This is the Pre-Published Version.

International Journal of Mental Health Nursing

This is the peer reviewed version of the following article: Wang, S., Huang, Y., Fan, A.Y.N., Ho, M.-H. & Davidson, P.M. (2024) Factors influencing the psychosocial well-being of people with dementia and their informal caregivers: A systematic review of dyadic studies. International Journal of Mental Health Nursing, 33, 560–581, which has been published in final form at https://doi.org/10.1111/jinm.13279. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions. This article may not be enhanced, enriched or otherwise transformed into a derivative work, without express permission from Wiley or by statutory rights under applicable legislation. Copyright notices must not be removed, obscured or modified. The article must be linked to Wiley's version of record on Wiley Online Library and any embedding, framing or otherwise making available the article or pages thereof by third parties from platforms, services and websites other than Wiley Online Library must be prohibited.



Factors influencing the psychosocial well-being of people with dementia and their informal caregivers: A systematic review of dyadic studies

| Manuscript ID Manuscript type: Review Article Keywords: dementia, caregiver, dyad, psychosocial well-being, systematic review Individuals with dementia and their informal caregivers face significant challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial well-being and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixed-method studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life warranted to elucidate the underlying mechanisms through which one member's factors sexert influence on both their own and partner's quality of life warranted to elucidate the underlying mechanisms through which dyadic members influence their own and their partner's psychosocial well-being. | | |
|---|--------------------------|---|
| Wiley - Manuscript type: Review Article dementia, caregiver, dyad, psychosocial well-being, systematic review Individuals with dementia and their informal caregivers face significant challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial well-being and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixed-method studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life within the dyad. This gap also exists for other psychosocial well-being outcomes, such as depression and anxiety. Further research is warranted to elucidate the underlying mechanisms through which dyadic members influence their own and | Journal: | International Journal of Mental Health Nursing |
| Keywords: dementia, caregiver, dyad, psychosocial well-being, systematic review Individuals with dementia and their informal caregivers face significant challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial well-being and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixed-method studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life within the dyad. This gap also exists for other psychosocial well-being outcomes, such as depression and anxiety. Further research is warranted to elucidate the underlying mechanisms through which dyadic members influence their own and | Manuscript ID | IJMHN-2023-911.R1 |
| Individuals with dementia and their informal caregivers face significant challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial well-being and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixed-method studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life within the dyad. This gap also exists for other psychosocial well-being outcomes, such as depression and anxiety. Further research is warranted to elucidate the underlying mechanisms through which dyadic members influence their own and | Wiley - Manuscript type: | Review Article |
| challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial well-being and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixed-method studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life within the dyad. This gap also exists for other psychosocial well-being outcomes, such as depression and anxiety. Further research is warranted to elucidate the underlying mechanisms through which dyadic members influence their own and | Keywords: | dementia, caregiver, dyad, psychosocial well-being, systematic review |
| | Abstract: | challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial well-being and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixed-method studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life within the dyad. This gap also exists for other psychosocial well-being outcomes, such as depression and anxiety. Further research is warranted to elucidate the underlying mechanisms through which dyadic members influence their own and |

SCHOLARONE™ Manuscripts Factors influencing the psychosocial well-being of people with dementia and their informal caregivers: A systematic review of dyadic studies

Abstract

Individuals with dementia and their informal caregivers face significant challenges to their psychosocial well-being, necessitating immediate attention. In spite of the prevalence of this problem there is limited data regarding the factors that influence the dyadic psychosocial wellbeing and potential actor-partner influencing mechanisms. Therefore, this review was conducted to synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers. MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were systematically searched to identify relevant studies. Quantitative, qualitative, or mixedmethod studies examining the factors influencing dyadic psychosocial well-being outcomes were included. The quality of included studies was assessed using Joanna Briggs Institute Critical Appraisal checklists. A narrative synthesis approach was employed for data analysis. A total of 3217 records were yield, out of which 26 studies were included in the analysis. Quality of life emerged as the most extensively investigated dyadic psychosocial well-being outcome, followed by depression. The interrelation between the quality of life for people with dementia and caregivers was observed, where individual members' quality of life was influenced by their own, partner, and dyadic factors. However, there is a dearth of research exploring the mechanisms through which one member's factors exert influence on both their own and partner's quality of life within the dyad. This gap also exists for other psychosocial well-being outcomes, such as depression and anxiety. Further research is warranted to elucidate the underlying mechanisms through which dyadic members influence their own and their partner's psychosocial well-being.

Keywords: dementia, caregiver, dyad, psychosocial well-being, systematic review

Background

Dementia is an escalating public health concern that necessitates immediate attention. According to a report published by the World Health Organization, there are more than 55 million individuals worldwide living with dementia, and every year, there are nearly 10 million new cases (World Health Organization, 2023). Consequently, there exists a growing demand for caregivers. Informal caregivers, including family members and friends, often shoulder the primary responsibilities of providing care for individuals with dementia. While global data on the exact number of informal caregivers remains unavailable, it is estimated that in the United States alone, around 16 million informal caregivers offer assistance to people with dementia ("2020 Alzheimer's disease facts and figures," 2020). Notably, this issue becomes even more pressing in rapidly aging regions across other parts of the world.

Dementia exerts a significant impact on the psychosocial well-being of both individuals with this condition and their caregivers. The construct of psychosocial well-being encompasses emotional, psychological, social, and collective well-being (Larson, 1996), thereby sharing similarities with the concept of "quality of life" (Eiroa-Orosa, 2020). The progressive and incurable nature of dementia is a simultaneous stressor for individuals with dementia and their caregivers (Minyo & Judge, 2022; Wawrziczny et al., 2017). Almost all older adults living in communities with dementia will experience symptoms such as depression, anxiety, or a combination within five years (Onyike, 2016). Conversely, the demanding responsibilities associated with caregiving contribute to an increased susceptibility to depression, anxiety, and other mental health issues among caregivers (Wulff et al., 2020), thereby diminishing the quality of life for these dyads (Karg et al., 2018).

A comprehensive understanding of the factors and mechanisms influencing dyadic psychosocial well-being is imperative for implementing effective interventions. A systematic review indicates that the effectiveness of current dyadic interventions varies across different outcomes for people with dementia and caregivers (Poon, 2022). One potential explanation is that individuals with dementia are often perceived as care recipients rather than active participants capable of perceiving and experiencing emotions. Conversely, investigations into caregiver well-being more frequently concentrate on the impact of caregiving responsibilities or patient behavioral problems (Carbone et al., 2021). However, it is noteworthy that caregiving dyads function as an interconnected emotional system during the long-term care journey (Nelson et al., 2022).

According to Lyons and Lee's Dyadic Illness Management Theory, the health behaviors and outcomes within a dyad are mutually dependent (Lyons & Lee, 2018). Neglecting the interdependence between dyads hinders progress in improving dyadic well-being. The theory identifies that caregiver factors exert actor effects on their own health outcomes, while patient factors have partner effects, and vice versa. Research has demonstrated that the psychosocial well-being of both individuals with dementia and their caregivers is interconnected (Bruvik et al., 2012). By targeting factors influencing the psychosocial well-being of both partners, interventions can effectively enhance health outcomes and improve the quality of life for individuals with dementia and their caregivers (Schölzel-Dorenbos et al., 2010). However, there is currently a lack of synthesized evidence regarding the factors and potential mechanisms influencing the psychosocial well-being of the dyads. Undertaking a systematic review is an important strategy to address this research gap comprehensively and facilitate the development of more effective interventions in future studies.

Objectives

To synthesize the factors associated with the psychosocial well-being of people with dementia and their informal caregivers and explore the potential influencing mechanism between dyads.

Methods

Research design

A systematic review was conducted and registered at PROSPERO (ref: CRD xxxxxxxxxx).

Search strategy

MEDLINE via EBSCOhost, CINAHL, PsycINFO, Embase, and Scopus were searched on 22 February 2023. The search strategy was set up by discussing with a librarian. The keywords included dementia (i.e., "neurocognitive disorder" OR "cognitive impairment" OR dement* OR Alzheimer* OR (MH "Dementia+")), informal caregiver (i.e., informal OR spouse OR family OR relatives OR partner OR couple OR carer* OR caregiv* OR care giver*), dyad (i.e., dyad*), and psychosocial well-being (i.e., well-being OR "quality of life" OR psychosocial OR (MH "psychological well-being") OR stress OR anxiety OR strain OR depression). No restrictions on the publication date were set. Search alerts were set up for the databases to receive updated publications after the search date, continuing until 1 Oct 2023, prior to the submission of this manuscript.

Eligibility criteria

Inclusion criteria: (1) Sample: studies including both the person with dementia and their informal caregivers; (2) Outcome/evaluation: studies investigating any aspect of the psychosocial well-being of people with dementia and their informal caregivers; (3) Phenomenon of interest: studies exploring factors influencing the dyadic psychosocial well-being; (4) Research type: studies using quantitative, qualitative or mixed-method design; and (5) Setting: studies conducted

in community settings.

Exclusion criteria: (1) Sample: Studies that solely involve people with dementia or caregivers as the target population; studies that mix people with dementia with people with other health conditions without reporting dementia subgroup data separately; (2) Outcome/evaluation: studies that focus on other aspects of the dyad instead of the psychosocial well-being; studies that involve dyads but only focus on one partner's well-being problems; (3) Research type: interventional studies; instrument development and validation studies; cohort studies which only use psychosocial well-being outcomes as exposure, and mainly measure the onset of another phenomenon; (4) Setting: studies conducted in hospital or nursing homes; (5) Publication type: short reports, conference abstracts, or discussion papers without original data; (6) Publication language: languages other than English.

Data screening and extraction

Endnote 20 was used for data management. Title and abstract screening were conducted by the first and second authors. Discrepancies were discussed, and consensus was achieved. Full-text screening was conducted by the first, second, and third authors independently. Data extraction was conducted by the second and third authors, who extracted the research design, demographics of the dyads, outcomes of interest with measurement tools, and main findings for each study.

Quality appraisal

The Joanna Briggs Institute (JBI) Critical Appraisal checklists: "Checklist for Cross-sectional studies", "Checklist for Cohort Studies", and "Checklist for Qualitative Studies" were used to assess the methodological quality of included studies (Moola, 2017). All these tools have been commonly used by systematic reviews. Two reviewers (the second and third author) appraised the quality independently, and any discrepancies between the appraisals were discussed with a third

reviewer (the first author).

Data analysis

Due to the limited number of studies available for each outcome of interest and the fact that qualitative and quantitative studies were designed to address different research questions, conducting a meta-analysis, meta-ethnography, or mixed-method synthesis was not feasible in this review. Therefore, narrative synthesis was employed to extract the influencing factors associated with health outcomes in individuals with dementia and their informal caregivers (Popay et al., 2006). By constantly comparing the extracted data, these factors were further categorized into caregiver, care recipient, and dyadic factors. During data synthesis, variables that demonstrated significance in adjusted models were extracted when both unadjusted models and adjusted models were utilized for influence testing. In cases where studies used both full sample analysis and subgroup analysis (Linton, 2020), only results from the full sample analysis were included in this synthesis. A figure illustrating these research findings was manually created through constant comparison.

