

# Relationship quality and sense of coherence in dementia

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# Relationship quality and sense of coherence in dementia: Results of a European cohort study

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**Objective:** Quality of life of people with dementia and their family carers is strongly influenced by interpersonal issues and personal resources. In this context, relationship quality (RQ) and sense of coherence (SOC) potentially protect and promote health. We aimed to identify what influences RQ in dyads of people with dementia and their carers and to examine differences in their perspectives.

**Methods:** Cross-sectional data were used from the Actifcare cohort study of 451 community-dwelling people with dementia and their primary carers in eight European countries. Comprehensive assessments included the Positive Affect Index (RQ) and the Orientation to Life Questionnaire (SOC).

**Results:** Regression analyses revealed that RQ as perceived by people with dementia was associated with carer education, stress, and spouse caregiving. RQ as perceived by carers was associated with carer stress, depression, being a spouse, social support, reported neuropsychiatric symptoms of dementia, and carer SOC. Neuropsychiatric symptoms and carer stress contributed to discrepancies in RQ ratings within the dyad. The only factor associated with both individual RQ ratings and discrepancies was carer stress (negative feelings subscore). No significant differences in the overall perception of RQ were evident between spouses and adult children carers, but RQ determinants differed between the two.

**Conclusions:** In this European sample, carer SOC was associated with carer-reported RQ. RQ determinants differed according to the perspective considered (person with dementia or carer) and carer subgroup. A deeper understanding of RQ and its determinants will help to tailor interventions that address these distinct perspectives and potentially improve dementia outcomes.

## KEYWORDS

Alzheimer disease, dementia, dyadic perspective, family care, relationship quality, sense of coherence

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**1 | INTRODUCTION**

Relationship quality (RQ) between people with dementia and their family carers and sense of coherence (SOC), as conceptualised by Antonovsky,<sup>1</sup> potentially protect and promote health and contribute to quality of life in dementia.<sup>2,3</sup>

In people with dementia, a good current RQ contributes to higher self-reported quality of life,<sup>3,4</sup> slower cognitive and functional decline particularly for those with spouse carers,<sup>5</sup> and lower institutionalisation risk.<sup>6,7</sup> Recently, a review highlighted the scarcity of evidence on links with institutionalisation and quality of life.<sup>8</sup> As for carers, a stronger past and current RQ predicts better carer quality of life<sup>9</sup> and lower depression, anxiety, and burden.<sup>10,11</sup>

Despite research on RQ outcomes, knowledge of RQ determinants is scarce<sup>12</sup> and few studies include the perspectives of both people with dementia and carers<sup>13,14</sup> or compare relationship types (eg, spouses/partners versus adult children carers).<sup>12,14</sup> Current RQ is generally rated lower by carers than by people with dementia,<sup>15,16</sup> although the difference may not be always significant.<sup>17</sup> Factors contributing to a more positive perspective of RQ according to people with dementia include less behavioural disturbances (eg, aggression/agitation and irritability towards the carer), less depressed mood, and higher self-reported quality of life.<sup>16,17</sup> Factors determining a better RQ as reported by family carers include lower levels of their own anxiety, depression, and stress,<sup>16,17</sup> together with higher quality of life or less behavioural disturbances of the person with dementia (as rated by the carer).<sup>16-19</sup> The effect of dementia behavioural profiles in RQ remains unclear. RQ deterioration may be predicted by apathy<sup>16</sup> and hyperactivity.<sup>17</sup> Overall, the few studies rely on relatively small convenience samples,<sup>16-19</sup> include participants with particular profiles (higher anxiety in dementia<sup>16</sup> or distress in carers<sup>19</sup>) and only one type of carer (spouse),<sup>17,18</sup> or do not differentiate carer subgroups while analysing RQ determinants.<sup>16</sup> A single study reported poorer relationships viewed by spouses/partners as compared with adult/children-in-law carers.<sup>19</sup>

The SOC construct explains why some people respond well to stressful situations while others do not.<sup>1</sup> SOC is a dispositional orientation (rather than a personality trait or coping strategy), reflecting the

**Key points**

- In a large European cohort study of people with dementia and their primary carers, people with dementia tended to rate their dyadic relationship quality more positively than carers.
- Carer stress, expressed in negative feelings such as anger and frustration, emerged as the only factor significantly associated with both individual relationship quality perceptions and the discrepancy between person with dementia and carer ratings.
- A stronger sense of coherence in carers related to better relationship quality as perceived by them, but not with discrepancies in relationship quality ratings within the dyad.
- Relationship quality determinants differed according to the perspective considered (person with dementia or carer) and carer subgroup (spouses and adult children carers).

