

RESEARCH PAPER

Impact of care–recipient relationship type on quality of life in caregivers of older adults with dementia over time

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Abstract

Background: Dementia caregiving is a dynamic and multidimensional process. To gain a comprehensive understanding of informal caregiving for people living with dementia (PLWD), it is pivotal to assess the quality of life (QoL) of informal caregivers.

Objective: To evaluate whether the care–recipient relationship type predicts changes in the QoL of informal caregivers of PLWD over a two-year period.

Methods: This was a secondary analysis of longitudinal data. The data were drawn from two waves of linked data from the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) (2015: NHATS R5 & NSOC II; 2017: NHATS R7 & NSOC III). Caregivers were categorized into spousal, adult–child, “other” caregiver and “multiple” caregivers. QoL was assessed through negative emotional burden (NEB), positive emotional benefits and social strain (SS). Generalized estimating equation modelling was used to examine changes in caregivers’ QoL outcomes across types of relationship over time.

Results: About, 882 caregivers were included who linked to 601 PLWD. After adjusting caregivers’ socio-demographics, “other” caregivers had lower risk of NEB and SS than spousal caregivers (OR = 0.34, $P = 0.003$, 95%CI [0.17, 0.70]; OR = 0.37, $P = 0.019$, 95%CI 0.16, 0.85], respectively), and PLWD’s dementia status would not change these significance (OR = 0.33, $P = 0.003$, 95%CI [0.16, 0.68]; OR = 0.31, $P = 0.005$, 95%CI [0.14, 0.71], respectively).

Conclusions: The study demonstrates that spousal caregivers face a higher risk of NEB and SS over time, underscoring the pressing need to offer accessible and effective support for informal caregivers of PLWD, especially those caring for their spouses.

Keywords: older adults; people living with dementia (PLWD); quality of life (QoL); informal caregivers; care–recipient relationship type; older people

Key Points

- First longitudinal study examining the impact of different relationships on the quality of life (QoL) for informal caregivers of people living with dementia (PLWD).
 - Tailor interventions for caregiver QoL improvement to address specific subgroups based on relationship type or risk level.
 - Spousal caregivers of PLWD require special attention in social and healthcare services due to their high demands.
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Introduction

Globally, the number of people living with dementia (PLWD) is rising steadily with nearly 9.9 million new cases each year. This figure translates into one every 3 s [1], increasing the demand on caregivers and the healthcare system. In the UK, approximately 700,000 informal caregivers of PLWD contributed an estimated 1.3 billion hours of informal assistance [2], valued at GBP 13.9 billion [3]. Extended caregiving may represent increased risk of caregiver burden [4] and cognitive impairment in PLWD adversely affects caregivers' well-being [5–8].

Despite the negative outcomes of caregiving, studies also show PLWD caregivers often experience positive outcomes from providing care, such as strengthened family relationships, lower depression and increased life satisfaction [9–13]. The Stress Process Model [14–16] suggests caregiving is a stressful experience, influenced by objective indicators, such as dementia severity, care duration and intensity, as well as subjective appraisals and caregiver characteristics. Caregiver outcomes are further impacted by secondary stressors like challenges of balancing employment and caregiving and are mediated by the availability of coping mechanisms and support resources. Therefore, dementia caregiving is a dynamic and multidimensional process [17]. To gain a comprehensive understanding of informal caregiving for PLWD, it is pivotal to assess the quality of life (QoL) of informal caregivers, enabling a subjective assessment of both its positive and negative aspects [18, 19].

The QoL of caregivers not only impacts their own well-being but also affects that of the PLWD [20]. Therefore, improving caregivers' QoL is a primary goal of the WHO's dementia strategy [21]. This area has been explored through both qualitative and quantitative studies, leading to the identification of key factors affecting QoL, such as relationship, characteristics of both caregiver and care-recipient, health, caregiving demands and social involvement, which have been synthesized in systematic reviews [22–27]. However, despite recognizing the importance of the caregiver-care recipient relationship type (hereafter referred to as the "relationship type") in quantitative studies, literature on this topic remains limited [22, 28]. Furthermore, much of the research has focused on spousal and adult-child caregivers [29] where the latter reportedly had significantly higher QoL than spousal caregivers [30]. It is important to note that caregiving dynamics are evolving due to changing societal trends, such as baby boomers' marital patterns and family structures compared to previous generations [31]. As a result, caregivers with other relations to care recipients and shared caregiving roles are expected to have a more significant caregiving role in the future. Furthermore, the challenges and needs of informal caregivers change as dementia progresses [32]. However, there is a dearth of longitudinal studies that investigate whether and how the type of relationship predicts caregivers' QoL over time.

When evaluating relationship type effects on caregivers' QoL, it is essential to also consider caregivers' characteristics. The impact of caregivers' socio-demographic

factors, such as age, gender, education, race, marital status and co-residence with a dependent child (<18 years), on QoL of PLWD caregivers is significant [33–35]. These factors affect both the positive and negative aspects of caregiving [36] and influence the relationship type's impact on QoL over time. Research [37] on informal caregivers for persons with Alzheimer's disease showed the combined influence of gender and relationship type on caregiving experience over time. A Canadian study further revealed that caregivers' well-being is shaped by the intersection of gender, relationship type and caregiving demands [38]. It noted differences in depressive symptoms and life satisfaction among spousal caregivers, sons and daughters, based on the intensity of their caregiving. Additionally, dementia characteristics, such as the illness progression and severity, have been identified as impact factors of caregivers' QoL [26, 39]. A systematic review found that caregiver burden, health-related characteristics of informal caregivers, dementia-related characteristics, socio-demographic and contextual factors were all significantly and negatively associated with the QoL of informal caregivers [40].

