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

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Complete List of Authors:	Marques, Maria J.; NOVA NOVA Medical School / Faculdade de Ciências Médicas, Woods, Bob; Bangor University, DSDC Hopper, Louise; Dublin City University Faculty of Science and Health, School of Nursing and Human Sciences Jelley, Hannah; Bangor University Irving, Kate; Dublin City University, Kerpershoek, Liselot; Maastricht University, Neuropsychology and Psyciatry Meyer, Gabriele; University of Witten/Herdecke, School of Nursing Science Bieber, Anja; Martin-Luther-Universitat Halle-Wittenberg, Institute of Health and Nursing Science Stephan, Astrid; Martin-Luther-University Halle-Wittenberg, Sköldunger, Anders; Karolinska Institutet Department of Neurobiology Care Sciences and Society Sjölund , Britt-Marie; Karolinska Institutet and Stockholm University, Department of Neurobiology, Care Sciences and Society; University of Gävle, Faculty of Health and Occupational Studies, Department of Health and Caring Sciences Selbæk, Geir; Norwegian Advisory Unit on Ageing and Health, Rosvik, Janne; Vestfold Hospital Trust, Norwegian National Advisory Unit on Ageing and Health; Oslo University Hospital, Department of Geriatric Medicine Zanetti, Orazio; IRCCS "Centro S.Giovanni di Dio, Alzheimer's Research Unit-Memory Clinic Portolani, Elisa; IRCCS "Centro S.Giovanni di Dio, Alzheimer's Research Unit-Memory Clinic de Vugt, Marjolein; Maastricht University, Verhey, Frans; Maastricht University Medical Centre, Department of Psychiatry and Neuropsychology Gonçalves-Pereira, Manuel; Universidade Nova de Lisboa , CEDOC, Nova Medical School/Faculdade de Ciências Médicas
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Authors: Maria J. Marques[1], Bob Woods[2], Louise Hopper[3], Hannah Jelley[2], Kate Irving[3], Liselot Kerpershoek[4], Gabriele Meyer[5], Anja Bieber[5], Astrid Stephan[5], Anders Sköldunger[6], Britt-Marie Sjölund[7], Geir Selbaek[8], Janne Rosvik[9], Orazio Zanetti[10], Elisa Portolani[10], Marjolein de Vugt[4], Frans Verhey[4] and Manuel Gonçalves-Pereira[1] on behalf of the Actifcare Consortium

[1] CEDOC, Nova Medical School/Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Portugal

[2] Dementia Services Development Centre (DSDC) Wales, Bangor University, United Kingdom

[3] School of Nursing and Human Sciences, Dublin City University, Dublin, Ireland

[4] Department of Psychiatry and Neuropsychology and Alzheimer Centre Limburg, School for Mental Health and Neurosciences, Maastricht University, Maastricht, The Netherlands

[5] Institute for Health and Nursing Science, Martin Luther University Halle-Wittenberg, Halle (Saale), Germany

[6] Department of Neurobiology, Care sciences and Society, Karolinska Institutet, Stockholm, Sweden

[7] Department of Neurobiology, Care sciences and Society, Karolinska Institutet, Stockholm, University of Gävle, Department of Health and Caring Sciences, Gävle, Sweden

[8] Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Faculty of Medicine, University of Oslo, Oslo, Centre for Old Age Psychiatric Research, Ottestad, Norway

[9] Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Department of Geriatric Medicine, Oslo University Hospital, Oslo, Norway

[10] Alzheimer's Research Unit-Memory Clinic, IRCCS Istituto Centro San Giovanni di Dio Fatebenefratelli, Brescia, Italy

Corresponding author: Maria J. Marques, CEDOC, Nova Medical School / Faculdade de Ciências Médicas, Universidade Nova de Lisboa. Campo dos Mártires da Pátria, 130, 1169-056 Lisboa, Portugal. Phone +351218803046, Fax +351218 803079, E-mail maria.marques@nms.unl.pt

Abstract

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 people with dementia and their carers, and might explain different perspectives in the members of the dyad, and among carers' subgroups.