ability to understand what is happening (comprehensibility/cognitive component), to manage challenging situations (manageability/instrumental component), and to find meaning in these situations (meaningfulness/motivational component).<sup>20</sup> The influence of this salutogenic model has grown, and SOC is acknowledged as an important variable in public health and mental health promotion.<sup>21-23</sup> The role of SOC within dementia has yet to be explored, despite its potential.<sup>24</sup> The few findings to date relate mainly to carers, suggesting that a stronger SOC is associated with less depression and anxiety,<sup>2,25</sup> less burden,<sup>26,27</sup> and higher health-related quality of life in carers.<sup>2,28</sup>

Knowledge of the relationship of RQ and SOC in dementia is scarce, but in a small sample of young healthy couples, SOC was related to RQ as perceived by both dyad members.<sup>29</sup> A previous study found that poor relationships were a major threat to SOC.<sup>30</sup> The association between RQ and SOC in dementia merits study, given previous findings with healthy samples and the potential for preventive interventions.

Moreover, three literature reviews called for research on RQ determinants<sup>12</sup> integrating the perspectives of both dyad members<sup>13,14</sup> and differentiating between carer subgroups.<sup>14</sup> Finally, the evidence is inconsistent on discrepancies between dyad members.<sup>15-17</sup>

In this study, we aim to explore factors associated with the quality of the carer-person with dementia relationship and the link with SOC. Specifically, we intend to (1) compare RQ from the perspective of carer and person with dementia; (2) analyse factors associated with RQ, including SOC; and (3) explore differences in carer RQ perceptions according to the type of relationship with care receivers (spouses/partners and adult child carers).

## 2 | METHODS

In this study, we used cross-sectional baseline data from 451 dyads of people with dementia and their corresponding family carers (total  $n = 902$ ) from the Actifcare (ACcess to TImely Formal Care) EU-JPND project. The 1-year European prospective cohort study protocol was detailed elsewhere.<sup>31</sup>

Actifcare aimed at optimising dementia formal care in the community by identifying best practices and finding the best fit between needs and appropriate access and use of services in eight European countries: Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Sweden, and the United Kingdom ([www.actifcare.eu](http://www.actifcare.eu)).

### 2.1 | Participants

Participants were community-dwelling people with mild or moderate according to the *Diagnostic and Statistical Manual of Mental Disorders* and the (DSM-IV) Clinical Dementia Rating (CDR)<sup>32</sup> and their primary/family carers (being in contact at least once a week). Exclusion criteria included alcohol-related dementia or Huntington's disease and receipt of significant care on account of dementia at baseline from formal services. Participants were recruited from various settings, including general practices, memory clinics, and Alzheimer's Associations.<sup>31</sup>

### 2.2 | Measures

Baseline assessments were conducted between November 2014 and July 2015 at a place convenient to participants (mostly at home).

From a wide range of scales,<sup>31</sup> only the main measures used in the present study are outlined below. Instruments were translated whenever necessary. Careful translation-back translation procedures helped to ensure validity and reliability.

The Positive Affect Index (PAI)<sup>33</sup> assessed RQ and was rated separately by both people with dementia and their carers. This five-item scale measures the current quality of a relationship (closeness, communication, similar views, shared activities, and generally getting along). Responses are rated on a 6-point scale from 1 (not well) to 6 (extremely well), with a total sum score (ranging 5 to 30, higher scores reflecting better RQ). This scale was used with people with dementia,<sup>12,17</sup> showing good internal consistency (Cronbach  $\alpha = 0.81$ ) and

test-retest reliability over 12 weeks ( $r = 0.66$ ).<sup>15</sup> In the present study, Cronbach's  $\alpha$ 's were 0.82 (people with dementia) and 0.79 (carers).

The 13-item version of the Orientation to Life Questionnaire was used to assess carer SOC.<sup>1,20</sup> Responses are rated on a 7-point scale from 1 (very rarely) to 7 (very often). Total SOC score ranges from 13 to 91, higher scores indicating a stronger SOC. The scale has been used in at least 49 different languages.<sup>34</sup> Reported  $\alpha$  coefficients range from 0.70 to 0.92 for the 13-item version, with adequate reliability and validity.<sup>35</sup> In the present study, Cronbach's  $\alpha$  was 0.83.