Therefore, this study aims to evaluate whether the care-recipient relationship type predicts changes in the QoL of informal caregivers of older adults with dementia over a two-year period. Specifically, the research questions are:

- 1) After adjusting for caregivers' socio-demographic factors, does the type of relationship or shared caregiving predict changes in caregivers of PLWD's QoL over a two-year period?
- 2) Does PLWD's dementia status impact the prediction of relationship type on caregivers' QoL change?

Methods

This was a secondary analysis of longitudinal data. The access and re-use of the data were approved by National Health and Aging Trends Study (NHATS) under NHATS Sensitive Data Use Agreements. The study's reporting adheres to the Strengthening the Reporting of Observational Studies in Epidemiology guidelines (STROBE) [41].

Data sources

The data were drawn from two waves of linked NHATS and the National Study of Caregiving (NSOC) (2015: NHATS R5 & NSOC II; 2017: NHATS R7 & NSOC III). NHATS is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by Johns Hopkins University. Together the NHATS and NSOC are the only national platform for studying caregiving from the perspective of older adults and their caregivers [42].

Sample selection

The care recipient sample in this study were R5 NHATS participants who live in the community and receive help with certain activities of daily living (ADL)—getting around

inside, getting out of bed, eating, bathing/showering/washing up, getting to or using the toilet, dressing– from their informal caregivers at the time of enrolment [42]. NHATS participants could identify up to five caregivers as helpers, but we only included the informal caregivers (i.e. family and unpaid caregivers) who were either (i) related to the older adults or (ii) unrelated to the older adult and not paid to help [43]. Sample selection criteria were the same for both waves. However, if the NHATS participants that caregivers cared for in R5 (2015) was marked as non-response in R6 (2016) or R7 (2017), no attempt was made to contact the caregiver for NSOC III.

Measures

Type of relationship

Informal caregivers are people who provide care to those who need it within the context of an existing relationship, such as a family member, a friend, or a neighbour [44]. If NHATS participants only indicated having a single caregiver, these caregivers were categorized into three groups: (i) care from a spouse/partner, (ii) care from an adult child, (iii) care from an informal caregiver other than a spouse/partner and adult child, such as child-in-law, sibling and friend. (referred to from here on as “other” caregiver). (iv) If NHATS participants indicated having multiple caregivers, each caregiver was included separately with a designation of “multiple” caregivers, as opposed to a single caregiver.

QoL outcomes

Caregivers can have either negative or positive caregiving experiences [27, 45]. Negative outcomes result when caregivers experience emotional difficulty, depression, anxiety, strained relationships with care recipients and demands interfering with social participation. On the other hand, positive outcomes stem from feelings of self-fulfilment, appreciation, satisfaction with care recipients and the development of self-competencies [46, 47]. Consequently, caregivers’ QoL should encompass both positive and negative aspects. Therefore, caregivers’ QoL was assessed through three outcomes: negative aspects, including negative emotional burden (NEB) and social strain (SS), and positive aspects, that is, positive emotional benefit (PEB). These outcomes were measured using items from the NSOC questionnaire (see Appendix I), as described in our previous study [33]. The measures have been confirmed through exploratory factor analysis with high eigenvalues and variability (NEB, PEB, SS are 5.45 & 28.71%, 2.68 & 14.13%; 1.38 & 7.27%, respectively) and their application in the literature [33, 48–51].

Dementia status was classified into probable dementia, possible dementia and no dementia, as generated from the NHATS R5. The measurement process was detailed in our prior study [51].

The following caregiver socio-demographic variables were used in analyses: age range (<45 year, 45–54 year,

55–64 year, ≥65 year), gender, race/ethnicity, annual income, education, marital status and whether having a dependent child (<18 years). Socio-demographic variables contribute significantly to shaping caregivers’ outcomes [16, 46]. Research has shown that the relationships between caregiving intensity and QoL vary substantially based on factors like race/ethnicity, gender, age and income [49, 52]. Living arrangements, such as whether a caregiver lives with a child or not, have also been reported to impact QoL [47, 50]. These variables have been identified as influential factors in caregivers’ QoL and applied in previous studies [22, 33].

Statistical analysis

Categorical variables, including the type of relationship, dementia status, socio-demographic characteristics, and QoL subscales (PEB, NEB, SS), were described using counts and percentages. Changes in “high” vs. “low” of QoL subscales over a 2-year period (2015–2017) were described using descriptive statistics. The association between baseline QoL subscale burden level and type of relationship was examined using Chi-square tests. Generalized estimating equations (GEE) was employed to investigate potential differences in QoL changes across four groups over two years. The application of GEE enhances the robustness of our analysis by accommodating the longitudinal structure of the data, providing insights into group-specific variations in QoL trajectories over time. Three models were built with sequential adjustment for covariates: Model 1 was unadjusted; Model 2 adjusted for caregivers’ socio-demographics and Model 3 additionally controlled for care recipients’ dementia status.

To assess the robustness of our results, we compared baseline QoL and socio-demographics between missing and initially included data. All analyses were conducted using Stata 16.0, with a two-tailed significance test set at an alpha level of 0.05.

Results

In 2015 NSOCII, 1,871 caregivers were included to the study, linked to 1,230 older adults in NHATS R5. By 2017, 882 caregivers remained eligible for the analysis, linked to 601 older adults in NHATS R7 (see Appendix II). Most caregivers were female ($n=593$, 67.54%), white ($n=477$, 55.85%), had no dependent child co-residency ($n=734$, 84.95%), married or living with a partner ($n=515$, 58.66%), had an education above high school ($n=291$, 36.42%), and were aged above 65 years ($n=365$, 42.05%). Among them, 497 were single caregivers and were divided into three groups: spousal caregivers ($n=201$, 40.4%), adult–child caregivers ($n=230$, 46.3%) and “other” caregivers ($n=66$, 13.3%). Four hundred ninety-nine were multiple caregivers assisting for 218 older adults (see Table 1). Table 2 presents the demographic information of the older adults, including their age, gender, race and dementia status. Compared to those with complete data,