Methods: Data from the Actifcare study of 451 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: RQ as perceived by people with dementia was associated with carer's education, stress and spouse caregiving. RQ as perceived by carers was associated with carer's stress, depression, being a spouse, social support, reported neuropsychiatric symptoms of dementia and carer's SOC. Neuropsychiatric symptoms and carer's stress contributed to discrepancy in RQ ratings within the dyad. The only factor associated with both individual RQ ratings and with discrepancies was carer's stress (specifically, the 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's SOC was associated with carer-reported RQ. RQ determinants differed according to the perspective considered (person with dementia or carer's) 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: dementia; Alzheimer's disease; relationship quality; sense of coherence; quality of life; family care; dyadic perspective

Key points:

1. In a large European cohort study of people with dementia and their primary carers, people with dementia tended to rate their dyad's relationship quality more positively than carers.
2. Carer's 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.
3. 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.
4. Relationship quality determinants differed according to the perspective considered (person with dementia or carer's) and carer subgroup (spouses and adult children carers).

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Introduction

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

A good past and current RQ is associated with higher quality of life, less depression and anxiety in people with dementia and their carers[4,5], lower carer burden[6], decreased neuropsychiatric symptoms-related distress[7], less behavioural disturbances[5,8], slower cognitive and functional decline[9], and lower institutionalisation risk.[10,11] Current RQ is generally rated lower by carers than by people with dementia.[5,12]

Despite research on RQ outcomes, knowledge of RQ determinants is scarce comparing the perspectives of people with dementia and carers, and comparing relationship types (e.g. spouses/partners versus adult children carers).[13,14] From the perspective of the person with dementia, worse RQ has been related to behavioural disturbances (including aggression and agitation towards carers), depressed mood and lower quality of life.[5] Factors associated with poorer RQ rated by family carers include their own anxiety and depression, and lower quality of life of the person with dementia[5], increased behavioural disturbances[15] and apathy[8]. Poorer relationships were reported by spouses/partners compared with adult children/children-in-law carers.[15]

The SOC construct explains why some people respond well to stressful situations while others do not.[1] SOC is a dispositional orientation (rather than a personality trait/type or coping strategy), reflecting the 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).[16] The influence of this salutogenic model has grown, and SOC is acknowledged as an important variable in public health and mental health promotion.[17–19] The role of SOC within dementia has yet to be explored, despite its potential.[20] The few findings to date relate mainly to carers, suggesting that a stronger SOC is associated with less depression and anxiety[2,21], less carer burden[22,23] and higher health-related quality of life.[2,24]

Knowledge of the relationship of RQ and SOC in dementia is scarce, but in couples without major health difficulties SOC was related to RQ as perceived by both dyad members.[25] A previous study found that poor relationships were a major threat to SOC.[26]

Living in a difficult, unsatisfactory relationship and not being able to improve it will perhaps weaken SOC. On the other hand, a lower SOC, making the situation less meaningful, comprehensible or manageable, may be less protective of RQ as the dyad seek to adjust to the on-going changes following the onset of dementia. This intuitive, circular association merits study, given previous findings, and the potential for preventive interventions.

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; (3) explore differences in carers' RQ perceptions according to the type of relationship with care-receivers (spouses/partners; adult child carers).

Methods

In this study we used cross-sectional baseline data, collected between November 2014 and July 2015, 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 European cohort study protocol was detailed elsewhere.[27]

Actifcare aimed at optimizing 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, Netherlands, Norway, Portugal, Sweden and United Kingdom (www.actifcare.eu).

Participants

Participants were community-dwelling people with mild or moderate DSM-IV dementia (Clinical Dementia Rating, CDR)[28], and their primary/family carers (being in contact at least once a week). Participants were excluded if they received significant care on account of dementia at baseline from formal services, and were recruited from various settings, including general practices, memory clinics and Alzheimer's Associations. [27]

Measures

From a wide range of scales[27], only the main measures used in the present study are outlined below. Instruments were translated whenever necessary. Careful cross-checking of back-translations helped to ensure validity and reliability.

The Positive Affect Index (PAI)[29] assessed RQ, and was rated separately by both people with dementia and their carers. This 5-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[12,14], showing good internal consistency (Cronbach α .81) and test-retest reliability over 12 weeks (r = .66).[30] In the present study, Cronbach's alphas were .82 (people with dementia) and .79 (carers).

The 13-item version of the *Orientation to Life Questionnaire* was used to assess carers' SOC.[1,16] 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.[31] Reported alpha coefficients range from .70 - .92 for the 13-item version, with adequate reliability and validity.[32] In the present study, Cronbach's alpha was .83.