The Resource Utilisation in Dementia Instrument (RUD 4.0)<sup>36</sup> was completed based on carer reports. Measures specific for people with dementia included CDR,<sup>32</sup> Mini-Mental State Examination (MMSE),<sup>37</sup> Neuropsychiatric Inventory Questionnaire (NPI-Q), with symptom count and separate scores for severity and carer distress,<sup>38</sup> Instrumental Activities of Daily Living (IADL), and Physical Self-Maintenance Scale (PSMS).<sup>39</sup>

Carers also completed the Hospital Anxiety and Depression Scale (HADS)<sup>40</sup> and the Relative Stress Scale (RSS)<sup>41</sup> for caregiving-related stress. In addition to RSS total scores, three subscores were calculated (emotional distress, social distress, and negative feelings towards the person with dementia).<sup>42</sup> Carer social network was measured with the Lubben Social Network Scale (LSNS-6).<sup>43</sup> Perseverance time (a single-item measure) assessed the period of time that the carer expected to be able to provide care.<sup>44</sup>

### 2.3 | Ethical considerations

The study protocol was approved by ethics committees in each of the eight countries. The carer and the person with dementia both gave written informed consent according to national regulations.

### 2.4 | Statistical analysis

Parametric (independent-sample  $t$  test, Pearson correlation coefficient, and biserial correlation) and nonparametric tests (Wilcoxon signed rank test, Fisher exact, and Spearman correlation coefficient) were used as required. The assumptions of homogeneity of variance (Levene) and normality (Shapiro-Wilk) of independent-sample  $t$  tests were assessed.

RQ dyadic discrepancy scores, defined as an index of similarity/dissimilarity of RQ in members of the dyad, were calculated for each dyad by subtracting carer scores from person with dementia scores and then dividing by the mean of the two contributing scores.<sup>17</sup> Zero indicates no discrepancy; positive values indicate higher RQ ratings by the person with dementia and vice versa.

A stepwise multiple linear regression analysed the extent to which other variables contribute to individual and dyadic discrepancy RQ ratings. A hierarchical regression analysis was conducted to explore variables influencing RQ among carer subgroups. Independent variables were selected based on the literature review and the presence of significant correlations with the dependent variables. Normal distribution and homogeneity were graphically validated, and independence

of errors was assessed with Durbin-Watson statistic. Variance inflation factor (VIF) was used to diagnose multicollinearity.

The significance threshold was set at  $\leq 0.05$ . The statistical analyses were carried out using Statistical Package for the Social Sciences (SPSS) for Windows version 24.

### 3 | RESULTS

Demographic and clinical characteristics of the 451 person with dementia-carer dyads are summarised in Table 1 and detailed elsewhere.<sup>45</sup>

#### 3.1 | Person with dementia and carer perspectives of RQ

Mean PAI scores were 22.7 (SD = 3.9) as rated by people with dementia and 20.9 (SD = 4.5) as rated by carers (Table 1). These ratings were positively correlated ( $r = 0.385$ ,  $P = 0.001$ ), but people with dementia scored significantly higher than carers ( $t_{431} = 7.547$ ,  $P = 0.001$ ).

In PAI individual items, carer ratings were significantly lower than their pairs for communication ( $Z = -10.887$ ,  $P = 0.001$ ), similarity of views ( $Z = -6.171$ ,  $P = 0.001$ ), and generally getting along ( $Z = -5.256$ ,  $P = 0.001$ ) but did not diverge significantly for closeness and shared activities (Table 2).

#### 3.2 | Factors associated with RQ

Bivariate correlations between PAI ratings and potential predictors were calculated (Table 3). Carer age, cognitive impairment (MMSE) and dementia severity (CDR) of the person with dementia, time spent caring for the person with dementia (assisting with basic instrumental activities and supervision), and number of informal carers (RUD) showed no association with any of the PAI ratings. NPI-Q ratings for symptoms, severity, and distress were highly intercorrelated; therefore, only symptom score was included in regression analyses.

Stepwise regression analyses were conducted of RQ (dependent variable, measured by PAI), first as perceived by the carer and then by people with dementia. The final carer model explained 25.4% of the variance (Table 4). Carer stress (negative feelings subscale), carer depression, and neuropsychiatric symptoms related to lower RQ. Carers' stronger SOC and perceived social support, spouse/partner relationship, and greater proportion of time spent by primary carer among all carers were associated with higher carer RQ ratings. Basic ADL function of person with dementia, carer anxiety, perseverance time, and coresidency was excluded from the final model.

The final model for RQ ratings by people with dementia only explained 7.4% of the variance (Table 4). Carer stress (negative feelings) was associated with lower RQ ratings. Higher carer education and the spouse/partner relationship type related to higher RQ ratings. Variables excluded from the model were person with dementia age and education, carer SOC and depression, perceived social support, and perseverance time.