Results

Study selection

The five databases yielded a total of 3167 records, out of which 2022 duplicate records were identified and subsequently removed, resulting in 1145 records for screening. Following title and abstract screening, 1020 records were excluded, leaving 125 for full-text screening. Ultimately, after further scrutiny during the full-text screening process, only 25 studies met the inclusion criteria.

Forty-three updated records were obtained from databases during our data search until manuscript submission, and seven records were included for screening from citation searching.

Out of these 50 records, 43 were excluded based on title and abstract screening. Six out of the remaining seven records were also excluded due to not meeting our inclusion criteria in terms of sample size (n=2), outcome/evaluation (n=1), or phenomenon of interest (n=3), leaving only one study included from other sources. Consequently, a total of 26 studies were included for data extraction and analysis (Figure 1).

** Insert Figure 1. The PRISMA Flowchart**

Study characteristics

Among the 26 studies included, the majority of them were cross-sectional, with only five longitudinal studies and two qualitative studies. No mixed-method study was identified. The United States (n=11) and the United Kingdom (n=7) accounted for most of the conducted studies. The sample size ranged from 10 to 1283 dyads. Among the studies that reported the age of the dyads, individuals with dementia had an average age ranging from 61.3 to 83.04, while caregivers had an average age ranging from 52.9 to 73.02. Quality of life was the most extensively studied dyadic psychosocial well-being outcome, followed by depression. Only five studies utilized the actor-partner interdependence model for analysis (Gellert et al., 2018; Martincin, 2018; Monin et al., 2020; Rippon et al., 2020; Wu et al., 2021), which accounted for interdependence within dyads, distinguishes between actor and partner effects, and examined simultaneous effects on both members involved in caregiving relationships. Detailed characteristics of the included studies are presented in Table 1.

**Insert Table 1. Characteristics of included studies (n=26) **

Quality of included studies

The results of the quality appraisal of the included studies are presented in Supplementary File 1-3. The cross-sectional studies obtained critical appraisal scores ranging from 5 to 8 out of a maximum score of 8 (appraised "Yes") across eight aspects. All the studies provided comprehensive details regarding study subjects and settings, objective/standard criteria used for measuring the condition, employed valid and reliable outcome measurement methods, and utilized appropriate statistical analyses. Sixteen studies clearly outlined inclusion criteria for sample selection, while 18 studies explicitly described exposure measurement methods. Additionally, confounding factors, such as caregiver's educational status and patient's illness severity, were identified and addressed in 15 studies. The quality scores of the five longitudinal studies ranged from 7 to 9 out of a possible score of 11. The main methodological flaw was identified in failing to demonstrate that the participants were free from the outcome at the beginning of the study. However, all studies measured exposure and outcomes using valid and reliable methods and also addressed confounding factors in the analysis. Additionally, appropriate statistical analyses were employed. The critical appraisal scores for both qualitative studies were 9 out of a possible score of 10. A methodological limitation observed in both studies was the failure to indicate whether they considered the potential influence of the researcher's cultural and theoretical orientation on the study.

Factors influencing the dyadic psychosocial well-being outcomes

Factors influencing the depression of the dyads

Table 2 and Figure 2 displays the factors influencing the depression of the dyads. Correlation has been observed between the depression of people with dementia and their caregivers (Martincin, 2018; Ornstein et al., 2012). Furthermore, the contributing factors to depression among people with dementia and their caregivers can be categorized into three primary domains: factors related to people with dementia, caregiver-related factors, and dyadic factors.

The factors negatively influencing depression among people with dementia included their

quality of life (Bruvik et al., 2012), functional ability (Linton, 2020), participating in past pleasant activities (Burgener & Twigg, 2002), and capacity to live well (Wu et al., 2021), while perceived strain in the dyadic relationship was a positive influencing factor (Wu et al., 2021). Discrepancies were observed in the correlation between caregiver-rated relationship quality and depression among people with dementia, as a cross-sectional study found no significant association (Rippon et al., 2020), while another longitudinal study reported a significant association (Burgener & Twigg, 2002). The positive influencing factors of caregivers encompassed psychological morbidity (Brodaty & Luscombe, 1998), and caregiving burden and distress (Parrotta et al., 2020); while the caregiver's capacity to live well was negatively associated (Wu et al., 2021). Dyadic factors that were negatively associated with depression in people with dementia comprised dyadic coping (Gellert et al., 2018), and dyadic relationship quality (Rippon et al., 2020); while strains in the dyadic relationship were positively associated with depression in people with dementia (Miller et al., 2019). However, discrepancies were found regarding the influence of self-rated versus partner-rated relationship quality; while self-rated relationship quality emerged as a significant influencing factor, partner-rated relationship quality did not show similar significance (Rippon et al., 2020).

Caregiver depression was negatively influenced by various factors related to the care recipient, including their capacity to live well (Wu et al., 2021) and quality of life (Bruvik et al., 2012), and was positively associated with neuropsychiatric symptoms (Chen et al., 2023; Ornstein et al., 2012) and behavioral symptoms (Campbell et al., 2011). On the other hand, caregiver factors encompassed caregiver burden (Chen et al., 2023; Linton, 2020; Ornstein et al., 2012), quality of life (Bruvik et al., 2012; Fang et al., 2021; Orgeta, Orrell, Hounsome, et al., 2015), caregiver having a hobby (Bruvik et al., 2012), competence (Zanetti et al., 1998), caregiving related strain

(Miller et al., 2019), caregiver's capacity to live well (Wu et al., 2021), and self-rated health (Zanetti et al., 1998). Although three studies examined the influence of caregiving burden on caregiver depression (Chen et al., 2023; Linton, 2020; Ornstein et al., 2012), Ornstein et al. (2012) only reported that caregiver burden acts as a mediator between patient depressive symptoms and caregiver depression without providing data on the relationship itself; hence meta-analysis was not feasible. Dyadic factors influencing caregiver depression included dyadic relationships, which indicated that spousal caregivers are more susceptible to depression (Zanetti et al., 1998). Dyadic coping (Gellert et al., 2018) and dementia-affiliated stigma (Chen et al., 2023) were also associated with caregiver depression. However, the partner-rated dyadic relationship quality (Rippon et al., 2020) and strain (Martincin, 2018) were not significant influencing factors.

Insert Table 2. Influencing factors of the depression of dementia caregiving dyads

Insert Figure 2. Influencing factors of the depression of people with dementia and informal caregivers

Factors influencing the quality of life of the dyads

Table 3 and Figure 3 displays the factors influencing the quality of life of the dyads. The majority of dyadic research has focused on the quality of life for people with dementia and their informal caregivers. There was a correlation between the quality of life for these dyads (Bonds et al., 2021; Miller et al., 2019). Disease severity (Bruvik et al., 2012; Orgeta, Orrell, Hounsome, et al., 2015), mental status (e.g., stress, depression, mood) (Bruvik et al., 2012; Häusler et al., 2016) (Nelis et al., 2012), decision-making involvement (Bonds et al., 2021), and unmet needs (Bonds et al., 2021) all influenced the quality of life for individuals with dementia. Additionally, caregiver type played a role in determining the care recipient's quality of life, as those cared for by non-spousal caregivers had lower levels of well-being (Bonds et al., 2021). The caregiver's physical

and mental health and the caregiver burden also impacted the care recipient's quality of life (Bruvik et al., 2012; Orgeta, Orrell, Hounsome, et al., 2015). Dyadic relationship quality (Burgener & Twigg, 2002; Miller et al., 2019) and incongruence in PWD's care values (Moon et al., 2017) significantly negatively affected the quality of life of people with dementia, while dyadic coping (Häusler et al., 2016; Moon et al., 2017) and incongruent perceptions (Moon et al., 2017) were not found to be significant factors.

For caregiver quality of life, caregiver depression emerged as a significant influencing factor, supported by evidence from two cross-sectional studies (Bruvik et al., 2012; Orgeta, Orrell, Hounsome, et al., 2015), and it was found to be predictive of lower quality of life in a longitudinal study (Fang et al., 2021). Similar to its impact on care recipients' quality of life, the mental health of caregivers (Fang et al., 2021), including caregiving stress (Häusler et al., 2016; Nelis et al., 2012) and burden (Fang et al., 2021), as well as their physical health (Fang et al., 2021), also influenced their own quality of life. Conversely, engaging in hobbies may enhance caregivers' quality of life (Bruvik et al., 2012). Additionally, better caregiver quality of life was associated with younger age among people with dementia (Orgeta, Orrell, Hounsome, et al., 2015), fewer unmet needs (Monin et al., 2020), higher functional ability (Orgeta, Orrell, Hounsome, et al., 2015), and reduced depression levels in care recipients themselves (Parrotta et al., 2020). The quality of the dyadic relationship and dyadic coping exhibited a positive correlation with caregiver quality of life (Häusler et al., 2016), whereas strain in the dyadic relationship and incongruence regarding people with dementia's care values were found to have a negative association (Bonds et al., 2021; Miller et al., 2019). However, incongruent perceptions of people with dementia's involvement in decision-making emerged as a significant influencing factor (Moon et al., 2017).

** Insert Table 3. Influencing factors of quality of life of dementia caregiving dyads**

** Insert Figure 3. Influencing factors of the quality of life of people with dementia and informal caregivers**

Factors influencing anxiety of the dyads

Table 4 and Figure 4 displays the factors influencing the anxiety of the dyads. No dyadic investigations have been conducted in the domain of anxiety, leaving unexplored the potential correlation between anxiety levels among individuals with dementia and their informal caregivers. Regarding people with dementia, self-reported pain (Orgeta, Orrell, Edwards, et al., 2015) exhibited a positive association with anxiety, while attachment security (Nelis et al., 2012) and caregiver mastery (Hwang & Hodgson, 2021) demonstrated negative associations. Caregiver anxiety positively correlated with caregiver burden, affiliated stigma, and neuropsychiatric symptoms in care recipients (Chen et al., 2023).

- ** Insert Table 4. Influencing factors of anxiety of dementia caregiving dyads**
- ** Insert Figure 4. Influencing factors of the anxiety of people with dementia and informal caregivers**

Other aspects of the dyad's psychosocial well-being and influencing factors

Caregiver stress and distress were primarily influenced by the symptoms exhibited by care recipients, including their neuropsychiatric symptoms (Campbell et al., 2011; Lorenzo-López et al., 2017; Orgeta, Orrell, Hounsome, et al., 2015) and cognitive function (Nelis et al., 2012). Additionally, caregivers' distress at these symptoms played a significant role in contributing to their own stress levels (Nelis et al., 2012). A qualitative study also revealed similar findings among couples dealing with young-onset dementia. This study highlighted the impact of changing roles and responsibilities, diagnosis-related challenges, social and family relationships, planning for an

uncertain future, as well as communication difficulties and relationship strain within the couple (Bannon et al., 2022). Interestingly, shared experiences of humor may serve as a protective factor against stressors associated with dementia (Hickman et al., 2020).