The Resource Utilisation in Dementia Instrument (RUD 4.0)[33] was completed based on carers' reports. Measures specific for people with dementia included: CDR[28], Mini Mental State Examination (MMSE)[34], Neuropsychiatric Inventory Questionnaire (NPI-Q), with symptom count and separate scores for severity and carer distress[35], Instrumental Activities of Daily Living (IADL) and Physical Self-Maintenance Scale (PSMS).[36]

Carers also completed the Hospital and Anxiety Depression Scale (HADS)[37], and the Relative Stress Scale (RSS)[38] for caregiving-related stress. In addition to RSS total scores, 3 subscores were calculated (emotional distress, social distress, negative feelings toward the person with dementia).[39] Carer's social network was measured with the Lubben Social Network Scale (LSNS-6)[40]. Perseverance time (a single-item measure) assessed the period of time that the carer expects to be able to provide care.[41]

Ethical considerations

The study protocol was approved by ethics committees in each of the 8 countries. The carer and the person with dementia both gave written informed consent. [27]

Statistical analysis

Paired samples t-test, Wilcoxon-test, Mann-Whitney test, Pearson or Spearman correlation coefficients were used as appropriate. RQ dyadic discrepancy scores, defined as an index of dis(similarity) of RQ in members of the dyad, were calculated for each dyad by subtracting carer scores from person with dementia scores, and then divided by the mean of the two contributing scores.[12] 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 carers' subgroups. Independent variables were chosen based on the literature and the presence of significant bivariate relationships with the dependent variables, and examined for multicollinearity.

The significance threshold was set at ≤ .05. The statistical analyses were carried out using SPSS (Statistical Package for the Social Sciences) for Windows version 24.

Results

Demographic and clinical characteristics of the 451 person with dementia-carer dyads are summarized in Table 1 and detailed elsewhere.[42]

<Table 1 here>

Person with dementia and carer perspectives of Relationship Quality

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 = .385, p = .001), but people with dementia scored significantly higher than carers (t_{431} = 7.547, p = .001).

In PAI individual items, carer ratings were significantly lower than their pairs for communication (Z = -10.887, p =.001), similarity of views (Z = -6.171, p =.001) and generally getting along (Z = -5.256, p =.001), but did not diverge significantly for closeness and shared activities (Table 2).

<Table 2 here>

Factors associated with Relationship Quality

Bivariate correlations between PAI ratings and potential predictors were calculated (Table 3). Carer's 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 symptoms ratings were included in regression analyses.

<Table 3 here>

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's stress (negative feelings subscale), carer's depression and neuropsychiatric symptoms related to lower RQ. Carer's 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 carers' RQ ratings. Basic ADL function of person with dementia, carer's anxiety, perseverance time and co-residency were 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's stress (negative feelings) was associated with lower RQ ratings. Higher carer's education and the spouse/partner relationship type related to higher RQ ratings. Variables excluded from the model were person with dementia's age and education, carer's SOC and depression, perceived social support and perseverance time.

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

<Table 4 here>

Differences between carers subgroups' perspectives of Relationship Quality

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 (e.g. children-in-law, 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 at item-level. Adult children scored lower on shared activities (U = 13374, *p* =.001) and similarity of views (U = 15038, *p* = .001).

People with dementia rated RQ significantly higher when carers were spouses/partners compared to adult children (t_{340} = 2.097, *p* = .037). At item-level, people with dementia scored higher on shared activities (U = 14865, *p* = .001) and similarity of views (U = 13103, *p* = .001) when their carer was a spouse/partner.

<Table 5 here>

Separate hierarchical multiple regression analyses were conducted of RQ determinants in carer subgroups. Person with dementia background variables (e.g. age, neuropsychiatric symptoms) were entered into Block 1, carer background variables in Block 2 (e.g. education, depression), and caregiving context variables in Block 3 (e.g. 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's stress (negative feelings subscore) and depression were associated with lower RQ. Some person with dementia characteristics (Block 1) e.g., being male, neuropsychiatric symptoms, 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's 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's stress (negative feelings) and lower carer's education. Carer's stress (negative feelings) was the only variable associated with lower RQ in those receiving care from adult children.

<Table 6 here>

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 most previous evidence[5,30,43], suggesting a negative effect of caregiving on RQ perception. Alternatively, people with dementia perhaps acknowledge support provided by relatives and thus accentuate positive aspects of their relationship. In one study[12], 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[8,12] but also similar views and generally getting along. Ratings did not differ for closeness and shared activities, in line with other findings.[8,12] Although the overall quality of the relationship is likely to decline, aspects such as closeness may remain or even strengthen.[8] Positive and negative aspects of RQ coexist, thus difficulties in communication do not preclude positive experiences.