Table 1. Caregivers’ socio-demographics 2015 baseline

| Variables, count (percentage) | Care–recipient relationship types | | | | |
|-------------------------------|-----------------------------------|----------------------------------|--------------------------------------|--------------------------------|------------------------------------|
| | Total (<i>n</i> = 882) | Spousal caregiver 173 (19.61) | Adult–child caregiver 166 (18.82) | “Other” caregiver 44 (4.99) | Multiple caregivers 499 (56.58) |
| <hr/> | | | | | |
| Sex | | | | | |
| Male | 285 (32.46) | 76 (43.93) | 45 (27.11) | 7 (16.28) | 157 (31.65) |
| Female | 593 (67.54) | 97 (56.07) | 121 (72.89) | 36 (83.72) | 339 (68.35) |
| Age | | | | | |
| < 45 yrs | 89 (10.25) | 1 (0.58) | 12 (7.36) | 7 (15.91) | 69 (14.11) |
| 45 to 54 yrs | 169 (19.47) | 2 (1.16) | 54 (33.13) | 9 (20.45) | 104 (21.27) |
| 55 to 64 yrs | 245 (28.23) | 12 (6.98) | 62 (38.04) | 10 (22.73) | 161 (32.92) |
| 65 + yrs | 365 (42.05) | 157 (91.28) | 35 (21.47) | 18 (40.91) | 155 (31.70) |
| Mean (SD) | 61.62 (14.36) | 75.72 (8.12) | 57.32 (8.61) | 58.77 (17.28) | 58.36 (14.30) |
| Race/ethnicity | | | | | |
| Non-Hispanic White | 477 (55.85) | 122 (73.05) | 79 (48.77) | 18 (40.91) | 258 (53.64) |
| Non-Hispanic Black | 296 (34.66) | 32 (19.16) | 63 (38.89) | 19 (43.18) | 182 (37.84) |
| Hispanic | 28 (3.28) | 5 (2.99) | 8 (4.94) | 3 (6.82) | 12 (2.49) |
| Other | 53 (6.21) | 8 (4.79) | 12 (7.41) | 4 (9.09) | 29 (6.03) |
| Annual income | | | | | |
| <1st quartile | 234 (26.53) | 18 (10.40) | 60 (36.14) | 16 (36.36) | 140 (28.06) |
| 1st–2nd quartiles | 228 (25.85) | 64 (36.99) | 36 (21.69) | 11 (25.00) | 117 (23.45) |
| 2nd–3rd quartiles | 231 (26.19) | 46 (26.59) | 33 (19.88) | 8 (18.18) | 144 (28.86) |
| >3rd quartile | 189 (21.43) | 45 (26.01) | 37 (22.29) | 9 (20.45) | 98 (19.64) |
| Education | | | | | |
| Below high school | 113 (14.14) | 36 (21.05) | 18 (11.04) | 5 (11.36) | 54 (12.83) |
| High school | 203 (25.41) | 47 (27.49) | 37 (22.70) | 17 (38.64) | 102 (24.23) |
| Above high school | 291 (36.42) | 50 (29.24) | 61 (37.42) | 17 (38.64) | 163 (38.72) |
| Bachelor and above | 192 (24.03) | 38 (22.22) | 47 (28.83) | 5 (11.36) | 102 (24.23) |
| Marital status | | | | | |
| Married/living with a partner | 515 (58.66) | 173 (100) | 69 (42.07) | 10 (22.73) | 263 (52.92) |
| Unmarried | 363 (41.34) | N/A | 95 (57.93) | 34 (77.27) | 234 (47.08) |
| Living with a child <18 yrs | | | | | |
| No | 734 (84.95) | 170 (98.27) | 134 (81.71) | 39 (88.64) | 391 (80.95) |
| Yes | 130 (15.05) | 3 (1.73) | 30 (18.29) | 5 (11.36) | 92 (19.05) |

yrs: years

caregivers with missing data tend to be younger, while care recipients are older. Additionally, they are more likely to be unmarried (including single, widowed, divorced), and a greater number of care recipients are probable or possible dementia cases. Appendix II provides details regarding the reasons and differences for care recipients and caregivers missing in NSOC III (2017) compared to NSOC II (2015).

As shown in Table 3, overall the odds of being high burden for each QoL subscale (PEB, NEB and SS) was higher in 2017 compared to 2015 (OR = 63.62, *P* < 0.001, 95% CI [46.76, 86.55]; OR = 48.69, *P* < 0.001, 95% CI [36.50, 64.94]; OR = 51.44, *P* < 0.001, 95% CI [38.58, 68.58], respectively). Baseline SS significantly differed among four groups (Chi2 [3] = 15.703, *P* = 0.001), with adult–child caregivers experiencing higher SS (Table 3). GEE revealed the same pattern in assessing QoL over time for the four groups. Adult–child caregivers exhibited a significantly higher risk of SS than spousal caregivers in the unadjusted model, but this was not statistically significant after adjusting for caregivers’ socio-demographics and PLWD’s dementia status (Table 4).

“Other” caregivers demonstrated a lower risk of experiencing NEB and SS than spousal caregivers (OR = 0.34, *P* = 0.003, 95% CI [0.17, 0.70]; OR = 0.37, *P* = 0.019,

95%CI [0.16, 0.85]; in the adjusted model, respectively) (Table 4). This significant difference between “other” and spousal caregivers remained after additional adjustment for care recipients’ dementia status (OR = 0.33, *P* = 0.003, 95%CI [0.16, 0.68]; OR = 0.33, *P* = 0.005, 95%CI [0.14, 0.71], respectively).

Discussion

This study is the first longitudinal investigation assessing how different types of relationship and sharing caregiving approaches impact QoL outcomes across multiple aspects for informal caregivers of PLWD. Our results indicate that, in comparison with “other” caregivers, spousal caregivers showed a greater tendency for increased NEB and SS over time.