Loneliness in dementia caregiving dyads has received relatively less attention and is worthy of investigation given the increasing demonstration of adverse health outcomes. A longitudinal study conducted during the COVID-19 pandemic suggested that loneliness is influenced by different factors for people with dementia and their caregivers. For individuals with dementia, loneliness was directly associated with having a non-spouse coresident caregiver, higher levels of social resources, anxiety, and cognitive impairment. In contrast, caregiver loneliness was linked to having a non-spouse coresident caregiver, higher levels and increases in caregiver anxiety, more formal day activities for the person with dementia, and greater cognitive impairment in the care recipient (Perach et al., 2022) (Supplementary File 4).

Discussion

This systematic review represents a pioneering study that investigates the factors influencing psychosocial well-being among individuals with dementia and their informal caregivers from a dyadic perspective. The findings reveal that only five studies comprehensively examined the interdependence nature within dyads using the actor-partner interdependence model (Gellert et al., 2018; Martincin, 2018; Monin et al., 2020; Rippon et al., 2020; Wu et al., 2021). While all studies assessed both members, most primarily focused on one member's well-being while considering the other member as an influencing factor. As a result, there is a lack of authentic dyadic research that equally underscores the well-being of both individuals and enables us to comprehensively analyze the influencing mechanisms between dyads. This may be due to concerns raised regarding the reliability of information provided by people with dementia in the context of dementia research.

However, previous research has demonstrated that individuals with mild to moderate stage dementia can provide accurate and consistent information (Clark et al., 2008). Moreover, these individuals exhibit awareness of their cognitive impairments and share emotional connections with caregivers, enabling active participation in research (Alsawy et al., 2020). These findings underscore the imperative for enhanced inclusion of people with dementia in both research endeavors and care planning. Without integrating both members of the dyad into research, our understanding of how caregiving dyads work together to manage illness and the impact this has on their health as a unit may be limited (Lyons & Lee, 2018). Furthermore, the absence of any mixed-method study and use of the actor-partner interdependence model has imposed limitations on attaining a comprehensive understanding of the dyadic influencing mechanism. Utilizing the actor-partner interdependence model could provide valuable insights into how individual psychosocial well-being is influenced by their own characteristics and those of their partners. Hence, it is recommended to conduct additional dyadic studies to explore the underlying mechanisms that impact these dyads and facilitate the development of more efficacious strategies for health promotion.

The most well-studied dyadic outcome was quality of life. The correlation between the quality of life of the dyads indicates the interconnectedness between members of the dyad. The psychosocial well-being of the dyads, such as depression, stress, and mood are significant influencing factors of dyadic quality of life. Treatments effective at improving psychosocial well-being problems, such as cognitive behavioral therapy, may be explored to improve the quality of life for the dyads (Hofmann et al., 2017). The neuropsychiatric symptoms of people with dementia and their unmet needs influence the quality of life for both members of the dyad, emphasizing the far-reaching influence of dementia symptoms. This finding highlights the importance of

recognizing and addressing these symptoms and needs to improve the well-being and overall functioning of the dyad. It is also worth noting that caregiver burden and caregiver's health influence the dyad's quality of life, signifying the importance of caring for caregivers during the long-term caregiving journey. Cultivating or keeping a hobby for the caregiver may be a possible solution, as suggested by Bruvik et al. (2012).

Depression has been extensively studied as an outcome of psychosocial well-being. The correlation of depression within dyads aligns with the systematic transaction model of dyadic coping, which suggests that stress experienced by one partner is communicated verbally or nonverbally to the other partner, leading to dyadic coping. This, in turn, influences the psychosocial well-being of both partners (Bodenmann et al., 2017). Hence, this review made it clear that the depression of both the person with dementia and their informal caregiver are closely intertwined, and that a dyadic approach to understanding their health behaviors and outcomes is essential. Although the influencing factors were classified according to the theory of dyadic illness management (Lyons & Lee, 2018), there has been limited research on dyadic appraisal and dyadic management behaviors among dementia caregiving dyads, which makes it difficult to establish the potential mediation effects of these variables. In the context of dyadic illness management theory, dyadic coping can be considered a form of dyadic management behavior. A longitudinal study found a significant relationship between dyadic coping and patients' depressive symptoms, but not caregivers' (Gellert et al., 2018). However, further research is needed to validate this conclusion. Moreover, it is crucial to investigate whether or not dyadic coping mediates the association between risk/proactive factors and depression in the dementia caregiving context. As the disease progresses, the dyadic relationship gradually transitions into a compassionate bond, resulting in alterations in both the quality and stability of home-based care arrangements (Hochgraeber et al.,

2023). This study underscores the significance of enhancing dyadic relationship quality and promoting the dyad's capability to live well to alleviate depression among the dyads. Future research could explore dyadic activities such as engaging in leisure activities and reminiscing about positive shared experiences to foster sustained dyadic relationships and ameliorate depressive symptoms (Wang et al., 2023; Yang et al., 2022).

Other aspects of psychosocial well-being, such as anxiety, stress, and loneliness, have received relatively less attention, warranting further exploration. For instance, existing studies on anxiety have primarily focused on identifying influencing factors for one partner only, leaving unexplored the potential dynamic influences between dyads. Research conducted among parents and children has demonstrated that anxiety can be transmitted through dyadic social dynamics, which capture daily moment-to-moment interactions (Perlman et al., 2022). Similarly, within dementia caregiving dyads, it is plausible to observe similar phenomena due to the common utilization of emotional-focused dyadic coping strategies where stress or anxiety signals are communicated between partners who then respond with relevant coping mechanisms (Colclough et al., 2023). Studies investigating loneliness also suggest that caregivers may prioritize protecting individuals with dementia from experiencing loneliness at their own expense (Perach et al., 2022), yet these feelings may still permeate across dyads over time (Tough et al., 2018). Therefore, further research is needed to explore how the psychosocial well-being of both partners in a dyad mutually influences each other and how collaborative efforts between partners can enhance overall wellbeing status.

Limitations of this systematic review

Although this systematic review has yielded significant findings, it is important to consider certain limitations when interpreting the results. The restricted number of studies necessitated a

narrative approach for synthesizing the main findings, which limited our ability to analyze the strength of association and underlying mechanisms. Additionally, we observed a potential publication bias as only a few studies reported insignificant findings. Furthermore, most of the included studies were cross-sectional in nature, restricting our ability to establish causal relationships between variables. Finally, enriching the findings by including non-English publications could further enhance their comprehensiveness.

Conclusion

Psychosocial well-being from a dyadic perspective has garnered increased attention in dementia research. However, studies on the influencing factors are scattered across various aspects of dyadic psychosocial well-being. The most extensively studied outcomes include depression and quality of life; nevertheless, further research is warranted to explore the underlying mechanisms that influence dyads. These findings may offer valuable insights to guide future empirical studies investigating influencing mechanisms and enhance our understanding of how to effectively capture and promote dyadic psychosocial well-being within the context of dementia.

Relevance to clinical practice

The findings underscore the importance of screening for psychosocial well-being not only in individuals with dementia but also in their caregivers. Healthcare professionals, including home care staff, should proactively provide timely interventions targeting both individual and dyadic factors to effectively benefit dementia caregiving dyads. Therefore, we advocate for a paradigm shift in research and clinical practice from solely focusing on individual interventions towards providing comprehensive dyadic support that promotes the psychosocial well-being of both caregivers and individuals with dementia.



References

- 2020 Alzheimer's disease facts and figures. (2020). *Alzheimers Dement*. https://doi.org/10.1002/alz.12068
- Alsawy, S., Tai, S., McEvoy, P., & Mansell, W. (2020). 'It's nice to think somebody's listening to me instead of saying "oh shut up"'. People with dementia reflect on what makes communication good and meaningful. *Journal of psychiatric and mental health nursing*, 27(2), 151-161. https://doi.org/10.1111/jpm.12559
- Bannon, S. M., Reichman, M., Popok, P., Grunberg, V. A., Traeger, L., Gates, M. V., Krahn, E. A., Brandt, K., Quimby, M., Wong, B., Dickerson, B. C., & Vranceanu, A.-M. (2022). Psychosocial Stressors and Adaptive Coping Strategies in Couples After a Diagnosis of Young-Onset Dementia. *The Gerontologist*, 62(2), 262-275. https://doi.org/10.1093/geront/gnab053
- Bodenmann, G., Falconier, M., & Randall, A. K. (2017). Systemic-Transactional Model of Dyadic Coping. In (pp. 1-7). Springer International Publishing. https://doi.org/10.1007/978-3-319-15877-8 761-1
- Bonds, K., Whitlatch, C. J., Song, M., & Lyons, K. S. (2021). Factors influencing quality of life in African-American dementia dyads. *Aging & mental health*, 25(4), 703-710. https://doi.org/10.1080/13607863.2020.1711865
- Brodaty, H., & Luscombe, G. (1998). Psychological morbidity in caregivers is associated with depression in patients with dementia. *Alzheimer disease and associated disorders*, 12(2), 62-70. https://doi.org/10.1097/00002093-199806000-00002
- Bruvik, F. K., Ulstein, I. D., Ranhoff, A. H., & Engedal, K. (2012). The quality of life of people with dementia and their family carers. *Dementia and geriatric cognitive disorders*, 34(1), 7-14. https://doi.org/10.1159/000341584
- Burgener, S., & Twigg, P. (2002). Relationships Among Caregiver Factors and Quality of Life in Care Recipients with Irreversible Dementia. *Alzheimer Disease & Associated Disorders*, 16(2).
 - https://journals.lww.com/alzheimerjournal/fulltext/2002/04000/relationships_among_care giver_factors_and_quality.6.aspx
- Campbell, J. L., Rowe, M. A., & Marsiske, M. (2011). Behavioral symptoms of dementia: a dyadic effect of caregivers' stress process? [Article]. *Research in gerontological nursing*, 4(3), 168-184. https://doi.org/10.3928/19404921-20100901-02
- Carbone, E. A., de Filippis, R., Roberti, R., Rania, M., Destefano, L., Russo, E., De Sarro, G., Segura-Garcia, C., & De Fazio, P. (2021). The Mental Health of Caregivers and Their Patients With Dementia During the COVID-19 Pandemic: A Systematic Review. *Front Psychol*, *12*, 782833. https://doi.org/10.3389/fpsyg.2021.782833
- Chen, Y. J., Su, J. A., Chen, J. S., Liu, C. H., Griffiths, M. D., Tsai, H. C., Chang, C. C., & Lin, C. Y. (2023). Examining the association between neuropsychiatric symptoms among people with dementia and caregiver mental health: are caregiver burden and affiliate stigma mediators? [Article]. *BMC geriatrics*, 23(1), 27. https://doi.org/10.1186/s12877-023-03735-2
- Clark, P. A., Tucke, S. S., & Whitlatch, C. J. (2008). Consistency of information from persons with dementia: An analysis of differences by question type. *Dementia*, 7(3), 341-358.
- Colclough, C., Miles, E., Rusted, J., Perach, R., Hicks, B., Dixon, J., Dangoor, M., Gridley, K., Birks, Y., Donaghy, P., McArdle, R., Moseley, E., Sondh, H. K., Banerjee, S., & team, D.

