://doi.org/10.1017/s1041610218000303

Daniels, K. J., Lamson, A. L., & Hodgson, J. (2007). An exploration of the marital relationship and Alzheimer's disease: One couple's story. *Families, Systems, & Health*, *25*(2), 162–177. https://doi.org/10.1037/1091-7527.25.2.162

Davies, H. D., Newkirk, L. A., Pitts, C. B., Coughlin, C. A., Sridhar, S. B., Zeiss, L. M., & Zeiss, A. M. (2010). The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality in spousal relationships. *International Psychogeriatrics*, *22*(4), 618–628. https://doi.org/10.1017/s1041610210000177

Davies, J. C. (2011). Preserving the "us identity" through marriage commitment while living with early-stage dementia. *Dementia*, *10*(2), 217–234. https://doi.org/10.1177/1471301211398991

DeCaporale, L., Mensie, L., & Steffen, A. (2013). Respite utilization and responses to loss among family caregivers: Relationship matters. *Death Studies*, *37*(5), 483–492. https://doi.org/10.1080/07481187.2012.654593

Ducharme, F., Kergoat, M.-J., Antoine, P., Pasquier, F., & Coulombe, R. (2013). The unique experience of spouses in early-onset dementia. *American Journal of Alzheimer's Disease and Other Dementias*, *®*, *28*(6), 634–641. https://doi.org/10.1177/1533317513494443

Egilstrod, B., Ravn, M. B., & Petersen, K. S. (2019). Living with a partner with dementia: A systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives. *Aging & Mental Health*, *23*(5), 541–550. https://doi.org/10.1080/13607863.2018.1433634

Esandi, N., Nolan, M., Alfaro, C., & Canga-Armayor, A. (2018). Keeping things in balance: Family experiences of living with Alzheimer's disease. *The Gerontologist*, *58*(2), e56–e67. https://doi.org/10.1093/geront/gnx084

Esandi, N., Nolan, M., Canga-Armayor, N., Pardavila-Belio, M., & Canga-Armayor, A. (2021). Family dynamics and the Alzheimer's disease experience. *Journal of Family Nursing*, *27*(2), 124–135. https://doi.org/10.1177/1074840720986611

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, *20*(8), 423–428. https://doi.org/10.1111/j.1745-7599.2008.00342.x

Evans, D., & Lee, E. (2014). Impact of dementia on marriage: A qualitative systematic review. *Dementia (London, England)*, *13*(3), 330–349. https://doi.org/10.1177/1471301212473882

Fletcher, J. R. (2021). Structuring unequal relations: Role trajectories in informal dementia care. *Sociology of Health & Illness*, *43*(1), 65–81. https://doi.org/10.1111/1467-9566.13194

Gallagher, E., & Beard, R. L. (2020). Buffer or blade: Perceived relationship closeness in couples navigating Alzheimer's. *Journal of Aging Studies*, *52*, 100832. https://doi.org/10.1016/j.jaging.2020.100832

Gallagher, E., & Rickenbach, E. H. (2020). Perceptions of couplehood among community-dwelling spousal caregivers. *Aging & Mental Health*, *24*(9), 1429–1436. https://doi.org/10.1080/13607863.2019.1594168

Gauthier, S., Rosa-Neto, P., Morais, J. A., & Webster, C. (2021). World Alzheimer Report. 2021. *Journey through the diagnosis of dementia*. London, England.

Gopinath, M., Peace, S., & Holland, C. (2018). Conserving habitus: Home, couplehood and dementia. *Home Cultures*, *15*(3), 223–263. https://doi.org/10.1080/17406315.2018.1690284

Harris, P. B. (2009). Intimacy, sexuality, and early-stage dementia: The changing marital relationship. *Alzheimer's Care Today*, *10*(2), 63–77.

Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies*, *23*(1), 48–59. https://doi.org/10.1016/j.jaging.2007.09.002

Hellström, I., Nolan, M., & Lundh, U. (2005). We do things together. *Dementia*, *4*(1), 7–22. https://doi.org/10.1177/1471301205049188

Hellström, I., Nolan, M., & Lundh, U. (2016a). Sustaining 'couplehood. *Dementia*, *6*(3), 383–409. https://doi.org/10.1177/1471301207081571

Hellström, I., Nolan, M., & Lundh, U. (2016b). We do things together. *Dementia*, *4*(1), 7–22. https://doi.org/10.1177/1471301205049188