Type of relationship, which was referred to as “Kinship” in a recent systematic review, is reported as one of the important risk factors for the trajectory of caregiver burden for PLWD; being a spouse increases the risk of experiencing caregiver burden over time [53]. Our study demonstrates that spousal caregivers are more prone to experiencing NEB, which aligns with this review and our prior cross-sectional analysis [33]

Table 2. Care recipients’ socio-demographics 2015 baseline

| Variables, count (percentage) | Total (n = 601) | By spouse/partner 173 (28.79) | By adult child 166 (27.62) | By “other” 44 (7.32) | By multiple caregivers 218 (36.27) |
|-------------------------------|--------------------|----------------------------------|-------------------------------|-------------------------|---------------------------------------|
| Sex | | | | | |
| Male | 207 (34.44) | 100 (57.80) | 20 (12.05) | 15 (34.09) | 72 (33.03) |
| Female | 394 (65.56) | 73 (42.20) | 146 (87.95) | 29 (65.91) | 146 (66.97) |
| Age | | | | | |
| 65–69 yrs | 51 (8.49) | 32 (18.50) | 8 (4.82) | 2 (4.55) | 9 (4.13) |
| 70–74 yrs | 101 (16.81) | 34 (19.65) | 18 (10.84) | 14 (31.82) | 35 (16.06) |
| 75–79 yrs | 121 (20.13) | 49 (28.32) | 28 (16.87) | 5 (11.36) | 39 (17.89) |
| 80–84 yrs | 129 (21.46) | 37 (21.39) | 34 (20.48) | 10 (22.73) | 48 (22.02) |
| 85–89 yrs | 112 (18.64) | 17 (9.83) | 38 (22.89) | 10 (22.73) | 47 (21.56) |
| 90+ yrs | 87 (14.48) | 4 (2.31) | 40 (24.10) | 3 (6.82) | 40 (18.35) |
| Race/ethnicity | | | | | |
| Non-Hispanic White | 360 (60.40) | 138 (80.23) | 82 (49.70) | 19 (45.24) | 121 (55.76) |
| Non-Hispanic Black | 192 (32.21) | 28 (16.28) | 66 (40.00) | 20 (47.62) | 78 (35.94) |
| Hispanic | 29 (4.87) | 4 (2.33) | 10 (6.06) | 2 (4.76) | 13 (5.99) |
| Other | 15 (2.52) | 2 (1.16) | 7 (4.24) | 1 (2.38) | 5 (2.30) |
| Dementia status | | | | | |
| Probable dementia | 150 (25.00) | 30 (17.34) | 50 (30.12) | 12 (27.27) | 58 (26.73) |
| Possible dementia | 78 (13.00) | 16 (9.25) | 25 (15.06) | 6 (13.64) | 31 (14.29) |
| No dementia | 372 (62.00) | 127 (73.41) | 91 (54.82) | 26 (56.09) | 128 (58.99) |

Table 3. Caregivers’ QoL outcomes

| | | Care–recipient relationship types | | | |
|-----|----------|--|-----------------------|-----------------|---------------------|
| | | Spousal caregiver | Adult–child caregiver | Other caregiver | Multiple caregivers |
| PEB | NSOC II | | | | |
| | Low | 115 (72.33) | 99 (62.66) | 35 (81.40) | 345 (71.88) |
| | High | 44 (27.67) | 59 (37.34) | 8 (18.60) | 135 (28.13) |
| | | Pearson chi ² [3] = 7.832 P = 0.050 | | | |
| NEB | NSOC III | | | | |
| | Low | 120 (73.62) | 107 (69.93) | 32 (82.05) | 337 (75.56) |
| | High | 43 (26.38) | 46 (30.07) | 7 (17.95) | 109 (24.44) |
| | | Pearson chi ² [3] = 7.1707 P = 0.067 | | | |
| SS | NSOC II | | | | |
| | Low | 105 (64.81) | 107 (67.72) | 33 (76.74) | 357 (74.38) |
| | High | 57 (35.19) | 51 (32.28) | 10 (23.26) | 123 (25.63) |
| | | Pearson chi ² (3) = 15.703, P = 0.001 | | | |
| | NSOC III | | | | |
| | Low | 121 (74.69) | 105 (68.18) | 33 (86.84) | 346 (75.88) |
| | High | 41 (25.31) | 49 (31.82) | 5 (13.16) | 110 (24.12) |
| | | Pearson chi ² (3) = 15.703, P = 0.001 | | | |

Notes: Positive emotional benefit was assessed through 14 questions related to positive feelings about caregiving, life satisfaction, personal growth and well-being. Scores ranged from 0 to 38, with higher scores indicating fewer positive emotion benefits. NEB was measured through 12 questions concerning negative caregiving experience, mental health and loneliness, with scores ranging from 0 to 34. A higher score indicates a greater NEB. SS was measured using six questions related to participation, assessing whether they participated in activities, and whether caregiving responsibilities hindered their participation. Scores ranged from 0 to 6, with a higher score indicating higher social strain. Each outcome were coded as “high burden” for the top quartile and “low burden” for the remainder. These outcomes have been previously substantiated through exploratory factor analysis and applied in previous caregiver-related studies. [3, 27, 42, 43].

where spousal caregivers had higher odds of experiencing NEB than other caregivers. One of the primary contributing factors is cohabitation [53–55]. In our study, it is notable that all spousal caregivers lived with the care recipients, while

other caregivers usually lived elsewhere. Additionally, spouses tend to be of an older age themselves, a factor consistently associated with an increased burden compared to younger caregivers, as evidenced by previous research [53, 54, 56, 57].