- (2023). Emotion-focused dyadic coping styles used by family carers of people with dementia during the COVID-19 pandemic. *Dementia (London)*, 22(6), 1205-1226. https://doi.org/10.1177/14713012231173812
- Eiroa-Orosa, F. J. (2020). Understanding Psychosocial Wellbeing in the Context of Complex and Multidimensional Problems. *Int J Environ Res Public Health*, *17*(16). https://doi.org/10.3390/ijerph17165937
- Fang, B., Liu, H., & Yan, E. (2021). Association Between Caregiver Depression and Elder Mistreatment-Examining the Moderating Effect of Care Recipient Neuropsychiatric Symptoms and Caregiver-Perceived Burden. *The journals of gerontology. Series B, Psychological sciences and social sciences, 76*(10), 2098-2111. https://doi.org/10.1093/geronb/gbab025
- Gellert, P., Häusler, A., Gholami, M., Rapp, M., Kuhlmey, A., & Nordheim, J. (2018). Own and partners' dyadic coping and depressive symptoms in individuals with early-stage dementia and their caregiving partners [Article]. *Aging and Mental Health*, 22(8), 1008-1016. https://doi.org/10.1080/13607863.2017.1334759
- Häusler, A., Sánchez, A., Gellert, P., Deeken, F., Rapp, M. A., & Nordheim, J. (2016). Perceived stress and quality of life in dementia patients and their caregiving spouses: does dyadic coping matter? *International psychogeriatrics*, 28(11), 1857-1866. https://doi.org/10.1017/S1041610216001046
- Hickman, H., Clarke, C., & Wolverson, E. (2020). A qualitative study of the shared experience of humour between people living with dementia and their partners. *Dementia (London, England)*, 19(6), 1794-1810. https://doi.org/10.1177/1471301218805895
- Hochgraeber, I., Kohler, K., Stocker, H., & Holle, B. (2023). The dyadic relationship of family carers and people living with dementia an umbrella review. *Aging Ment Health*, *27*(10), 1965-1974. https://doi.org/10.1080/13607863.2023.2215191
- Hofmann, S. G., Curtiss, J., Carpenter, J. K., & Kind, S. (2017). Effect of treatments for depression on quality of life: a meta-analysis. *Cognitive behaviour therapy*, 46(4), 265-286.
- Hwang, Y., & Hodgson, N. (2021). Associations between caregiver mastery and anxiety in persons living with dementia: A study of dyads living in community. *Geriatric nursing (New York, N.Y.)*, 42(5), 993-997. https://doi.org/10.1016/j.gerinurse.2021.06.019
- Karg, N., Graessel, E., Randzio, O., & Pendergrass, A. (2018). Dementia as a predictor of carerelated quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. BMC Geriatr, 18(1), 189. https://doi.org/10.1186/s12877-018-0885-1
- Larson, J. S. (1996). The World Health Organization's definition of health: Social versus spiritual health. *Social Indicators Research*, *38*(2), 181-192. https://doi.org/10.1007/BF00300458
- Linton, K. F. (2020). Latina/o and non-Latina/o brain injury and dementia patients' and caregivers' health: An actor/partner interdependence model. *Brain Impairment*, 21(3), 237-246. https://doi.org/https://doi.org/10.1017/BrImp.2020.1
- Lorenzo-López, L., de Labra, C., Maseda, A., Lorenzo, T., Agrafojo, H., Rodríguez-Villamil, J. L., González-Abraldes, I., & Millán-Calenti, J. C. (2017). Caregiver's distress related to the patient's neuropsychiatric symptoms as a function of the care-setting. *Geriatric nursing (New York, N.Y.)*, 38(2), 110-118. https://doi.org/10.1016/j.gerinurse.2016.08.004
- Lyons, K. S., & Lee, C. S. (2018). The Theory of Dyadic Illness Management. *J Fam Nurs*, *24*(1), 8-28. https://doi.org/10.1177/1074840717745669
- Martincin, K. (2018). The relationship between depression and dyad relationship strain in

- caregiving dyads of Veterans with dementia (Publication Number AAI10659956) [Ph.D., Cleveland State University]. APA PsycInfo®. http://ezproxy.lb.polyu.edu.hk/login?url=https://www.proquest.com/dissertations-theses/relationship-between-depression-dyad-strain/docview/2025390609/se-2?accountid=16210
- Miller, L. M., Kaye, J. A., Lyons, K. S., Lee, C. S., Whitlatch, C. J., & Caserta, M. S. (2019). Well-being in dementia: a cross-sectional dyadic study of the impact of multiple dimensions of strain on persons living with dementia and their family care partners. *International psychogeriatrics*, 31(5), 617-626. https://doi.org/10.1017/S104161021800203X
- Minyo, M. J., & Judge, K. S. (2022). Perceived Unmet Need and Need-Related Distress of People Living With Dementia. *Gerontology and Geriatric Medicine*, 8, 23337214221092886.
- Monin, J. K., Jorgensen, T. D., & MacNeil Vroomen, J. L. (2020). Self-Reports and Caregivers' Proxy Reports of Unmet Needs of Persons With Dementia: Implications for Both Partners' Health-Related Quality of Life. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*, 28(3), 363-367. https://doi.org/10.1016/j.jagp.2019.10.006
- Moola, S. (2017). Chapter 7: Systematic reviews of etiology and risk. Aromataris E, Munn Z. *Joanna Briggs Institute Reviewer's Manual. The Joanna Briggs Institute*.
- Moon, H., Townsend, A. L., Whitlatch, C. J., & Dilworth-Anderson, P. (2017). Quality of Life for Dementia Caregiving Dyads: Effects of Incongruent Perceptions of Everyday Care and Values. *The Gerontologist*, 57(4), 657-666. https://doi.org/10.1093/geront/gnw055
- Nelis, S. M., Clare, L., & Whitaker, C. J. (2012). Attachment representations in people with dementia and their carers: implications for well-being within the dyad. *Aging & mental health*, *16*(7), 845-854. https://doi.org/10.1080/13607863.2012.667779
- Nelson, K. E., Saylor, M. A., Anderson, A., Buck, H., Davidson, P. M., DeGroot, L., Fisher, M., Gilotra, N. A., Pavlovic, N., & Szanton, S. L. (2022). "We're all we got is each other": Mixed-methods analysis of patient-caregiver dyads' management of heart failure. *Heart Lung*, 55, 24-28. https://doi.org/10.1016/j.hrtlng.2022.04.009
- Orgeta, V., Orrell, M., Edwards, R. T., Hounsome, B., & Woods, B. (2015). Self- and Carer-Rated Pain in People With Dementia: Influences of Pain in Carers. *Journal of pain and symptom management*, 49(6), 1042-1049. https://doi.org/10.1016/j.jpainsymman.2014.10.014
- Orgeta, V., Orrell, M., Hounsome, B., & Woods, B. (2015). Self and carer perspectives of quality of life in dementia using the QoL-AD. *International journal of geriatric psychiatry*, *30*(1), 97-104. https://doi.org/10.1002/gps.4130
- Ornstein, K., Gaugler, J. E., Devanand, D. P., Scarmeas, N., Zhu, C., & Stern, Y. (2012). The differential impact of unique behavioral and psychological symptoms for the dementia caregiver: How and why do patients' individual symptom clusters impact caregiver depressive symptoms? [Article in Press]. *American Journal of Geriatric Psychiatry*. https://doi.org/10.1097/JGP.0b013e31826d6b31
- Parrotta, I., De Mauleon, A., Abdeljalil, A. B., De Souto Barreto, P., Lethin, C., Veerbek, H., Stephan, A., Saks, K., Zabalegui, A., & Soto Martin, M. E. (2020). Depression in People With Dementia and Caregiver Outcomes: Results From the European Right Time Place Care Study. *Journal of the American Medical Directors Association*, 21(6), 872.