Greater discrepancies in RQ ratings within the dyad were associated with higher carer stress scores (negative feelings) and neuropsychiatric symptoms of the person with dementia (Table 4).

#### 3.3 | RQ perspectives among subgroups of carers

We examined the role of relationship type (spouses/partners versus adult child carers) on RQ perspectives of both dyad members. These carer subgroups are characterised in Table 5. We did not consider a third subgroup (eg, children-in-law and friends) due to its heterogeneity and small sample size ( $n = 26$ ).

No significant differences in RQ perception were evident between spouses/partners and adult child carers overall, although there were differences on RQ-specific domains. Adult children rated lower on shared activities ( $U = 13\ 374$ ,  $P = 0.001$ ) and similarity of views ( $U = 15\ 038$ ,  $P = 0.001$ ).

People with dementia rated RQ significantly higher when carers were spouses/partners compared with adult children ( $t_{340} = 2.097$ ,  $P = 0.037$ ). At item level, people with dementia scored higher on shared activities ( $U = 14\ 865$ ,  $P = 0.001$ ) and similarity of views ( $U = 13\ 103$ ,  $P = 0.001$ ) when their carer was a spouse/partner.

Separate hierarchical multiple regression analyses were conducted of RQ determinants in carer subgroups. Person with dementia background variables (eg, age and neuropsychiatric symptoms) were entered into block 1, carer background variables in block 2 (eg, education and depression), and caregiving context variables in block 3 (eg, time spent with person with dementia) (Table 6).

Regarding spouse/partners' RQ perspective, the overall model explained 33.4% of variance in PAI (block 2 carer variables explaining 17.4%). Higher carer stress (negative feelings subscore) and depression were associated with lower RQ. Some person with dementia characteristics (block 1), eg, being male, neuropsychiatric symptoms, and less education, also related to lower ratings (Table 6).

Regarding adult children's RQ perspectives, the model explained 26.4% of the variance in PAI (block 2, carer variables explaining 18.1%). Higher carer age and stress (negative feelings) and lower SOC related to lower RQ ratings.

Finally, regarding variables associated with people with dementia's RQ perspective in the two carer subgroups, lower PAI ratings in spouse/partner relationships related to carer stress (negative feelings) and lower carer education. Carer stress (negative feelings) was the only variable associated with lower RQ in those receiving care from adult children.

### 4 | DISCUSSION

We explored factors associated with RQ in a large European sample of dyads of people with dementia and their carers.

Our first aim was to examine differences between person with dementia and carer RQ perspectives. Carers rated RQ significantly lower than people with dementia in accordance with previous evidence,<sup>16</sup> suggesting a negative effect of caregiving on RQ perception. Alternatively, people with dementia perhaps acknowledge support

**TABLE 1** Characteristics and summary of measures of people with dementia and their carers at baseline (n = 902)

		Score Range
Person with dementia (n = 451)		
Sex, women, n (%)	246 (54.5)	
Age, y, mean (SD)	77.7 (7.8, range 47-98)	
Education, y, mean (SD)	9.8 (4.4)	
Living alone, n (%)	88 (19.5)	
Type of dementia, n (%)		
Alzheimer disease	218 (48.6)	
Vascular	52 (11.6)	
Mixed vascular/Alzheimer disease	56 (12.5)	
Lewy body	6 (1.3)	
Other	27 (6)	
Unspecified/unknown type of dementia	90 (20)	
Cognitive impairment (MMSE), mean (SD)	19 (4.9)	0-30
Dementia severity (CDR), n (%)		
1 (mild)	354 (78.5)	
2 (moderate)	87 (19.3)	
Missing	10 (2.2)	
Neuropsychiatric symptoms (NPI-Q), mean (SD)	7.7 (5.5)	0-12
Severity (NPI-Q), mean (SD)	8.08 (5.4)	0-36
IADL function (IADL), mean (SD)	3.45 (1.9)	0-8
Basic ADL function (PSMS), mean (SD)	3.65 (1.8)	0-6
Relationship quality (PAI), mean (SD)	22.7 (3.9)	5-30
Carer (n = 451)		
Sex, female, n (%)	299 (66.4)	
Age, y, mean (SD)	66.4 (13.2, range 25-92)	
Education, y, mean (SD)	11.9 (4.4)	
Relationship to the person with dementia, n (%)		
Spouse/partner	288 (63.9)	
Adult children	137 (30.4)	
Other (eg, son/daughter in law, sibling, other relative, friend, and neighbour)	26 (5.8)	
Living together with person with dementia, n (%)	323 (71.6)	
Time spent assisting with basic and instrumental activities of daily living in hours per day, mean (SD)	3.7 (3.1)	
Depression (HADS), mean (SD)	4.7 (3.6)	0-21
Anxiety (HADS), mean (SD)	6.1 (3.8)	0-21
Distress (NPI-Q), mean (SD)	9.3 (7.8)	0-60
Stress (RSS), mean (SD)	21.30 (10.9)	0-60
Sense of coherence (SOC), mean (SD) <sup>a</sup>	67.1 (10.9)	13-91
Relationship quality (PAI), mean (SD) <sup>a</sup>	20.9 (4.5)	5-30
Dyads (n = 451)		
Relationship quality dyadic discrepancy score (PAI), mean (SD)	0.87 (0.3)	