Table 4. Prediction of care-recipient relationship type on QoL changes over 2 years (2015–2017) (*n* = 882)

| | Model 1 | | | | Model 2 | | | | Model 3 | | | | | | |
|--|-------------|-------------|--------------|-------------|-------------|-------------|-------------|--------------|-------------|-------------|-------------|-------------|--------------|-------------|-------------|
| | OR | SE | <i>P</i> | 95% CI | OR | SE | <i>P</i> | 95% CI | OR | SE | <i>P</i> | 95% CI | | | |
| PEB | | | | | | | | | | | | | | | |
| 2015 vs. 2017: OR = 63.62, <i>P</i> < 0.001, 95% CI [46.76, 86.55] | | | | | | | | | | | | | | | |
| Adult-child caregivers | 1.07 | 0.28 | 0.783 | 0.65 | 1.79 | 1.15 | 0.37 | 0.662 | 0.61 | 2.17 | 1.07 | 0.35 | 0.844 | 0.56 | 2.02 |
| “Other” caregivers | 0.78 | 0.32 | 0.541 | 0.35 | 1.72 | 0.78 | 0.35 | 0.582 | 0.33 | 1.87 | 0.73 | 0.32 | 0.474 | 0.30 | 1.74 |
| Multiple caregivers | 1.00 | 0.24 | 0.984 | 0.63 | 1.61 | 0.95 | 0.29 | 0.867 | 0.52 | 1.74 | 0.89 | 0.28 | 0.706 | 0.48 | 1.64 |
| NEB | | | | | | | | | | | | | | | |
| 2015 vs. 2017: OR = 48.69, <i>P</i> < 0.001, 95% CI [36.50, 64.94] | | | | | | | | | | | | | | | |
| Adult-child caregivers | 1.52 | 0.38 | 0.095 | 0.93 | 2.50 | 1.33 | 0.39 | 0.342 | 0.74 | 2.37 | 1.28 | 0.38 | 0.419 | 0.71 | 2.30 |
| “Other” caregivers | 0.59 | 0.20 | 0.119 | 0.30 | 1.15 | 0.34 | 0.12 | 0.003 | 0.17 | 0.70 | 0.33 | 0.12 | 0.003 | 0.16 | 0.68 |
| Multiple caregivers | 1.14 | 0.25 | 0.545 | 0.74 | 1.75 | 0.87 | 0.24 | 0.596 | 0.51 | 1.48 | 0.84 | 0.24 | 0.530 | 0.48 | 1.45 |
| SS | | | | | | | | | | | | | | | |
| 2015 vs. 2017: OR = 51.44, <i>P</i> < 0.001, 95% CI [38.58, 68.58] | | | | | | | | | | | | | | | |
| Adult-child caregivers | 1.92 | 0.47 | 0.008 | 1.19 | 3.11 | 1.12 | 0.36 | 0.718 | 0.60 | 2.12 | 0.97 | 0.32 | 0.916 | 0.51 | 1.84 |
| “Other” caregivers | 0.58 | 0.23 | 0.164 | 0.27 | 1.25 | 0.37 | 0.16 | 0.019 | 0.16 | 0.85 | 0.31 | 0.13 | 0.005 | 0.14 | 0.71 |
| Multiple caregivers | 1.24 | 0.25 | 0.289 | 0.83 | 1.85 | 0.78 | 0.23 | 0.404 | 0.43 | 1.40 | 0.67 | 0.20 | 0.188 | 0.37 | 1.21 |

Note: Three generalized estimating equation (GEE) models with a logit link function for each QoL outcomes and with spouse/partner caregivers as a reference group. Model 1 without adjustment for socio-demographics. Model 2 were adjusted for caregivers’ socio-demographic characteristics including age, gender, race, income, education, marital status and living with a dependent child (<18 years). Model 3 additionally controlled for care-recipients’ dementia status. OR: odds ratio; SE: standard error; 95% CI: 95% confidence intervals. Bold values denote statistical significance at the *p* < 0.05 level.

Our findings provide evidence that type of relationship predicts SS over time, with spousal caregivers being more likely to experience SS. This aligns with our previous study that “other” caregivers had lower odds of experiencing SS than spousal caregivers [33]. This may be associated with the sense of “role captivity,” a situation where a caregiver feels trapped or constrained in their caregiving role, which was often due to the demands of caring for a person with a challenging diagnosis such as dementia [58]. “Role captivity” was reported as one of the strongest predictors of negative caregiving experience according to the caregiver stress model [59, 60]. Spousal caregivers often experience a greater obligation to their caregiving role, leading to sacrifices like giving up leisure activities, reducing social time and limiting employment opportunities [61, 62]. As a result, they may find themselves feeling “trapped” in their caregiving role. Additionally, previous research has shown that caregiving motivations, particularly when it is a choice, can impact caregiver wellbeing. Lower QoL has been associated with caregivers who perceived inadequate alternative care options [63]. Our findings imply the high need for social support to spousal caregivers for better SS self-management.

Although adult-child caregivers showed a significantly higher risk of SS over time than spousal caregivers in unadjusted model, this difference diminished after adjusting for their socio-demographics and their care-recipients’ dementia status (Table 4). This finding is consistent with our previous cross-sectional study [33]. Existing literature has consistently reported that many factors, such as caregivers’ race, age and care recipients’ cognitive functions impact the dementia caregiving experience [64, 65]. Considering the notable differences in race, age and education level between spousal and

adult-child caregivers, along with the variations in dementia status of care recipients in these two groups, our findings show that the impact of relationship type on caregivers’ QoL trajectories can be influenced by caregivers’ socio-demographics and care recipients’ dementia status.

Research has indicated that the positive aspects of caregiving can be influenced by the caregiver’s relationship to the care-recipient [66, 67]. Our previous cross-sectional study also reported that “other” caregivers had a significantly higher PEB compared to spousal caregivers [33]. However, the current findings does not provide sufficient evidence to support the idea that the PEB for caregivers of PLWD differs based on the type of relationship. This paper uses a stress model [16] and focuses on questions that address caregivers’ current experiences. However, the concept of positive aspects of caregiving is multidimensional and can also encompass self-efficacy, satisfaction and competence [68]. The diversity in conceptual and operational terms makes it challenging to compare outcomes across studies. Future studies could consider to use more standardized measurements to explore this theme comprehensively.