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.[25,26]

In this sample, stronger carer SOC related to carer higher 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 re-interpret and compensate for the impact of dementia, whilst 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). A small mixed-methods study demonstrated that it is feasible to consider the perspective of people with dementia on SOC.[44]

We were among the few to use a dyadic score to assess discrepancies between person with dementia and corresponding carer regarding RQ, supporting previous research.[12,14] In our sample, only carers' stress (negative feelings subscore) and neuropsychiatric symptoms of the person with dementia were associated with discrepancies in RQ ratings. For Woods (2009) and Clare et al. (2012)[12,30], stress was also a significant predictor of discrepancies.

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, consistent with previous evidence.[5,12,45] Neuropsychiatric symptoms of dementia also played an important role in carer RQ perceptions, consistent with studies where increased behavioural disturbances were associated with to poorer relationships.[5,8,15,46] Contrasting with findings from Spector and colleagues (2016)[5], carer anxiety was not significantly related with RQ in our sample. However, they used a different RQ measure (Quality of Carer and Patient Relationship), and their sample specifically included people with dementia and 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's social network to the RQ.[15] 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 carers' characteristics (education, stress and spouse/partner relationship type). The ratings of RQ made by people with dementia appear to be especially responsive to the negative feelings, including anger and frustration, reported by their carer. Spector et al. (2016)[5] found neuropsychiatric symptoms, namely aggression/agitation and irritability, to affect RQ from person with dementia's 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 sample, Clare et al. (2012)[12] 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's 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.[47,48]

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 to 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.[15] 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.

Whilst 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 (e.g. age, stress) rather than those of the person with dementia. In spouses, both carer and person with dementia characteristics (e.g. 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 which we did not evaluate (e.g. personality, attributions), may influence RQ perceptions throughout the course of dementia.

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 middle 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.[49]

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 assess pre-caregiving RQ, hindering an examination of whether this was different from current RQ. We also did not account for the impact of relationship and caregiving duration, which frequently impacts on carers' commitment to continuing care. Neither did we assess other members of the family system or close social networks (except the indirect assessment of carers' social support), with plausible systemic influence on RQ as viewed by our dyads. Fourth, RQ was only evaluated with PAI, a self-report measure that may be affected by e.g. 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.

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[4] and by increasing our understanding of RQ we can begin to build a better picture of the many facets of quality of life.

The distinct perspectives of RQ (person with dementia versus carer; 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.

Whilst 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.

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

***Person with dementia* (*n*= 451)**		**Score range**
Sex, women, n (%)	246 (54.5)	
Age, years, mean (SD)	77.7 (7.8, range 47-98)	
Education, years, mean (SD)	9.8 (4.4)	
Living alone, n (%)	88 (19.5)	
Type of dementia, n (%)		
Alzheimer's disease	218 (48.6)	
Vascular	52 (11.6)	
Mixed vascular/Alzheimer's disease	56 (12.5)	
Lewy Body	6 (1.3)	
Other	27 (6)	
Unknown	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
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, years, mean (SD)	66.4 (13.2, range 25-92)	
Education, years, mean (SD)	11.9 (4.4)	
Relationship to the person with dementia, n (%)		
Spouse/partner	288 (63.9)	
Adult children	137 (30.4)	
Other (e.g. son/daughter in law; sibling; other relative; friend; 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/day, mean (SD)	3.7 (3.1)	
Depression (HADS)	4.7 (3.6)	0-21
Anxiety (HADS)	6.1 (3.8)	0-21
Distress (NPI-Q)	9.3 (7.8)	0-60
Stress (RSS)	21.30 (10.9)	0-60
Sense of coherence (SOC), mean (SD) [a]	67.1 (10.9)	13-91
Relationship quality (PAI), mean (SD) [a]	20.9 (4.5)	5-30
***Dyads* (*n* = 415)**		
Relationship quality dyadic discrepancy score (PAI), mean (SD)	.87 (0.3)	

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, Relatives' Stress Scale; SOC, Sense of Coherence.

[a] Higher PAI scores indicate better RQ; higher SOC scores indicate stronger SOC.

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

	Person with dementia		Carer			
Item	M	SD	M	SD	Z	Sig.
Closeness	4.84	1.01	4.82	0.96	-.240	.810
Communication	4.43	1.07	3.46	1.38	- 10.887***	.001
Similarity of views	4.00	1.10	3.55	1.29	- 6.171***	.001
Shared activities	4.73	1.10	4.75	1.17	-.548	.584
Generally getting along	4.71	.96	4.41	1.11	- 5.256***	.001

* $p \leq .05$ ** $p \leq .01$ *** $p \leq .001$

PAI is rated on a 6-point scale (from 1 = not well to 6 = extremely well)