https://doi.org/10.1016/j.jamda.2020.02.023

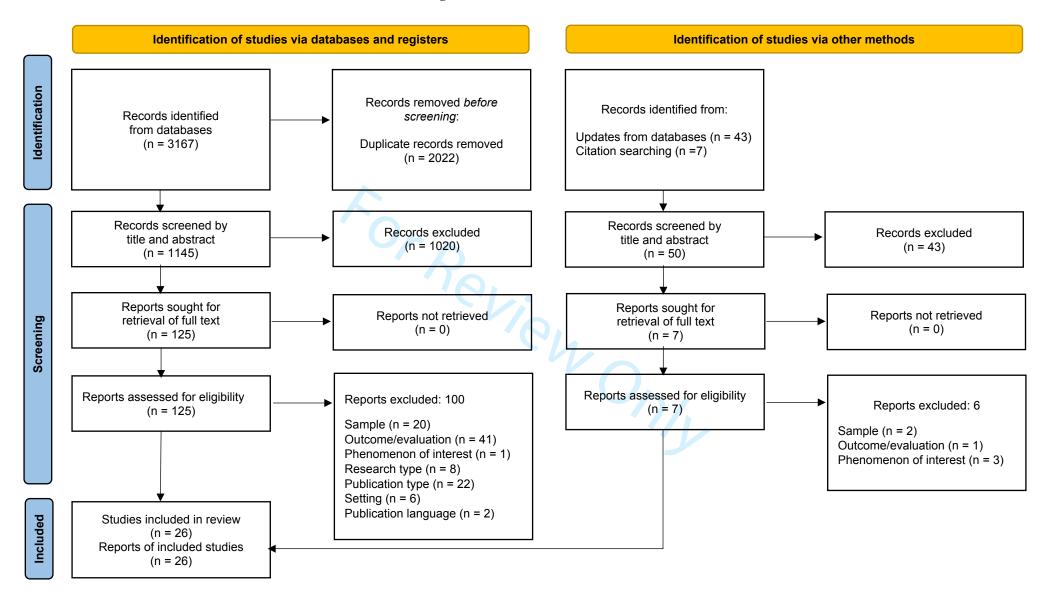
- Perach, R., Read, S., Hicks, B., Harris, P. R., Rusted, J., Brayne, C., Dangoor, M., Miles, E., Dixon, J., Robinson, L., Thomas, A., & Banerjee, S. (2022). Predictors of loneliness during the Covid-19 pandemic in people with dementia and their carers in England: findings from the DETERMIND-C19 study. *Aging & mental health*, 1-12. https://doi.org/10.1080/13607863.2022.2080179
- Perlman, S. B., Lunkenheimer, E., Panlilio, C., & Perez-Edgar, K. (2022). Parent-to-Child Anxiety Transmission Through Dyadic Social Dynamics: A Dynamic Developmental Model. *Clin Child Fam Psychol Rev*, 25(1), 110-129. https://doi.org/10.1007/s10567-022-00391-7
- Poon, E. (2022). A Systematic Review and Meta-Analysis of Dyadic Psychological Interventions for BPSD, Quality of Life and/or Caregiver Burden in Dementia or MCI. *Clin Gerontol*, 45(4), 777-797. https://doi.org/10.1080/07317115.2019.1694117
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version*, *1*(1), b92.
- Rippon, I., Quinn, C., Martyr, A., Morris, R., Nelis, S. M., Jones, I. R., Victor, C. R., & Clare, L. (2020). The impact of relationship quality on life satisfaction and well-being in dementia caregiving dyads: findings from the IDEAL study. *Aging & mental health*, *24*(9), 1411-1420. https://doi.org/10.1080/13607863.2019.1617238
- Schölzel-Dorenbos, C., Meeuwsen, E., Adang, E., Krabbe, P., Olde Rikkert, M., & Melis, R. (2010). A cross-sectional study on how dementia patients' and their caregivers' quality of life are associated provides possibilities to improve dementia care [Conference Abstract]. *European Geriatric Medicine*, 1, S10. https://doi.org/10.1016/j.eurger.2010.07.007
- Tough, H., Brinkhof, M., Siegrist, J., & Fekete, C. (2018). Being alone together: a longitudinal dyadic analysis on the impact of loneliness and relationship quality on wellbeing in couples coping with disability. *d'Épidémiologie et de Santé Publiqu*, 66. https://doi.org/https://doi.org/10.1016/j.respe.2018.05.288
- Wang, S., Molassiotis, A., Guo, C., Leung, I. S. H., & Leung, A. Y. M. (2023). Association between social integration and risk of dementia: A systematic review and meta-analysis of longitudinal studies. *Journal of the American Geriatrics Society*, 71(2), 632-645.
- Wawrziczny, E., Berna, G., Ducharme, F., Kergoat, M.-J., Pasquier, F., & Antoine, P. (2017). Modeling the distress of spousal caregivers of people with dementia. *Journal of Alzheimer's Disease*, 55(2), 703-716.
- World Health Organization. (2023, 15 March 2023). *Dementia*. Retrieved 4 October from https://www.who.int/news-room/fact-sheets/detail/dementia/?gclid=CjwKCAjwgsqoBhBNEiwAwe5w08zMoLYHpTD58hL8IGq1HaUdq6gm6Rt49TzyEV4L4gR_QRwL0p11zhoCslcQAvD_BwE
- Wu, Y.-T., Clare, L., & Matthews, F. E. (2021). Relationship between depressive symptoms and capability to live well in people with mild to moderate dementia and their carers: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) programme. *Aging & mental health*, 25(1), 38-45. https://doi.org/10.1080/13607863.2019.1671316
- Wulff, J., Fänge, A. M., Lethin, C., & Chiatti, C. (2020). Self-reported symptoms of depression and anxiety among informal caregivers of persons with dementia: a cross-sectional comparative study between Sweden and Italy. *BMC health services research*, 20(1), 1-15.
- Yang, X., Xu, X. Y., Guo, L., Zhang, Y., Wang, S. S., & Li, Y. (2022). Effect of leisure activities

on cognitive aging in older adults: A systematic review and meta-analysis. *Front Psychol*, 13, 1080740. https://doi.org/10.3389/fpsyg.2022.1080740

Zanetti, O., Frisoni, G. B., Bianchetti, A., Tamanza, G., Cigoli, V., & Trabucchi, M. (1998). Depressive symptoms of Alzheimer caregivers are mainly due to personal rather than patient factors [Article]. *International journal of geriatric psychiatry*, *13*(6), 358-367. https://doi.org/10.1002/(SICI)1099-1166(199806)13:6<358::AID-GPS772>3.0.CO;2-J



Figure 1 The PRISMA Flowchart



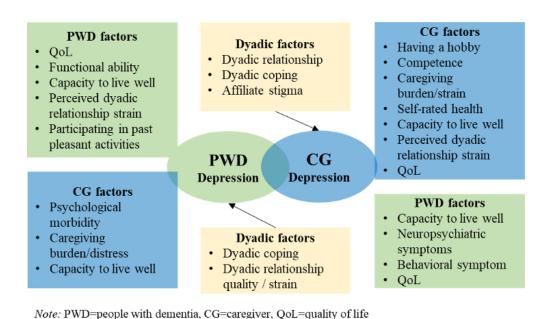
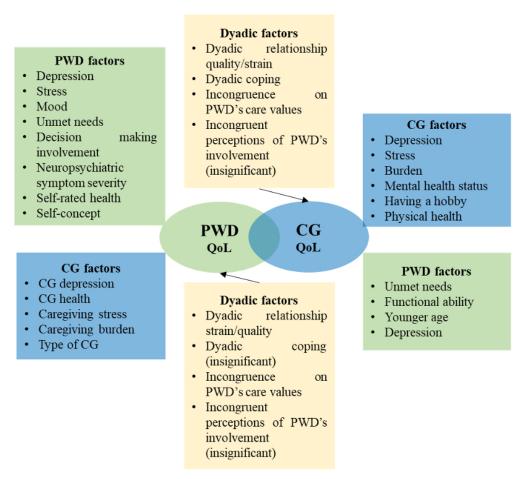
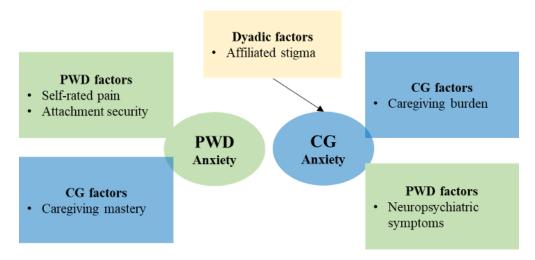


Figure 2 Influencing factors of the depression of people with dementia and informal caregivers $123x76mm (150 \times 150 DPI)$



Note: PWD=people with dementia, CG=caregiver

Figure 3 Influencing factors of the quality of life of people with dementia and informal caregivers $136 \times 132 \text{mm}$ (150 x 150 DPI)



Note: PWD=people with dementia, CG=caregiver

Figure 4 Influencing factors of the anxiety of people with dementia and informal caregivers $122x68mm \ (150 \ x \ 150 \ DPI)$

Table 1 Characteristics of included studies (n=26)

| 1 | | | | | | | | i f | | |
|---|---|--------------------|--------------|----------------------------------|-----------------------|--------------------------------|-----------------------|--|--|--|
| 1 2 3Study 4 | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
| Bannon et fal. (2022) 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 | Qualitative study | US | 23 | Mild to moderate YOD | 61.30 (4.65) | 60.52 (5.41) | NA NA | QoL: QoL-AD Dyadic relationship | NA | Thematic analysis of dyadic interviews revealed 5 themes related to psychological stressors in YOD couples: the impact of diagnosis, social and family relationships, changing roles and responsibilities, planning for an uncertain future, and couple communication and relationship strain. The interviews also revealed 7 themes related to couple-level adaptive coping strategies: processing emotions and cultivating acceptance, promoting normalcy, efforts to preserve persons with YOD's independence and identity, collaborative and open communication, social support, meaning-making, humor, and positivity, and lifestyle changes and self-care. |
| 286 onds et 281. (2021) 30 31 32 33 34 35 36 37 38 39 40 41 | Cross- sectional study (Secondary analysis of a longitudinal study) | US | 62 | Not specified, 13≤MMSE ≤26 | 76.55(7.84) | 60.49(13.35) | NA | QoL: QoL-AD Dyadic relationship quality (5-item measure): DRS | QoL: QoL-AD Decision making involvement: DMI Dyadic relationship quality (4-item measure): DRS | QoL within dyads covaried ($r = 0.26$), caregivers experienced significantly worse QoL when they reported greater dyadic strain with the African-American PWD ($r = 0.51$) and were non-spouses of African-American PWDs ($r = 0.26$). PWD QoL only influenced by caregiver type ($r = 0.48$) and PWD decision-making involvement ($r = 0.36$) |

| 1Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|--|---|--------------------|-----------------|--|-----------------------|--------------------------|-----------------------------|---|---|--|
| 4Brodaty 5and 6Luscombe 7(1998) 8 9 10 11 12 13 14 | Cross- sectional study | Australia | 193 | Generally mild to moderate (93.3%), only 6.1% have severe dementia | 72.2 (8.0) | 59.8 (15.5) | NA | Psychological morbidity: 30-item version GHQ Psychiatric symptoms: 30-item version GHQ Social functioning: 30-item version GHQ General life satisfaction: 30-item version GHQ | Depression: 21-item HRSD, GDS Dementia severity: CDR (rated by caregiver), MMSE Demanding problem behavior (rated by caregiver): PBCL | Patient depression and demanding problem behaviors independently and significantly associated with caregiver psychological morbidity. |
| 16 19 ruvik et 18. (2012) 19 20 21 22 23 24 25 26 | Cross- sectional study (Secondary analysis of a RCT study) | Norway | 230 | Not specified, 15≤MMSE | 78.4(7.5) | 63.5(12) | NA | QoL: QoL-AD Severity of depression: GDS | QoL: QoL-AD Neuro-psychiatric symptoms: NPI-Q Activity of daily living: PSMS, IADL Severity of depression: CSDD | PWD QoL is influenced by PWD depression, NPI severity, CG depression. CG QoL is influenced by CG depression and whether CG have a hobby. |
| 27 Surgener 28nd Twigg 2(2002) 30 31 32 33 34 35 36 37 38 39 | Longitudinal study | US | 73 | Not specified | 77.3 | 63.7 | 18months | Quality of dyadic relationship: ECFR of caregiving burden scale Caregiver role stress: relative's stress scale Maintenance of activities: The PESAD | QoL: CSDD; the psychological wellbeing in cognitively impaired persons; & the cumulative illness rating scale | Caregiver role stress, maintenance of activities, and quality of dyadic relationship significantly predicted three of the QoL outcomes The quality of the caregiver-care recipient relationship predicted care recipient's psychologic well-being. Participation in past pleasant activities predicted patient psychologic well-being. |

| 1Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|--|---|--------------------|--------------|--|-----------------------|--------------------------------|--------------------|---|---|--|
| 3 4Judy LM 5Campbell 6et al. 7(2011) 8 9 10 11 12 13 14 | Longitudinal study (secondary analysis of intervention data) | US | 53 | Primarily had Alzheimer's type dementia with moderate cognitive impairment (MMSE average = 14.67) | 80 | Not mentioned | 1 year | Perceived stress: short version ZBI | Behavioral symptoms (rated by caregiver): NPI-Q | Caregivers perceived stress predicted behavioral symptoms of dementia. |
| 1&hen et al. 1@023) 17 18 19 20 21 22 23 24 25 26 27 28 29 | Cross sectional study | Taiwan | 261 | Not mentioned | 79.3 (6.78) | 52.9 (12.33) | NA | Caregiver burden: CBI Affiliate stigma: 22- item Chinese version ASS Depression: 18-item TDQ Anxiety 21-item Chinese version BAI | Behavioral and psychological symptoms: NPI | Caregiver burden, affiliate stigma, caregiver depression, and caregiver anxiety were significantly associated with neuropsychiatric symptoms. PWD's neuropsychiatric symptoms, caregiver burden and affiliate stigma significantly explained 52.34% of the variance in caregiver depression and 37.72% of the variance in caregiver anxiety. |
| 3Qellert et 3dl. (2018) 32 33 34 35 36 37 38 39 40 41 42 | Longitudinal study | Germany | 82 | Early stage; 15≤MMSE | 75.44(5.89) | 72.96(6.76) | 6 months | Depressive symptoms: GDS-SF- 15 Own dyadic coping & Perceived partner dyadic coping: DCI subscales Individual coping (7-item subscale): PSS-14 | Depressive symptoms: GDS- SF-15 Own dyadic coping & Perceived partner dyadic coping: DCI subscales Individual coping: PSS-14 | Dyadic coping was significantly related to patients' but not to caregivers' depressive symptoms, when adjustments were made for individual coping. Perceived partner DC showed a negative association with depressive symptoms in patients, whereas own DC was adversely related for actor as well as for partner effects across individuals. |