Our hypothesis that shared caregiving would predict the QoL of caregivers of PLWD over time was not supported. The impact of PLWD’s dementia status caregivers’ QoL, observed in our previous cross-sectional analysis [33], was not confirmed in this study. This could be attributed to a relatively short follow-up period (only two years) and a limited number of observed time points (only two, in 2015 and 2017). Additionally, the heterogeneous nature of the structure of multiple caregivers, comprising spouse, adult child and other types, may have contributed to the lack of significant findings on shared caregiving. Future studies could benefit from larger sample size, longer study durations

and more frequent observations at various time points to provide a more comprehensive understanding of the impact of shared caregiving on caregivers' QoL.

Limitations and strength

Due to the secondary data analysis, the original data were not collected to address our specific research questions. While the QoL measures in our study were confirmed and applied in previous caregiver-related studies, they may not fully cover all QoL issues that arise from informal caregiving duties. Future studies should explore other aspects of QoL (e.g. material well-being [69], health status [70] and use validated measures (e.g. Carer well-being and support questionnaire [71]) to substantiate the study findings. Furthermore, care recipients' multi-morbidity was not captured in this study, potentially affecting the study's generalizability to the source population. Future research should explore additional factors for validation and generalization. Another limitation is that we only included baseline dementia status in the analysis, which was reported as the best predictor of cognitive change in older adults [72]. However, changes in dementia status over time could have potentially impacted the findings. Furthermore, some attrition in our longitudinal analysis may have been selective, and we included only care recipients with consistent caregivers, resulting in the exclusion of 21% of the recipients in 2017. Care recipients excluded were older and had a greater number of probable or possible dementia. However, sensitivity analysis revealed no significant differences in caregivers' QoL between complete and missing data.

Despite the acknowledged limitations, our study analysed two companion national datasets (NHATS and NSOC) to investigate the longitudinal impact of type of relationship and shared caregiving approaches on caregivers of PLWD. The study took into account caregivers' socio-demographic and care recipients' dementia status. The utilization of a GEE approach enhances the robustness of our findings. However, further research, particularly through long-term prospective studies, is needed to build on this study's results, address caregivers' evolving challenges and guide targeted support strategies.

Conclusion

In conclusion, the study demonstrates that spousal caregivers face a higher risk of NEB and SS over time. This highlights the pressing need for accessible and effective support for informal caregivers of PLWD, especially those caring for their spouses, in public policy, research and practical interventions.

Acknowledgements The authors gratefully acknowledge the National Health & Aging Trends Study for granting access to these data.

Declaration of Conflicts of Interest: None.

Declaration of Sources of Funding: None.

References

1. WHO. *Global Action Plan on the Public Health Response to Dementia 2017–2025*. Geneva, Switzerland: WHO Document Production Services; 2017. http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/ (20 January 2024, date last accessed).
2. Alzheimer's Society. Carers UK's 'State of Caring 2021' Report – Alzheimer's Society Responds in 2021. <https://www.alzheimers.org.uk/news/2021-11-03/carers-uks-state-caring-2021-report-alzheimers-society-responds> (9 January 2024, date last accessed).
3. Herron D, Runacres J. The support priorities of older carers of people living with dementia: a nominal group technique study. *Healthc* 2023;**11**:1–13.
4. Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JHC, Francke AL. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Open Nurs J* 2013;**7**:6–13.
5. Karg N, Graessel E, Randzio O, Pendergrass A. Dementia as a predictor of care-related 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* 2018;**18**:1–9.
6. Grau H, Graessel E, Berth H. The subjective burden of informal caregivers of persons with dementia: extended validation of the German language version of the burden scale for family caregivers (BSFC). *Aging Ment Health* 2015;**19**:159–68.
7. Germain S, Adam S, Olivier C *et al*. Does cognitive impairment influence burden in caregivers of patients with Alzheimer's disease? *J Alzheimers Dis* 2009;**17**: 105–14.
8. Van Bruggen S, Gussekloo J, Bode C, Touwen DP, Engberts DP, Blom JW. Problems experienced by informal caregivers with older care recipients with and without cognitive impairment. *Home Health Care Serv Q* 2016;**35**:11–24.
9. Lorenz-Dant K, Mittelman M. Sex and gender differences in caregiving patterns and caregivers' needs what are the patterns of care?. In *Book: Sex and Gender Differences in Alzheimer's Disease*. Published online. 2021, pp. 393–419. <https://doi.org/10.1016/B978-0-12-819344-0.00015-6>.
10. Hazzan AA, Dauenhauer J, Follansbee P, Hazzan JO, Allen K, Omobepade I. Family caregiver quality of life and the care provided to older people living with dementia: qualitative analyses of caregiver interviews. *BMC Geriatr* 2022;**22**: 1–11.
11. Wolff JL, Spillman B. Older adults receiving assistance with physician visits and prescribed medications and their family caregivers: prevalence, characteristics, and hours of care. *Journals Gerontol Ser B* 2014;**69**:S65–72.
12. Campbell LD. Sons who care: examining the experience and meaning of filial caregiving for married and never-married sons. *Can J Aging / La Rev Can du Vieil* 2010;**29**: 73–84.
13. Day JR, Anderson RA, Davis LL. Compassion fatigue in adult daughter caregivers of a parent with dementia. *Issues Ment Health Nurs* 2014; **35**:796–804.
14. Zarit SH. Caregiving revisited: old and new perspectives on families assisting elders. *J Chem Inf Model* 2019; **53**:1689–99.

15. Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ. *Profiles in Caregiving: The Unexpected Career*. California, US: Academic Press; 1995.
16. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the Stress Process: An Overview of Concepts and Their Measures Published online on 01 October 1990. *The Gerontologist* **30**:583–594. <https://doi.org/10.1093/geront/30.5.583>.
17. Gonçalves-Pereira M, Zarit SH, Papoila AL, Mateos R. Positive and negative experiences of caregiving in dementia: the role of sense of coherence. *Int J Geriatr Psychiatry* 2020; **36**:360–7.
18. Kieninger J, Trukeschitz B, Wosko P, Pleschberger S. Mapping the Domains and Influencing Factors of Quality of Life in Informal Carers of Community-Dwelling Older Adults. Discussion Paper 1/2019 of the WU Research Institute for Economics of Aging, WU Vienna University of Economics and Business. https://goeg.at/OPLA_Projekt (16 August 2020, date last accessed).
19. Ratcliffe J, Lester LH, Couzner L, Crotty M. An assessment of the relationship between informal caring and quality of life in older community-dwelling adults – more positives than negatives? *Health Soc Care Community* 2013; **21**:35–46.
20. Nasrun MWS, Kusumaningrum P, Redayani P et al. Relationship between quality of life of people with dementia and their caregivers in Indonesia article. *J Alzheimers Dis* 2021; **81**:1311–20.
21. *A Blueprint for Dementia Research*. Licence: CC BY-NC-SA 3.0 IGO. Geneva: World Health Organization, 2022.
22. Farina N, Page TE, Daley S et al. Factors associated with the quality of life of family carers of people with dementia: a systematic review. *Alzheimer's Dement Published online* 2017; **13**:572–81.
23. Asfia M, Binti SK. Understanding the quality of life impacts of providing informal care to people with dementia: a systematic review of qualitative studies. *J Alzheimers Dis* 2022; **88**: 1293–309.
24. Contreras ML, Mioshi E, Kishita N. Factors related to the quality of life in family carers of people with dementia: a meta-analysis. *J Geriatr Psychiatry Neurol* 2021; **34**:482–500.
25. Vellone E, Piras G, Talucci C, Cohen MZ. Quality of life for caregivers of people with Alzheimer's disease. *J Adv Nurs* 2008; **61**:222–31.
26. Frias CE, Cabrera E, Zabalegui A. Informal caregivers' roles in dementia : the impact on their quality of life. *Life* 2020; **10**:251.
27. Daley S, Murray J, Page TE, Knapp M. Understanding the quality of life of family carers of people with dementia: development of a new conceptual framework. *Int J Geriatr Psychiatry* 2019; **34**: 79–86.
28. Cross AJ, Garip G, Sheffield D. The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychol Health* 2018; **33**:1321–42.
29. Schulz R, Eden J. *Families Caring for an Aging America*. Washington (DC): National Academies Press (US); 2016 Nov 8. ISBN-13: 978-0-309-44806-2 ISBN-10: 0-309-44806-9. <https://dx.doi.org/10.17226/23606>.
30. Morrison B, Phillips BN, Huck GE. The impact of risk and resistance factors on quality of life in caregivers of individuals with dementia. *Clinical gerontologist* 2020; **43**: 585–97.
31. Spillman BC, Favreault M, Allen UI EH. *Family Structures and Support Strategies in the Older*. Population: Implications for Baby Boomers, 2020.
32. Wolff JL, Mulcahy J, Huang J, Roth DL, Covinsky K, Kasper JD. Family caregivers of older adults, 1999-2015: trends in characteristics, circumstances, and role-related appraisal. *Gerontol cite as Gerontol* 2018; **58**:1021–32.
33. Lai A, Richardson J, Griffith L, Kuspinar A, Smith-Turchyn J. The impact of care-recipient relationship type on health-related quality of life in community-dwelling older adults with dementia and their informal caregivers. *Qual Life Res* 2022; **31**:3377–90.
34. Lorenz KH. The well-being and quality of life of men and women of different ages providing care for a relative with dementia. PhD diss., Published 1 September 2018. UK: The London School of Economics and Political Science.
35. Cristina, De Oliveira D, Aubeeluck A. Ageing and quality of life in family carers of people with dementia being cared for at home: a literature review. *Quality in Primary Care* 2015; **23**:18–30.
36. Skolarus LE, Freedman VA, Feng C, Burke JF. African American stroke survivors. *Circ Cardiovasc Qual Outcomes* 2017; **10**:1–6.
37. Kokorelias KM, Naglie G, Gignac MAM, Rittenberg N, Cameron JI. A qualitative exploration of how gender and relationship shape family caregivers' experiences across the Alzheimer's disease trajectory. *Dementia* 2021; **20**:2851–66.
38. Chappell NL. Care-giver wellbeing: exploring gender, demands in the Canadian longitudinal study on aging. *Ageing Soc* Published online 2021; **43**:1–37.
39. Contreras M, Eneida Mioshi NK. Factors predicting quality of life in family carers of people with dementia: the role of psychological inflexibility Milena Contreras. *J Context Behav Sci* 2021; **22**:7–12.
40. Sophie Alltag IC& SGR-H. Caregiver burden among older informal caregivers of patients with dementia and its influence on quality of life. *Z Gerontol Geriatr* 2019; **52**:477–86.
41. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PCVJSI, Vandenbroucke JP. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *J Clin Epidemiol* 2008; **61**: 344–9.
42. Freedman VA, Schrack JA, Skehan ME, Kasper JD. National Health and aging trends study User guide: rounds 1-11 final release Published online. 2022. www.NHATS.org (12 March 2023, date last accessed).
43. Freedman et al. National study of caregiving (NSOC) I-III USER guide. *Balt Johns Hopkins Bloom Sch Public Heal* 2019. <https://www.nhats.org/> (20 January 2024, date last accessed).
44. (AIHW) AI of H and W. Informal carers. Published in 2023. <https://www.aihw.gov.au/reports/australias-welfare/informal-carers> (10 January 2024, date last accessed).
45. Lawton MP, Moss M, Kleban MH, Glicksman A, Rovine M. A two-factor model of caregiving appraisal and psychological well-being. *J Gerontol* 1991; **46**:P181–9.
46. Pristavec T. The burden and benefits of caregiving : a latent class analysis. *Gerontologist* 2019; **59**:1078–91.
47. Verbakel E, Metzels SF, Kempen GJIM. Caregiving to older adults: determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *The Journals of Gerontology: Series B, The Gerontological Society of America* 2018; **73**:1099–111.