Abbreviations: CDR, Clinical Dementia Rating Scale; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; MMSE, Mini-Mental State Examination; NPI-Q, Neuropsychiatric Inventory Questionnaire; PAI, Positive Affect Index; PSMS, Physical Self-Maintenance Scale; RSS, Relative Stress Scale; SD, standard deviation; SOC, sense of coherence.

<sup>a</sup>Higher PAI scores indicate better RQ; higher SOC scores indicate stronger SOC.

provided by relatives and thus accentuate positive aspects of their relationship. In one study,<sup>17</sup> person with dementia ratings did not diverge significantly from their pairs, but this study examined only spousal relationships in early-stage dementia.

Relationship domains rated lower by carers were communication, as reported by others,<sup>17,18</sup> similar views and generally getting

along. Ratings did not differ for closeness and shared activities, in line with other findings.<sup>17,18</sup> Although the overall quality of the relationship is likely to decline, aspects such as closeness may remain or even strengthen.<sup>18</sup> Positive and negative aspects of RQ coexist; thus, difficulties in communication do not preclude positive experiences.

**TABLE 2** Mean ratings on RQ (PAI) individual items at baseline

Item	Person with Dementia		Carer		Z	Sig <sup>a</sup>
	M	SD	M	SD		
Closeness	4.84	1.01	4.82	0.96	-0.240	0.810
Communication	4.43	1.07	3.46	1.38	-10.887	0.001***
Similarity of views	4.00	1.10	3.55	1.29	-6.171	0.001***
Shared activities	4.73	1.10	4.75	1.17	-0.548	0.584
Generally getting along	4.71	0.96	4.41	1.11	-5.256	0.001***

Abbreviations: PAI, Positive Affect Index; RQ, relationship quality; SD, standard deviation. PAI is rated on a 6-point scale (from 1 = not well to 6 = extremely well).

<sup>a</sup>Wilcoxon signed rank test.

\*\*\* $P \leq 0.001$ .

Our second aim was to analyse factors associated with RQ, including SOC. To our knowledge, this study was the first to explore links between RQ and SOC in dementia, documenting a positive association that calls for further research. This is in line with previous results outside caregiving contexts.<sup>29,30</sup>

In this sample, stronger carer SOC related to higher carer RQ ratings but did not independently influence a better consensus in RQ ratings within the dyad. It is plausible that there is a dynamic interaction between SOC and RQ, with SOC being a protective factor regarding carer RQ, by predisposing them to reinterpret and compensate for the impact of dementia, while RQ directly strengthens carer SOC levels, to a variable extent. We can only speculate whether RQ and SOC are associated in people with dementia (as we did not assess their SOC).

**TABLE 3** Bivariate correlations between RQ (PAI) and other variables

	PAI Rating by Carer	PAI Rating by Person with Dementia	PAI Dyadic Discrepancy Score
Age (carer)	0.049	0.025	-0.045
Age (person with dementia)	-0.087	-0.130**	0.008
Male sex (carer) <sup>a</sup>	0.075	-0.030	-0.171**
Male sex (person with dementia) <sup>a</sup>	0.019	-0.081	-0.101*
Education (carer)	0.084	0.112*	0.039
Education (person with dementia)	0.090	0.131**	0.062
Spouse/partner relationship to the person with dementia <sup>a</sup>	0.115**	0.128**	0.040
Living together with person with dementia <sup>a</sup>	-0.097*	-0.084	-0.062
Dementia severity (CDR)	0.006	0.045	0.021
Cognitive impairment (MMSE)	0.029	-0.074	-0.065
Sense of coherence (SOC)	0.328***	0.122*	-0.179***
Basic IADL function (IADL)	0.072	-0.044	-0.139**
Basic ADL function (PSMS)	0.164***	0.069	-0.118*
Neuropsychiatric symptoms (NPI-Q) <sup>b</sup>	-0.248***	-0.048	0.112*
Severity (NPI-Q)	-0.121*	-0.077	0.010
Distress (NPI-Q)	-0.158***	-0.050	0.046
Anxiety (HADS)	-0.317**	-0.081	0.245**
Depression (HADS)	-0.332**	-0.119*	0.199**
Stress (RSS total)	-0.364***	-0.134**	0.225**
Emotional distress (RSS)	-0.350***	-0.129**	0.228***
Social distress (RSS)	-0.231***	-0.064	0.149**
Negative feelings (RSS)	-0.389***	-0.180**	0.213**
Social support of carer (LSNS)	0.109*	0.211***	-0.064
Perseverance time <sup>a</sup>	0.107*	0.216***	-0.086
Time spent assisting with basic and instrumental activities of daily living	0.031	-0.023	0.060
Proportion of time spent by primary carer among all carers	0.120*	0.072	0.014
Number of informal carers involved in care	-0.087	-0.012	-0.051