Holdsworth, K., & McCabe, M. (2018a). The impact of dementia on relationships, intimacy, and sexuality in later life couples: An integrative qualitative analysis of existing literature. *Clinical Gerontologist*, *41*(1), 3–19. https://doi.org/10.1080/07317115.2017.1380102

Holdsworth, K., & McCabe, M. (2018b). The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: A systematic review. *International Psychogeriatrics*, *30*(1), 15–29. https://doi.org/10.1017/s1041610217001806

Hunt, H., Pollock, A., Campbell, P., Estcourt, L., & Brunton, G. (2018). An introduction to overviews of reviews: Planning a relevant research question and objective for an overview. *Systematic Reviews*, *7*(1), 39. https://doi.org/10.1186/s13643-018-0695-8

Köhler, K., Dreyer, J., Hochgraeber, I., Pinkert, C., von Kutzleben, M., Holle, B., & Roes, M. (2022). Dyadic relationship, carer role, and resources: A theory-driven thematic analysis of interviews with informal carers focusing on the stability of home-based care arrangements for people living with dementia. *BMC Geriatrics*, *22*(1), 908. https://doi.org/10.1186/s12877-022-03618-y

Köhler, K., Dreyer, J., Hochgraeber, I., von Kutzleben, M., Pinkert, C., Roes, M., & Holle, B. (2021). Towards a middle-range theory of 'Stability of home-based care arrangements for people living with dementia' (SoCA-Dem): findings from a meta-study on mixed research. *BMJ Open*, *11*(4), e042515. https://doi.org/10.1136/bmjopen-2020-042515

La Fontaine, J., & Oyebode, J. R. (2014). Family relationships and dementia: A synthesis of qualitative research including the person with dementia. *Ageing and Society*, *34*(7), 1243–1272. https://doi.org/10.1017/S0144686X13000056

Luiu, A. L., Favez, N., Betrancourt, M., Szilas, N., & Ehrler, F. (2020). Family relationships and Alzheimer's disease: A systematic review. *Journal of Alzheimer's Disease: JAD*, *76*(4), 1595–1608. https://doi.org/10.3233/JAD-200125

Macdonald, M., Martin-Misener, R., Weeks, L., Helwig, M., Moody, E., & MacLean, H. (2020). Experiences and perceptions of spousal/partner caregivers providing care for community-dwelling adults with dementia: A qualitative systematic review. *JBI Evidence Synthesis*, *18*(4), 647–703. https://doi.org/10.11124/JBISRIR-2017-003774

Massimo, L., Evans, L. K., & Benner, P. (2013). Caring for loved ones with frontotemporal degeneration: The lived experiences of spouses. *Geriatric Nursing (New York, N.Y.)*, *34*(4), 302–306. https://doi.org/10.1016/j.gerinurse.2013.05.001

McAllum, K., Simpson, M. L., Unson, C., Fox, S., & Kilpatrick, K. (2021). The socialization of unpaid family caregivers: A scoping review. *Research on Aging*, *43*(7-8), 263–273. 1640275211005092. https://doi.org/10.1177/01640275211005092

Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2016). Couples constructing their experiences of dementia: A relational perspective. *Dementia (London, England)*, *15*(1), 34–50. https://doi.org/10.1177/1471301213513029

Miller, V. J., Killian, M. O., & Fields, N. (2020). Caregiver identity theory and predictors of burden and depression: Findings from the REACH II study. *Aging & Mental Health*, *24*(2), 212–220. https://doi.org/10.1080/13607863.2018.1533522

Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. *Dementia*, *11*(4), 483–502. https://doi.org/10.1177/1471301211421070

Neubert, L., Gottschalk, S., Konig, H. H., & Brettschneider, C. (2022). Dementia care-giving from a family network perspective in Germany: A typology. *Health & Social Care in the Community*, *30*(2), 579–591. https://doi.org/10.1111/hsc.13161

Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care: A multidimensional model of caring and coping*. Open University Press.

O'Rourke, H. M., Duggleby, W., Fraser, K. D., & Jerke, L. (2015). Factors that affect quality of life from the perspective of people with dementia: A metasynthesis. *Journal of the American Geriatrics Society*, *63*(1), 24–38. https://doi.org/10.1111/jgs.13178

O'Shaughnessy, M., Lee, K., & Lintern, T. (2010). Changes in the couple relationship in dementia care. *Dementia*, *9*(2), 237–258. https://doi.org/10.1177/1471301209354021