| 1 2 2 3 | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|---|---|--------------------|--------------|---------------------------|-----------------------|--------------------------------|-----------------------|--|--|--|
| 4Häusler et 5al. (2016) 6 7 8 9 10 11 12 13 14 15 16 17 | Cross- sectional study (Secondary analysis of a prospective study) | Germany | 82 | Not specified, 15≤MMSE | 75.49(5.81) | 73.02(6.68) | NA | Stress: PSS-14 Depressive symptoms: GDS Dyadic Coping: DCI Dyadic relationship quality: 6th item QMI QoL: WHOQOL- BREF | Stress: PSS-14 Depressive symptoms: GDS Dyadic Coping: DCI Dyadic relationship quality: 6th item QMI QoL: QoL-AD | There were negative correlations between stress and QoL in both PWD $(r=-0.62, p < 0.001)$ and CG $(r=-0.27, p=0.02)$. Spousal caregivers had a significantly lower DCI total score than dementia patients $(p < 0.001)$. DC was a significant mediator of the relationship between stress and QoL in spousal caregivers $(z=0.28, p=0.02)$, but not in dementia patients. Relationship quality significantly mediated the relationship between stress and QoL in caregivers only $(z=-2.41, p=0.02)$. |
| 19 2Hickman 29t al. 22 ² 020) 23 24 25 | Qualitative study | UK | 10 | Not specified | 75.9 (6.74) | | NA | NA | NA | Humour, in different forms, can represent a salient and enduring relationship strength that helps dyads maintain well-being and couplehood by providing a buffer against stressors associated with dementia. |
| 26 Hwang and 27 Hodgson (2021) 29 30 31 32 33 34 35 36 37 | Cross sectional study (secondary analysis of baseline data from an RCT) | US | 170 | Not mentioned | 73.4 (8.7) | 57.8 (14.7) | NA | Caregiver mastery: Caregiver Mastery Index | Depression: PHQ-9 Pain: PROMIS Pain Behavior Short Form Anxiety: NPI | A higher level of caregiver mastery was related to lower odds of anxiety presentation in PWD (OR = 0.870, 95% CI: 0.759 - 0.998, p = 0.046) |

| 1 Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|--|------------------------------|--------------------|--------------|-------------------|-----------------------|--------------------------------|-----------------------|---|---|---|
| 4Linton 5(2020) 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 | Cross- sectional study | US | 71 | Not specified | 83.04(11.48) | 67.62(17.75) | NA | Depression: PHQ-9 scale Caregiver burden: A 4-item Caregiver Strain Index scale | Depression: PHQ-9 scale Functional ability: A seven-point scale created by Linton, 2020 | There was consistently a statistically significant positive relationship between caregiver depression and caregiver burden for all groups. For non-Latina/o patient and caregiver dementia dyads (n = 42), there were associations between patient depression and caregiver depression (r = 0.51, p < 0.012). For non-Latina/o dementia dyads, functional ability was only associated with patient depression (r = 0.46, p < 0.012). There was a statistically significant relationship between caregiver burden and caregiver depression among both ethnic groups (Latina/o r = 0.63; non-Latina/o r = 0.54, p < 0.012). |
| 23 orenzo- 24 ópez et 25 (2017) 26 27 28 29 30 31 32 33 34 | Cross sectional study | Spain | 39 | Not mentioned | 82.79 (7.99) | Not mentioned | NA | Caregiver distress: NPI-D | Cognitive Impairment: MMSE Neuro-psychiatric symptoms: Spanish version NPI | Agitation/aggression (β = 0.596, p < 0.001), delusions (β = 0.412, p < 0.001), disinhibition (β = 0.352, p < 0.001), apathy/indifference (β = 0.306, p < 0.001), depression/dysphoria (β = 0.282, p < 0.001), and elation/euphoria (β = 0.193, p < 0.05) were the best predictors of informal caregiver's distress. |

| 1Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|---|--|--------------------|--|---|-----------------------|--------------------------------|-----------------------------|--|--|--|
| 4Martincin 5(2018) 6 7 8 9 10 11 | Cross sectional survey (secondary analysis of an interventional study) | US | 508 vetera ns + 486 caregi vers | Not mentioned | 78.5 | 66.2 | NA | Depression: 11-item CES-D Dyad Relationship strain: six questions focused on perceptions of the quality of the relationship with their care partners | Depression: 11-item CES-D Dyad Relationship strain: six questions focused on perceptions of the quality of the relationship with their care partners | Actor effect: There was a significant positive relationship between caregiver's dyad relationship strain and caregiver's depression ($\beta = 0.26$, $p < 0.001$). There was a positive relationship between the PWD's dyad relationship strain and depression ($\beta = 0.31$, $p < 0.001$). |
| 13 14 15 16 17 18 19 20 21 22 23 24 25 26 | | | | | | | | | | Partner effect: The PWD dyadic strain's effect on CG depression was insignificant (β = 0.065, p = 0.247). CG dyadic strain's effect on PWD depression was also insignificant (β = -0.004, p = 0.985). There was a significant positive relationship between dyad relationship strain of the care partners (r = 0.25, p < 0.001). A significant positive relationship was found between depression of the care partners (r = 0.19, p < 0.001). |
| 27 28 (2019) 30 31 32 33 34 35 36 37 38 39 40 41 42 43 | Cross- sectional study | US | 42 | Mild to moderate dementia/ Irreversible progressive dementia | 79.81(7.76) | 61(12.95) | NA | QoL: QoL-AD Depression: CES-D Care-related strain: Role Overload scale Relationship strain: 5-item Dyadic Strain subscale of the Dyadic Relationship Scale | QoL: QoL-AD Depression: CES-D Cognitive impairment: MMSE Relationship strain: 5-item Dyadic Strain subscale of the Dyadic Relationship Scale | Within dyads, QoL reports demonstrated a low association (tau correlations $r=0.13$), while a moderate inverse association was found in depressive symptoms (tau correlations $r=-0.39$). The PWD's well-being (higher QoL and lower depressive symptoms) was associated with significantly less strain in the dyad's relationship ($r=-2.29$, $p<0.05$), ($r=5.33$, $p<0.01$). The care partner's well-being was associated with significantly less carerelated strain ($r=1.61$, $p<0.01$) and (for QoL scale) less relationship strain ($r=-3.21$, $p<0.05$). |

| ¹ Study 2 | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|--|--|--------------------|--------------|---|-----------------------|--------------------------------|-----------------------|---|--|---|
| 4Monin et 5al. (2020) 6 7 8 9 10 11 12 13 | Cross-sectional study (Secondary analysis of a cohort study) | US | 521 | Not mentioned | Not mentioned | Not mentioned | NA | Unmet needs: CANE Health related quality of life: EQ- 5D | Unmet needs: CANE Health related quality of life: EQ- 5D | Greater PWDs' self-reported unmet needs were significantly associated with lower PWDs' self-reported HRQoL (Actor effect; $b=-0.044$, $\beta=-0.226$, $z=-3.588$, $p<0.001$). Greater PWDs' self-reported unmet needs were also significantly associated with lower CGs' self-reported HRQoL (Partner effect; $b=-0.021$, $\beta=-0.131$, $z=-2.154$, $p=0.031$). |
| 15 Ioon et al. 16 2017) 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 | Cross-sectional study (Secondary analysis of a longitudinal study) | US | 205 | Mild to moderate dementia (13≤MMSE ≤26) | 75.98(9.24) | 62.49(13.44) | NA *** | Decision-making involvement: 14 items DMI scale QoL: QoL-AD CGs' perception of CRs' values about social relations: 5-item Social Relations Values subscale (VALUES) | Decision-making involvement: 14 items DMI scale QoL: QoL-AD The importance CR places on social relations: 5-item Social Relations Values subscale (VALUES) | Greater incongruence on CRs' values significantly predicted lower QoL of CG and CR. Absolute difference: (β = -0.46 , p < 0.05); One direction of difference on values: (β = -1.45 , p < 0.05) Incongruent perceptions of CRs' involvement in decisions were not a significant predictor of QoL. |

| 1Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|--|---|--------------------|--------------|---|-----------------------|--------------------------------|-----------------------------|---|--|--|
| 4Nelis et al. 5(2012) 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 | Cross- sectional study (Secondary analysis of a RCT study) | UK | 97 | Not specified, MMSE: 24.43 (SD 2.64) | 77.98(7.68) | 68.17(13.66) | NA | Attachment security: RQ Neuro-psychiatric symptoms in the PWD: NPI-Q Functional ability of PWD: FAQ Effects of caregiving: RSS Psychological health: GHQ-12, including symptoms of depression and anxiety | Attachment Security: RQ Self-concept: TSCS Mood: HADS QoL: QoL-AD | Attachment security for PWD was related to more positive self-concept (β = 0.347, p = 0.001) and less symptoms of anxiety among themselves (β = -0.230, p = 0.022). Attachment was not related to quality of life in PWD, but mood (β = -0.408, p = 0.001) and self-concept (β = 0.353, p = 0.006) were strong predictors of their quality of life. Carer attachment security was related to their psychological health (β = -0.231, p = 0.022). Caregiver distress at symptoms (β = 0.595, p = 0.000) and MMSE score of the PWD (β = -0.272, p = 0.004) were the strongest predictors of caregiver stress. PWD working models of attachment did not predict caregiver well-being and vice versa. |
| 29rgeta, 29rrell, 2₱dwards, 2\$ al. 29015) 30 31 32 33 34 35 36 37 38 39 40 41 | Cross- sectional study (Secondary analysis of a RCT study) | UK | 488 | Mild to moderate dementia | 77.6(54-95) | 69.8(23-91) | NA | QoL: QoL-AD Mental health: GHQ-28 Stress: RSS | QoL: QoL-AD Depression: CSDD Anxiety: RAID Scale Daily-living ability: BADLs Dementia severity: CDR Self-rated health: Visual Analogue Scale (EQ-VAS) of the EQ-5D | Higher levels of self-rated health in PWD (β = 0.284, p < 0.01), higher scores of CDR (β = -0.175, p < 0.05), the carer experienced less stress related to caregiving (β = -0.172, p < 0.05) were associated with higher PWD self-rated QoL. The age (β = -0.101, p < 0.05), BADLS (β = -0.415, p < 0.001) and depression (β = -0.233, p < 0.01) of PWD, less carer stress (β = -0.677, p < 0.001), better health for the family carer (β = 0.098, p < 0.05), carers lived with the PWD (β = 0.253, p < 0.001) were associated with carer-rated PWD's QoL. |