Abbreviations: CDR, Clinical Dementia Rating Scale; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; LSNS, Lubben Social Network Scale; MMSE, Mini-Mental State Examination; NPI-Q, Neuropsychiatric Inventory Questionnaire; PAI, Positive Affect Index; PSMS, Physical Self-Maintenance Scale; RQ, relationship quality; RSS, Relative Stress Scale; SOC, sense of coherence.

<sup>a</sup>Spearman correlation coefficient or biserial correlation coefficient. For the remaining analysis, Pearson correlation coefficient was used.

<sup>b</sup>For the NPI, the carer rated the person with dementia symptoms, their severity, and the degree of distress experienced by the carer.

\* $P \leq 0.05$ .

\*\* $P \leq 0.01$ .

\*\*\* $P \leq 0.001$ .

**TABLE 4** Summary of the stepwise regression analysis for the variables predicting RQ (PAI) ratings

	PAI Rating by Carer		PAI Rating by Person with Dementia		PAI Dyadic Discrepancy Score	
	$\beta$	Sig	$\beta$	Sig	$\beta$	Sig
Education (carer)			0.150	0.002**		
Spouse/partner relationship type	0.138	0.004**	0.187	0.000***		
Sense of coherence (SOC)	0.096	0.041*				
Neuropsychiatric symptoms (NPI-Q)	-0.099	0.036*			0.148	0.005**
Depression (HADS)	-0.151	0.006**				
Negative feelings (RSS)	-0.257	0.000***	-0.212	0.000***	0.153	0.003**
Social support of carer (LSNS)	0.120	0.007**				
Proportion of time spent by primary carer among all carers	0.105	0.026*				
Total $R^2$ adj	0.254		0.074		0.059	
	$F_{7,411} = 21.341***$		$F_{3,414} = 12.136***$		$F_{2,417} = 14.237***$	

Abbreviations: HADS, Hospital Anxiety and Depression Scale; LSNS, Lubben Social Network Scale; NPI-Q, Neuropsychiatric Inventory Questionnaire; PAI, Positive Affect Index; RQ, relationship quality; RSS, Relative Stress Scale; SOC, sense of coherence.

\* $P \leq 0.05$ .

\*\* $P \leq 0.01$ .

\*\*\* $P \leq 0.001$ .

**TABLE 5** Characteristics of carers' subgroups

	Spouses/Partners (n = 288)	Adult Children (n = 137)	Sig
Sex, female, n (%)	173 (60.3)	103 (75.2)	0.003 <sup>a,**</sup>
Age, y, mean (SD)	73.6 (8.1)	52.0 (8.5)	0.001 <sup>b,***</sup>
Education, y, mean (SD)	11.2 (4.7)	13.4 (13.4)	0.001 <sup>b,***</sup>
Time spent assisting with basic and instrumental activities of daily living in hours per day, mean (SD)	4.2 (3.1)	3.3 (3.3)	0.008 <sup>b,**</sup>
Living together with person with dementia, n (%)	285 (99.3)	32 (23.4)	0.001 <sup>a,***</sup>

<sup>a</sup>Fisher exact

<sup>b</sup>Independent-sample t test.

\* $P \leq 0.05$ .

\*\* $P \leq 0.01$ .

\*\*\* $P \leq 0.001$ .

We were among the few to use a dyadic score to assess discrepancies between person with dementia and corresponding carer regarding RQ, building on previous research.<sup>17</sup> In our sample, only carer stress (negative feelings subscore) and neuropsychiatric symptoms of the person with dementia were associated with discrepancies in RQ ratings. Carer stress has previously been identified as a significant predictor of discrepancies.<sup>15,17</sup>

Our findings suggest that RQ as perceived by carers was determined by a mix of carer and person with dementia characteristics. Both carer stress and depression influenced carer RQ perceptions, in line with previous evidence.<sup>16,17</sup> Neuropsychiatric symptoms of dementia also played an important role in carer RQ perceptions, consistent with studies where increased behavioural disturbances were associated with poorer relationships.<sup>16,18,19</sup> Contrasting with findings from Spector and colleagues,<sup>16</sup> carer anxiety was not significantly related with RQ in our sample. However, they used a different RQ measure and included only people with dementia with clinically relevant anxiety.