Pinkert, C., Köhler, K., von Kutzleben, M., Hochgräber, I., Cavazzini, C., Völz, S., Palm, R., & Holle, B. (2021). Social inclusion of people with dementia – an integrative review of theoretical frameworks, methods and findings in empirical studies. *Ageing and Society*, *41*(4), 773–793. https://doi.org/10.1017/S0144686X19001338

Popok, P. J., Reichman, M., LeFeber, L., Grunberg, V. A., Bannon, S. M., Vranceanu, A.-M., & Bowers, B. J. (2022). One diagnosis, two perspectives: Lived experiences of persons with young-onset dementia and their care-partners. *The Gerontologist*, *62*(9), 1311–1323. https://doi.org/10.1093/geront/gnac050

Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: A synthesis of the qualitative research. *International Psychogeriatrics*, *28*(4), 537–556. https://doi.org/10.1017/s1041610215002239

Quinn, C., Clare, L., Pearce, A., & Van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging & Mental Health*, *12*(6), 769–778. https://doi.org/10.1080/13607860802380623

Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia (London, England)*, *14*(2), 220–237. https://doi.org/10.1177/1471301213495863

Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health*, *9*(4), 337–347. https://doi.org/10.1080/13607860500114555

Roes, M., Laporte Uribe, F., Peters-Nehrenheim, V., Smits, C., Johannessen, A., Charlesworth, G., Parveen, S., Mueller, N., Hedd Jones, C., Thyrian, R., Monsees, J., & Tezcan-Güntekin, H. (2022). Intersectionality and its relevance for research in dementia care of people with a migration background. *Zeitschrift Für Gerontologie Und Geriatrie*, *55*(4), 287–291. https://doi.org/10.1007/s00391-022-02058-y

Roseneil, S. (2006). On not living with a partner: Unpicking coupledom and cohabitation. *Sociological Research Online*, *11*(3), 111–124. https://doi.org/10.5153/sro.1413

Rothgang, H., Iwansky, S., Müller, R., Sauer, S., & Unger, R. (2010). (Eds.). *BARMER GEK Pflegereport 2010*. Asgard-Verlag.

Shim, B., Barroso, J., & Davis, L. L. (2012). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International Journal of Nursing Studies*, *49*(2), 220–229. https://doi.org/10.1016/j.ijnurstu.2011.09.003

Steadman, P. L., Tremont, G., & Duncan Davis, J. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, *20*(2), 115–119. https://doi.org/10.1177/0891988706298624

Svanström, R., & Dahlberg, K. (2004). Living with dementia yields a heteronomous and lost existence. *Western Journal of Nursing Research*, *26*(6), 671–687. https://doi.org/10.1177/0193945904265920

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45. https://doi.org/10.1186/1471-2288-8-45

Tricco, A. C., Antony, J., Zarin, W., Strifler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D., & Straus, S. E. (2015). A scoping review of rapid review methods. *BMC Medicine*, *13*(1), 224. https://doi.org/10.1186/s12916-015-0465-6

Venters, S., & Jones, C. J. (2021). The experiences of grandchildren who provide care for a grandparent with dementia: A systematic review. *Dementia (London, England)*, *20*(6), 2205–2230. https://doi.org/10.1177/1471301220980243

Vikström, S., Josephsson, S., Stigsdotter-Neely, A., & Nygård, L. (2008). Engagement in activities. *Dementia*, *7*(2), 251–270. https://doi.org/10.1177/1471301208091164

von Kutzleben, M., Schmid, W., Halek, M., Holle, B., & Bartholomeyczik, S. (2012). Community-dwelling persons with dementia: What do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging & Mental Health*, *16*(3), 378–390. https://doi.org/10.1080/13607863.2011.614594

Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couples' shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. *Aging & Mental Health*, *20*(5), 463–473. https://doi.org/10.1080/13607863.2015.1023769

Ward-Griffin, C., Oudshoorn, A., Clark, K., & Bol, N. (2007). Mother-adult daughter relationships within dementia care. *Journal of Family Nursing*, *13*(1), 13–32. https://doi.org/10.1177/1074840706297424

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. S. (2012). The meaning of "aging in place" to older people. *The Gerontologist*, *52*(3), 357–366. https://doi.org/10.1093/geront/gnr098

World Health Organization (2012). *Dementia. A public health priority*. World Health Organisation (WHO), Department of Mental Health and Substance Abuse.

Yu, D. S. F., Cheng, S. T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, *79*, 1–26. https://doi.org/10.1016/j.ijnurstu.2017.10.008

Zigante, V. (2018). *Informal care in Europe: Exploring formalisation, availability and quality* (Report No. 978-92-79-86583-1). Brussels: E. Commission.