| 1Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|--|---|--|-----------------|---|-----------------------|--------------------------------|-----------------------|--|--|---|
| 4Orgeta, 5Orrell, 6Hounsome, 7et al. 8(2015) 9 10 11 12 13 14 15 | Cross sectional survey | UK | 488 | Mild to moderate dementia | 75.55 | 69.83 | NA | Anxiety and Depression: HADS Self-rated health: EuroQoL-5D | Pain: EQ-5D Anxiety: RAID Scale | PWD self-rated pain was more frequent in those with lower self-rated health (AOR 0.97, 95% CI: 0.96 - 0.99, p \leq 0.001) and higher anxiety (AOR 1.07, 95% CI: 1.01 - 1.12, P = 0.013). Carer-rated (proxy) pain was additionally predicted by poor proxy-rated health in the PWD (AOR 0.98, 95% CI: 0.96 - 0.99, P = 0.006) and carers' own experience of pain (AOR 0.36, 95% CI: 0.21 - 0.63, P \leq 0.001). |
| 1@rnstein et 1&l. (2012) 19 20 21 22 23 24 25 | Longitudinal study | US | 160 | Probable AD and dementia with Lewy bodies, 16≤MMSE | 75.4 (7.4) | 65.3 (14.4) | 6 months- 6 years | Depression : 6-item depression subsection BSI | BPSD symptom clusters: CUSPAD | Only the presence of patient depressive symptoms was associated with caregiver depression (OR 1.55, 95% CI: 1.14 - 2.1). This relationship was mediated by caregiver report of both the symptom's impact on the patient and perceived burden to caregivers. |
| 26 2Parrotta et 28. (2020) 29 30 31 32 33 34 35 36 37 38 39 | Cross sectional design (cross- sectional analysis of data from a longitudinal study) | Finland, Sweden, Germany , Estonia, England, Spain, France, and the Nether- lands | 1223 | Primary diagnosis of dementia, 24 <smmse< td=""><td>82 (6-7)</td><td>62 (13) to 65 (13)</td><td>NA</td><td>Caregiver burden: ZBI Distress: NPI-Q Quality of life: EQ- VAS, GHQ-12</td><td>Depression (rated by caregiver): CSDD</td><td>A significant association was found between PWB depression and CG burden (β = 3.7, p = 0.001, CI: 1.55 - 5.8), distress (β = 1.2, p = 0.002, CI: 0.4 - 1.9, and overall well-being.</td></smmse<> | 82 (6-7) | 62 (13) to 65 (13) | NA | Caregiver burden: ZBI Distress: NPI-Q Quality of life: EQ- VAS, GHQ-12 | Depression (rated by caregiver): CSDD | A significant association was found between PWB depression and CG burden (β = 3.7, p = 0.001, CI: 1.55 - 5.8), distress (β = 1.2, p = 0.002, CI: 0.4 - 1.9, and overall well-being. |

| 1 Study 2 | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
|---|--|--------------------|--------------|---|-----------------------|--------------------------------|-----------------------|---|--|---|
| 4Perach et 5 ^a l. (2022) 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 | Longitudinal study | UK | 114 | Not specified | 80.83(8.3) | 66.5(13.9) | 8.2 months | Independent Variables Anxiety: One National Statistics ONS4 item Carer type Quality of relationship: Positive Affect Index Social contact: Lubben Social Network Scale Dependent Variables Loneliness in the Covid-19: 3-item version of UCLA loneliness scale | Independent Variables Cognitive impairment: CDR Anxiety: One National Statistics ONS4 item Quality of relationship: Positive Affect Index Social contact: Lubben Social Network Scale Dependent Variables Loneliness in the Covid-19: 3-item version of UCLA loneliness scale | In carers, higher levels of loneliness were directly associated with nonspouse coresident carer type, higher level and increase of anxiety in carer, more formal day activities, and higher cognitive impairment in the person with dementia. In people with dementia, higher levels of loneliness were directly associated with non-spouse coresident carer type, higher initial levels of social resources (formal day activities, quality of relationship with person with dementia), wellbeing (anxiety), cognitive impairment. This produced indirect effects on social contacts and loneliness. |
| 28 ippon et 28 (2020) 26 27 28 29 30 31 32 33 34 35 | Cross- sectional study (Secondary analysis of a cohort study) | UK | 1283 | Mild to moderate dementia, 15≤MMSE | 76.2(8.2) | 69.1 (11.1) | NA | Relationship quality: PAI Life satisfaction: Satisfaction with Life Scale Wellbeing: WHO-5 Depressive symptoms: 20-item CESD-R | Relationship quality: PAI Life satisfaction: Satisfaction with Life Scale Wellbeing: WHO-5 Depressive symptoms: GDS-10 | Self-rated relationship quality was associated with own life satisfaction and well-being for both people with dementia and caregivers. Partner-rated relationship quality did not influence own life satisfaction or well-being for either member of the dyad. |

| l | | | | | | | | | | |
|--|--|--------------------|--------------|---|--|--|-----------------------------|--|--|--|
| 1Study | Research design | Country /Region | No. of dyads | Stage of dementia | Average age of PWD | Average age of caregiver | Duration of follow up | Caregiver outcomes | PWD outcomes | Main findings (with data) |
| 4Wu et al. 5(2021) 6 7 8 9 10 11 12 13 14 | Cross-sectional study (Secondary analysis of a cohort study) | UK | 1547 | Mild to moderate dementia, 15≤MMSE | Not specified, Five age group: <65, 65–69, 70– 74, 75–79 and ≥80 | Not specified, Five age group: <65, 65–69, 70– 74, 75–79 and ≥80 | NA | Capability to live well: Life satisfaction (SwLS); Wellbeing (WHO-5); QoL (WHOQOL-BREF) Depressive symptoms: 20-item CES-D | Capability to live well: Life satisfaction (SwLS); Wellbeing (WHO-5); QoL (QoL-AD) Depressive symptoms: GDS-10 | Depressive symptoms in people with dementia had negative associations with capability to live well both for the individual (-7.46, 95% CI: -8.06, -6.89) and for the partner (-1.51, 95% CI: -2.05, -0.98). Depressive symptoms in carers had negative associations with capability to live well both for the individuals (-0.85, 95% CI: -1.32, -0.38) and for the partner (-7.50, 95% CI: -8.15, -6.85). |
| 126anetti et 1271. (1998) 18 19 20 21 22 23 24 25 26 27 28 | Cross sectional survey | Italy | 103 | Probable 'AD, MMSE: 11.3 (SD 8.3) | 75.7 (7.9) | 54.6 (13.2) | NA | Self-rated health: A single item 'How would you rate your overall physical health at the present time Depression: Beck Depression Inventory Scale | Cognitive status: MMSE, CDR Functional status: Katz index (ADL), Lawton and Brody scale (IADL) Behavioural disturbances: BMDS | With multivariate analysis only relationship to the patient (husband/wife, $b = -11.09$, 95% CI: $-15.806.83$, $p < 0.001$), caregiver's self-rated health ($b = 2.49$, 95% CI: $0.56 - 4.41$, $p = 0.010$) and competence ($b = -1.43$, 95% CI: $-2.000.86$, $p < 0.001$) were independent predictors of caregiver's depressive symptoms. The main risk factor of CG depression are CG factors, rather than patient factors. |

Note: YOD = Young-onset dementia, MMSE = Mini-Mental State Examination, QoL = quality of life, AD = Alzheimer's disease, DRS = Dyadic Relationship Scale, DMI = Decision making involvement, PWD = people with dementia, GHQ = General Health Questionnaire, HRSD = Hamilton Rating Scale for Depression, GDS = Geriatric Depression Scale, PBCL = Problem Behaviour Check List, RCT = randomized controlled trial, NPI-Q = Neuropsychiatric Inventory Questionnaire, PSMS = Physical Self-Maintenance Scale, IADL = Instrumental Activities of Daily Living, CSDD = Cornell Scale for Depression in Dementia, CG = caregiver, ECFR = elder-caregiver-family relationship, PES = Pleasant Events Scale, ZBI = Zarit Burden Interview, CBI = Copenhagen Burnout Inventory, ASS = Adversity and Stress Scale, TDQ = Taiwanese Depression Questionnaire, BAI = Beck Anxiety Inventory, DCI = Dyadic Coping Inventory, PSS = Perceived Stress Scale, DC = dyadic coping, PHQ-9 = Patient Health Questionnaire-9, CES-D = Center for Epidemiological Studies Depression, CANE = Camberwell Assessment of Need for the Elderly, CR = care recipient, RQ = Relationships Questionnaire, FAQ = Functional Activities Questionnaire, RSS = Relatives' Stress Scale, TSCS = Tenesee Self-Concept Scale, HADS = Hospital Anxiety and Depression Scale, RAID = Rating Anxiety In Dementia, CDR = Clinical Dementia Rating, BPSD = Behavioral and psychological symptoms of dementia, BSI = Brief Symptom Inventory, CUSPAD = Columbia University Scale for Psychopathology in Alzheimer's Disease, PAI = Positive Affect Index, SwLS = Satisfaction With Life Scale, BMDS = Behaviour and Mood Disturbance Scale

Table 2 Influencing factors of the depression of dementia caregiving dyads

| DV | CG factors | PWD factors | Dyadic factors |
|-------------------|--|--|--|
| PWD depression | CG depression (Martincin, 2018; Ornstein et al., 2012) | PWD QoL (Bruvik et al., 2012) | Strain in dyadic relationship (Miller et al., 2019) |
| | CG psychological morbidity (Brodaty & Luscombe, 1998) | PWD functional ability (Linton, 2020) | Self-rated relationship quality (Rippon et al., 2020) |
| | CG burden (Parrotta et al., 2020) | PWD capacity to live well (Wu et al., 2021) | Partner-rated relationship quality × (Burgener & Twigg, 2002; Rippon et al., 2020) |
| | CG distress (Parrotta et al., 2020) | PWD perceived dyadic relationship strain (Martincin, 2018) | Dyadic coping (Gellert et al., 2018)(L) |
| | CG capacity to live well (Wu et al., 2021) | Participation in past pleasant activities (Burgener & Twigg, 2002)(L) | |
| CG depression | CG having a hobby (Bruvik et al., 2012) | PWD depression (Martincin, 2018; Ornstein et al., 2012) | dyadic relationship (husband and wife) (Zanetti et al., 1998) |
| | CG competence (Zanetti et al., 1998) | PWD neuropsychiatric symptoms (Chen et al., 2023; Ornstein et al., 2012) | Dyadic coping (Gellert et al., 2018)×(L) |
| | CG burden (Chen et al., 2023; Linton, 2020; Ornstein et al., 2012) | PWD behavioral symptom (J. L. Campbell et al., 2011) | Affiliate stigma (Chen et al., 2023) |
| | Care related strain (Miller et al., 2019) | PWD capacity to live well (Wu et al., 2021) | Self-rated relationship quality (Rippon et al., 2020) |
| | CG self-rated health (Zanetti et al., 1998) | PWD quality of life (Bruvik et al., 2012)) | Partner-rated relationship quality × (Rippon et al., 2020) |
| | CG capacity to live well (Wu et al., 2021) | | PWD dyadic relationship strain× (Martincin, 2018) |
| | CG perceived dyadic relationship strain (Martincin, 2018) | | |
| | CG QoL (Bruvik et al., 2012; Orgeta, Orrell, Hounsome, et al., 2015) | DWD-name with domantic CC-caracive | |