To our knowledge, this study is the first to demonstrate a link between greater amounts of time spent with the person with dementia by the primary carer (in relation to other carers) and better perceived RQ. This could be explained by the positive effect on carer commitment and sense of personal accomplishment and gratification. Our results also support the importance of the carer social network to the RQ.<sup>19</sup> Informal support mechanisms may be beneficial because they reduce the burden of caregiving and impact positively on the RQ.

RQ rated by people with dementia was predicted by carer characteristics (education, stress, and spouse/partner relationship type). The ratings of RQ made by people with dementia appear to be especially responsive to negative feelings, including anger and frustration, reported by their carer. Spector et al<sup>16</sup> found neuropsychiatric symptoms, namely, aggression/agitation and irritability, to affect RQ from person with dementia perspective, among other variables. Differences in findings may be partly related to sample profile, differing concepts of RQ and distinct ways of presenting NPI scores. In their spousal



**TABLE 6** Summary of the hierarchical regression analysis of the RQ (PAI) ratings among carers' subgroups

	PAI Rating by Carer				PAI Rating by Person with Dementia			
	Spouses/Partners (n = 288)		Adult Children (n = 137)		Spouses/Partners (n = 288)		Adult Children (n = 137)	
	$\Delta R^2$	$\beta$	$\Delta R^2$	$\beta$	$\Delta R^2$	$\beta$	$\Delta R^2$	$\beta$
Block 1: person with dementia variables	0.147		0.062		0.042		0.061	
Age		0.059		-0.176		-0.030		-0.197
Sex, male		-0.167*		-0.043		-0.002		-0.011
Education, y		0.183**		-0.039		0.064		0.021
Dementia severity (CDR)		-0.019		0.184		0.115		-0.149
IADL function (IADL)		-0.063		-0.040		-0.154		-0.271
Basic IADL function (PSMS)		0.114		0.079		0.166		0.034
Neuropsychiatric symptoms (NPI-Q)		-0.295***		-0.179		-0.075		-0.072
Block 2: carer variables	0.174		0.181		0.076		0.119	
Age		-0.106		-0.274**		0.128		-0.191
Sex, male		-0.056		-0.025		-0.148		-0.042
Education, y		0.077		-0.044		0.226*		0.000
Sense of coherence (SOC)		0.058		0.221*		0.001		0.086
Emotional distress (RSS)		-0.080		-0.222		-0.001		-0.176
Social distress (RSS)		0.005		0.176		-0.096		0.170
Negative feelings (RSS)		-0.209**		-0.276*		-0.221*		-0.321**
Distress (NPI)		-0.023		0.050		0.014		0.097
Anxiety (HADS)		-0.045		0.022		-0.014		0.147
Depression (HADS)		-0.172*		0.033		0.030		-0.009
Block 3: caregiving context variables	0.014		0.021		0.015		0.031	
Living together with person with dementia		-0.110		0.015		-0.114		-0.149
Time spent with person with dementia		-0.015		0.149		-0.002		-0.037
Proportion of time spent by primary carer among all carers		0.013		0.044		0.049		0.185
Number of other carers involved in care		-0.031		0.081		0.011		0.139
Total R <sup>2</sup>	0.334		0.264		0.133		0.210	
	$F_{21,219} = 5.223^{***}$		$F_{21,124} = 2.114^{**}$		$F_{21,216} = 1.579$		$F_{21,102} = 1.293$	

Abbreviations: CDR, Clinical Dementia Rating Scale; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; NPI-Q, Neuropsychiatric Inventory Questionnaire; PAI, Positive Affect Index; PSMS, Physical Self-Maintenance Scale; RQ, relationship quality; RSS, Relative Stress Scale; SOC, sense of coherence.

\* $P \leq 0.05$ .

\*\* $P \leq 0.01$ .

\*\*\* $P \leq 0.001$ .

sample, Clare et al<sup>17</sup> identified depression of the person with dementia as one of the most important correlates of their own RQ ratings. However, we did not assess care receiver depression, except as a component of the overall NPI-Q score.