48. Cohen SA, Cook S, Kelley L, Sando T, Bell AE. Psychosocial factors of caregiver burden in child caregivers: results from the new national study of caregiving. *Health Qual Life Outcomes* 2015;**13**:120.
49. Cook SK, Snellings L, Cohen SA. Socioeconomic and demographic factors modify observed relationship between caregiving intensity and three dimensions of quality of life in informal adult children caregivers. *Health Qual Life Outcomes* 2018;**16**:169.
50. Cohen SA, Cook SK, Sando TA, Brown MJ, Longo DR. Socioeconomic and demographic disparities in caregiving intensity and quality of life in informal caregivers: a first look at the national study of caregiving. *J Gerontol Nurs* 2017;**43**:17–24.
51. Lai A, Griffith LE, Kuspinar A, Turchyn JS, Richardson J. Impact of care-recipient relationship type on quality of life in community-dwelling older adults with dementia over time. *J Geriatr Psychiatry Neurol* 2023;**37**: 294–306.
52. Namkung EH, Greenberg JS, Mailick MR. Well-being of sibling caregivers: effects of kinship relationship and race. *Gerontologist* 2017; **57**:gnw008–636.
53. Van Den Kieboom R, Snaaphan L, Mark R, Bongers I. The trajectory of caregiver burden and risk factors in dementia progression: a systematic review. *J Alzheimers Dis* 2020; **77**:1107–15.
54. Hallikainen I, Koivisto AM, Välimäki T. The influence of the individual neuropsychiatric symptoms of people with Alzheimer disease on family caregiver distress—a longitudinal ALSOVA study. *Int J Geriatr Psychiatry*. Published online 2018 May 30. Advance online publication. <https://doi.org/10.1002/gps.4911>.
55. García-Martín V, de Hoyos-Alonso MC, Delgado-Puebla R, Ariza-Cardiel G, del Cura-González I. Burden in caregivers of primary care patients with dementia: influence of neuropsychiatric symptoms according to disease stage (NeDEM project). *BMC Geriatr* 2023;**23**:525–12.
56. Tsai CF, Hwang WS, Lee JJ *et al*. Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatr* 2021;**21**:1–9.
57. Conde-Sala JL, Turró-Garriga O, Calvó-Perxas L, Vilalta-Franch J, Lopez-Pousa S, Garre-Olmo J. Three-year trajectories of caregiver burden in Alzheimer’s disease. *J Alzheimers Dis* 2014; **42**:623–33.
58. Parkman S. Role captivity: a concept of constraining dimensions in dementia care. *Nurs Forum* 2020;**55**:128–35.
59. Brodaty H, Donkin M. Family caregivers of people with dementia Familiares que cuidan a personas con demencia les aidants familiaux des patients atteints de démence. *Dialogues Clin Neurosci* 2009;**11**:217–28.
60. Campbell P, Wright J, Oyebode J *et al*. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry* 2008;**23**:1078–85.
61. Baumgarten M, Battista RN, Infante-Rivard C, Hanley JA, Becker R, Gauthier S. The psychological and physical health of family members caring for an elderly person with dementia. *J Clin Epidemiol* 1992;**45**:61–70.
62. Leong J, Madjar I, Fiveash B. Needs of family carers of elderly people with dementia living in the community. *Australas J Ageing* 2001; **20**:133–8.
63. Rand S, Malley J, Forder J. Are reasons for care-giving related to carers’ care-related quality of life and strain? Evidence from a survey of carers in England. *Heal Soc Care Community* 2019;**27**: 151–60.
64. Hochgraeber I, Köhler K, Stöcker H, Holle B. The dyadic relationship of family carers and people living with dementia—an umbrella review. *Ageing Ment Heal* 2023;**27**:1965–74.
65. Wennberg AM, Anderson LR, Cagnin A, Chen-Edinboro LP, Pini L. How both positive and burdensome caregiver experiences are associated with care recipient cognitive performance: evidence from the National Health and aging trends study and National Study of caregiving. *Front Public Heal* 2023; **11**:11.
66. Fujii T, Yamagami T, Yamaguchi H, Yamazaki T. Development of the dementia caregiver positive feeling scale 21-item version (DCPFS-21) in Japan to recognise positive feelings about caregiving for people with dementia. *Psychogeriatrics* 2021;**21**:650–8.
67. de Labra C, Millán-Calenti JC, Buján A *et al*. Predictors of caregiving satisfaction in informal caregivers of people with dementia. *Arch Gerontol Geriatr* 2015;**60**:380–8.
68. Wang J, Li X, Liu W *et al*. The positive aspects of caregiving in dementia: a scoping review and bibliometric analysis. *Front Public Heal* 2022;**10**:985391.
69. Schalock RL, Alonso MAV. *Handbook on Quality of Life for Human Service Practitioners*. vol. **40**. DC, US: American Association on Mental Retardation, 2002;457–70. <https://psycnet.apa.org/record/2002-06790-000> (2 November 2023, date last accessed).
70. Jones P, Drummond PD. A summary of current findings on quality of life domains and a proposal for their inclusion in clinical interventions. *Front Psychol* 2021;**12**:1–13.
71. Dow J, Robinson J, Robalino S, Finch T, McColl E, Robinson L. How best to assess quality of life in informal carers of people with dementia; a systematic review of existing outcome measures. Thompson coon J, ed. *PLoS One* 2018; **13**:e0193398.
72. Schaeferbeke JM, Gabel S, Meersmans K *et al*. Baseline cognition is the best predictor of 4-year cognitive change in cognitively intact older adults. *Alzheimer’s Res Ther* 2021; **13**:1–16.

Received 27 January 2024; editorial decision 17 May 2024