Note: DV = dependent variable, L=longitudinal studies, PWD=people with dementia, CG=caregiver, ×=insignificant

Table 3 Influencing factors of quality of life of dementia caregiving dyads

| DV | CG factors | PWD factors | Dyadic factors |
|---------|--|--|--|
| PWD QoL | CG depression (Bruvik et al., 2012), | PWD depression (Bruvik et al., 2012) | Dyadic relationship strain/quality (L) (Burgener & Twigg, 2002; Miller et al., 2019) |
| | CG stress (Orgeta, Orrell, Hounsome, et al., 2015) | PWD stress (Häusler et al., 2016) | Incongruence on PWD's care values (Moon et al., 2017) |
| | CG type (non-spouse have lower QoL) (Bonds et al., 2021) | PWD unmet needs (Monin et al., 2020) | Dyadic coping×(Häusler et al., 2016; Moon et al., 2017) |
| | CG health (Orgeta, Orrell, Hounsome, et al., 2015) | PWD decision making involvement (Bonds et al., 2021) | Incongruent perceptions of PWD's involvement× (Moon et al., 2017) |
| | CG burden (Parrotta et al., 2020) | Neuropsychiatric symptom severity (Bruvik et al., 2012) | |
| | | Dementia severity (Orgeta, Orrell, Hounsome, et al., 2015) | |
| | | Self-rated health (Orgeta, Orrell, Hounsome, et al., 2015) | |
| | | Mood (Nelis et al., 2012) Self-concept (Nelis et al., 2012) | |
| CG QoL | CG depression (Bruvik et al., 2012; Orgeta, Orrell, Hounsome, et al., 2015) | PWD QoL (Bonds et al., 2021; Miller et al., 2019) | Dyadic relationship strain (Bonds et al., 2021; Miller et al., 2019) |
| | CG stress (Häusler et al., 2016; Nelis et al., 2012) | PWD unmet needs (Monin et al., 2020), | Dyadic relationship quality (Häusler et al., 2016) |
| | CG having a hobby (Bruvik et al., 2012) | PWD functional ability (Orgeta, Orrell, Hounsome, et al., 2015), | Dyadic coping (Häusler et al., 2016) |
| | | PWD younger age (Orgeta, Orrell, Hounsome, et al., 2015) | Incongruence on PWD's care values (Moon et al., 2017) |
| | | PWD depression (Parrotta et al., 2020), | Incongruent perceptions of PWD's involvement in decisions × (Moon et al., 2017) |

Note: DV = dependent variable, L=longitudinal studies, PWD=people with dementia, CG=caregiver, QoL=quality of life, ×=insignificant

Table 4 Influencing factors of anxiety of dementia caregiving dyads

| DV | CG factors | PWD factors | Dyadic factors |
|-------------|---|--|--------------------------------------|
| PWD anxiety | Caregiver mastery (Hwang & Hodgson, 2021) | Self-rated pain (Orgeta, Orrell, Edwards, et al., 2015) Attachment security (Nelis et al., 2012) | |
| CG anxiety | CG burden (Chen et al., 2023) | Neuropsychiatric symptoms (Chen et al., 2023) | Affiliate stigma (Chen et al., 2023) |

Note: DV = dependent variable, PWD=people with dementia, CG=caregiver



Supplementary File 1 Quality appraisal for the cross-sectional studies (n=19)

| Paper | Appraisal item CS1 | Appraisal item CS2 | Appraisal item CS3 | Appraisal item CS4 | Appraisal item CS5 | Appraisal item CS6 | Appraisal item CS7 | Appraisal item CS8 | Overall appraisal |
|---|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|----------------------|
| Bonds et al. (2021) | Yes | 8/8 |
| Bruvik et al. (2012) | Yes | 8/8 |
| Häusler et al. (2016) | Yes | Yes | Yes | Yes | No | No | Yes | Yes | 6/8 |
| Linton (2020) | Yes | Yes | Yes | Yes | No | No | Yes | Yes | 6/8 |
| McCurry et al. (2008) | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | 7/8 |
| Miller et al. (2019) | Yes | Yes | Yes | Yes | No | No | Yes | Yes | 6/8 |
| Monin et al. (2020) | Yes | 8/8 |
| Moon et al. (2017) | Yes | 8/8 |
| Nelis et al. (2012) | No | Yes | 7/8 |
| Orgeta, Orrell, Edwards, et al. (2015) | No | Yes | 7/8 |
| Rippon et al. (2020) | Yes | 8/8 |
| Wu et al. (2021) | Yes | 8/8 |
| Chen et al. (2023) | Yes | 8/8 |
| Hwang and Hodgson (2021) | Yes | 8/8 |
| Lorenzo-López et al. (2017) | Yes | 8/8 |

| Martincin (2018) | No | Yes | Yes | Yes | No | No | Yes | Yes | 5/8 |
|---|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| Orgeta, Orrell, Edwards, et al. (2015) | Yes | 8/8 |
| Parrotta et al. (2020) | Yes | 8/8 |
| Zanetti et al. (1998) | Yes | 8/8 |

Notes: Appraisal item CS1: clear criteria for sample inclusion; Appraisal item CS: detail study subject/setting; Appraisal item CS3: exposure measured in a valid and reliable way; Appraisal item CS4: patient included based on specified diagnosis or definition; Appraisal item CS5: identified confounding factors; Appraisal item CS7: outcomes measured in a valid and reliable way; Appraisal item CS8: appropriate statistical analysis

Supplementary File 2 Quality appraisal for longitudinal studies (n=5)

| Paper | Apprais al item C1 | Apprais al item C2 | Apprais al item C3 | Apprais al item C4 | Apprais al item C5 | Apprais al item C6 | Apprais al item C7 | Apprais al item C8 | Apprais al item C9 | Apprais al item C10 | Apprais al item C11 | Overall appraisa l |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---------------------------|---------------------------|--------------------------|
| Burgener and Twigg (2002) | N/A | Yes | Yes | Yes | Yes | N/A | Yes | Yes | Yes | N/A | Yes | 8/11 |
| Judy LM Campbell et al. (2011) | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | No | Yes | Yes | 9/11 |
| Gellert et al. (2018) | Yes | Yes | Yes | Yes | Yes | N/A | Yes | N/A | Yes | N/A | Yes | 8/11 |
| Ornstein et al. (2012) | N/A | N/A | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | 8/11 |
| Perach et al. (2022) | N/A | N/A | Yes | Yes | Yes | No | Yes | N/A | No | Yes | Yes | 7/11 |

Notes: Appraisal item C1: two groups similar, recruited from the same population; Appraisal item C2: detail study subject/setting; Appraisal item C3: clear method of exposure measurement; valid, reliablable; Appraisal item C4: identified confounding factors; Appraisal item C5: stated strategies to deal with confounding factors; Appraisal item C6: participants free of outcome from the beginning of the study; Appraisal item C7: outcomes measured in a valid and reliable way; Appraisal item C8: Sufficient follow-up time; Appraisal item C9: complete follow up: high drop-out rate with reason; Appraisal item C10: untilized strategies to address incomplete follow up; Appraisal item C11: appropriate statistical analysis

Supplementary File 3 Quality appraisal for qualitative studies (n=2)

| Paper | Appraisal item Q1 | Appraisal item Q2 | Appraisal item Q3 | Appraisal item Q4 | Appraisal item Q5 | Appraisal item Q6 | Appraisal item Q7 | Appraisal item Q8 | Appraisal item Q9 | Appraisal item Q10 | Overall appraisal |
|---------------------------------------|----------------------|-------------------|-------------------|----------------------|-------------------|----------------------|----------------------|----------------------|-------------------|-----------------------|----------------------|
| Bannon et al. (2022) Hickman | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | 9/10 |
| et al. (2020) | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | 9/10 |

Notes: Appraisal item Q1: Is there congruity between the stated philosophical perspective and the research methodology? Appraisal item Q2: Is there congruity between the research methodology and the research methodology and the methods used to collect data? Appraisal item Q4: Is there congruity between the research methodology and the representation and analysis of data? Appraisal item Q5: Is there congruity between the research methodology and the interpretation of results? Appraisal item Q6: Is there a statement locating the researcher culturally or theoretically? Appraisal item Q7: Is the influence of the researcher on the research, and vice-versa, addressed? Appraisal item Q8: Are participants, and their voices, adequately represented? Appraisal item Q9: Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? Appraisal item Q10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Supplementary File 4 Influencing factors of other dyadic psychosocial well-being outcomes

| DV | CG factors | PWD factors | Dyadic factors |
|--------------------------------|--|--|--|
| CG distress | | Neuropsychiatric symptoms (Lorenzo- López et al., 2017) | |
| | | PWD depression (Parrotta et al., 2020) | |
| CG stress | Distress at symptoms (Nelis et al., 2012) | MMSE score (Nelis et al., 2012) | |
| | CG QoL (Häusler et al., 2016; Nelis et al., 2012) | PWD QoL (Orgeta, Orrell, Hounsome, et al., 2015) | |
| | | Behavioral symptoms (J. L. Campbell et al., 2011) | |
| Dyadic psychological | Changing roles and responsibilities (Bannon et al., 2022) (QL) | The impact of diagnosis (Bannon et al., 2022) (QL) | Social and family relationships (Bannon et al., 2022) (QL) |
| stressor | | | Planning for an uncertain future (Bannon et al., 2022) (QL) |
| | | | Couple communication and relationship strain (Bannon et al., 2022) (QL) Shared experience of humor (Hickman et al., 2020) (QL) |
| PWD loneliness | Non-spouse coresident caregiver type (Perach et al., 2022) (L) | Cognitive impairment (Perach et al., 2022) (L) | Dyadic relationship quality (Perach et al., 2022) (L) |
| CG loneliness | CG anxiety (Perach et al., 2022) (L) | Higher cognitive impairment (Perach et al., 2022) (L) | |
| | Formal day activities (Perach et al., 2022) (L) Non-spouse coresident caregiver type | | |
| 7. 4 T —1 : L . 1'. | (Perach et al., 2022) (L) | antanida tamania CC | |

Notes: L=longitudinal study, QL=qualitative study, PWD=people with dementia, CG=caregiver