Our third aim was to examine differences in RQ perspectives according to the type of caregiving relationship. Differences in RQ perception according to caregiving relationship type (spouses/partners, or adult children or people with dementia) have not received much attention so far. Most studies focused on burden in spouse versus adult child carers.<sup>46,47</sup>

We found no significant differences between spouse/partner and adult children carers in overall perception of RQ. However, people with dementia rated RQ significantly higher when carers were spouses/partners, as compared with adult children. These findings differ from reports that care receivers had poorer relationships with

spouses/partners than with carers who were their children or children-in-law.<sup>19</sup> Of note, these authors used a different RQ measure, and the sample was composed of family carers previously engaged in a burden study. This aspect merits further research and qualitative investigation in view of the contradictions in findings and the dynamic nature of dyadic relationships.<sup>8</sup>

While spouses/partners and adult children may report similar RQ levels, different contributing factors emerge. In adult child carers, RQ was explained mostly by their own characteristics (eg, age and stress) rather than those of the person with dementia. In spouses, both carer and person with dementia characteristics (eg, neuropsychiatric symptoms) predicted RQ. One may expect that because spouses are most likely to live with the care receiver, their perception is more influenced by care receivers' characteristics. Caregiving experiences may be different for these two groups of carers, since the relationship with the

person with dementia will tend to differ in terms of history and commitment. These, among other factors that we did not evaluate (eg, personality and attributions), may influence RQ perceptions throughout the course of dementia.

#### 4.1 | Strengths and limitations

This study is novel in that it fosters insight into the role of RQ and SOC in dementia. We analysed RQ not only from carers' perspectives but also from those of people with dementia. Furthermore, we studied a large, typical sample from eight countries, in different European regions. Actifcare focused on the mild to moderate stages of dementia, where there is great potential to impact positively upon the quality of life of patients and families. Since it is a key predictor (indeed a component) of quality of life, the study of RQ allows us to better understand this broader and multifaceted construct. The complex determinants of quality of life were analysed in another Actifcare paper.<sup>48</sup>

Limitations must also be acknowledged. First, we analysed a non-random sample of community-dwelling people with dementia and their carers. Therefore, generalisability is not guaranteed. Second, these cross-sectional analyses are limited in showing association rather than causality. Third, our study did not consider the influence of a variety of potentially relevant factors including precaregiving RQ, caregiving duration, other members of the family system or close social networks (except the indirect assessment of carer social support), subtype of dementia, or cross-cultural/national aspects. The relatively low proportion of variance explained in our analyses suggests that other factors need to be explored. Fourth, RQ was only evaluated with PAI, a self-report measure that may be affected by, eg, memory bias, distortion due to carer exhaustion, or cognitive impairment. While PAI provides brevity and simplicity (rendering it suitable for completion by people with dementia), comprehensive measures would be more informative. Finally, SOC was only assessed in carers. We decided not to assess people with dementia's SOC given lower evidence on the validity of the 13-item measure in dementia and to reduce burden of assessment.

### 5 | CONCLUSION

Understanding RQ and its determinants will assist professionals in identifying how best to promote quality of life in dementia, maintain standards of care, and support carers who wish to maintain care at home. RQ is a key component of quality of life,<sup>4</sup> and by increasing our understanding of RQ, we can begin to build a better picture of the many facets of quality of life.

Our findings bring together a set of consistent predictors, resulting in a broader account of the influences on RQ in dementia. The distinct perspectives of RQ (person with dementia versus carer and spouse versus adult children carer) appear to be particularly affected by interpersonal stress factors reported by carers (including negative feelings such as anger, embarrassment, and frustration

associated with the person with dementia and their behaviour). By identifying potentially modifiable factors associated with individual and dyadic RQ perceptions, such as different patterns of carer stress, interventions can be tailored to optimise aspects of person with dementia-carer relationships that potentially improve dementia outcomes.

While spouses/partners and adult children reported similar levels of RQ, determinants of this perception seem different. Professionals need to recognise and respond appropriately to these two distinct perspectives.

#### 5.1 | Implications for further research

We demonstrated the feasibility of asking people with mild-to-moderate stages of dementia about their relationships with family carers and other emotional aspects of living with dementia. This should exemplify future research design, despite ethical and methodological challenges. Evidence is needed regarding the nature of different dyadic relationships and the trajectory of RQ overall or of RQ-specific domains throughout disease stages, as well as SOC in people with dementia. Follow-up analyses may enlighten causal links between quality of relationships in dementia and SOC, as a personal resource. A combination of quantitative and qualitative methods would enable more in-depth analyses of discrepancies between person with dementia and carer perspectives of RQ, as well as of their determinants.

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#### CONFLICT OF INTEREST

None declared.

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