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)	.049	.025	-.045
Age (person with dementia)	-.087	-.130**	.008
Male sex (carer)	.075	-.030	-.171**
Male sex (person with dementia)	.019	-.081	-.101*
Education (carer)	.084	.112*	.039
Education (person with dementia)	.090	.131**	.062
Spouse/partner relationship to the person with dementia	.115**	.128**	.040
Living together with person with dementia	-.097*	-.084	-.062
Dementia severity (CDR)	.006	.045	.021
Cognitive impairment (MMSE)	.029	-.074	-.065
Sense of Coherence (SOC)	.328***	.122*	-.179***
Basic IADL function (IADL)	.072	-.044	-.139**
Basic ADL function (PSMS)	.164***	.069	-.118*
Neuropsychiatric symptoms (NPI-Q)	-.248***	-.048	.112*
Severity (NPI-Q)	-.121*	-.077	.010
Distress (NPI-Q)	-.158***	-.050	.046
Anxiety (HADS)	-.317**	-.081	.245**
Depression (HADS)	-.332**	-.119*	.199**
Stress (RSS total)	-.364***	-.134**	.225**
Emotional distress (RSS)	-.350***	-.129**	.228***
Social distress (RSS)	-.231***	-.064	.149**
Negative feelings (RSS)	-.389***	-.180**	.213**
Social support of carer (LSNS)	.109*	.211***	-.064
Perseverance time	.107*	.216***	-.086
Time spent assisting with basic and instrumental activities of daily living	.031	-.023	.060
Proportion of time spent by primary carer among all carers	.120*	.072	.014
Number of informal carers involved in care	-.087	-.012	-.051

* *p* ≤ .05 ** *p* ≤ .01 *** *p* ≤ .001

For the NPI the carer rated the person with dementia' symptoms, their severity and the degree of distress experienced by the carer.

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	
	β	Sig.	*β*	Sig.	*β*	Sig.
Education (carer)			.150	.002**		
Spouse/partner relationship type	.138	.004**	.187	.000***		
Sense of Coherence (SOC)	.096	.041*				
Neuropsychiatric symptoms (NPI-Q)	-.099	.036*			.148	.005**
Depression (HADS)	-.151	.006**				
Negative feelings (RSS)	-.257	.000***	-.212	.000***	.153	.003**
Social support of carer (LSNS)	.120	.007**				
Proportion of time spent by primary carer among all carers	.105	.026*				
Total R^2 adj	.254 F (7, 411) = 21.341***		.074 F (3, 414) = 12.136***		.059 F (2, 417) = 14.237***	

* *p* ≤ .05 ** *p* ≤ .01 *** *p* ≤ .001

TABLE 5. Characteristics of carers' subgroups (*n*= 902)

	Spouses / Partners	Adult children	Sig.
Sex, female, n (%)	173 (60.3)	103 (75.2)	.003**
Age, years, mean (SD)	73.6 (8.1)	52.0 (8.5)	.001***
Education, years, mean (SD)	11.2 (4.7)	13.4 (13.4)	.001***
Time spent assisting with basic and instrumental activities of daily living in hours/day, mean (SD)	4.2 (3.1)	3.3 (3.3)	.008**
Living together with person with dementia, n (%)	285 (99.3)	32 (23.4)	.001***

* *p* ≤ .05 ** *p* ≤ .01 *** *p* ≤ .001

PAI is rated on a 6-point scale (from 1 = not well to 6 = extremely well)

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

	PAI rating by carers				PAI rating by person with dementia			
	Spouses/partners (*n*=288)		Adult children (*n*=137)		Spouses/partners (*n*=288)		Adult children (*n*=137)	
	Δ R^2	β	Δ R^2	β	Δ R^2	B	Δ R^2	β
Block 1: Person with dementia variables	.147		.062		.042		.061	
Age		.059		-.176		-.030		-.197
Sex (male)		-.167*		-.043		-.002		-.011
Education (years)		.183**		-.039		.064		.021
Dementia severity (CDR)		-.019		.184		.115		-.149
IADL function (IADL)		-.063		-.040		-.154		-.271
Basic IADL function (PSMS)		.114		.079		.166		.034
Neuropsychiatric symptoms (NPI-Q)		-.295***		-.179		-.075		-.072
Block 2: Carer variables	.174		.181		.076		.119	
Age		-.106		-.274**		.128		-.191
Sex (male)		-.056		-.025		-.148		-.042
Education (years)		.077		-.044		.226*		.000
Sense of coherence (SOC)		.058		.221*		.001		.086
Emotional distress (RSS)		-.080		-.222		-.001		-.176
Social distress (RSS)		.005		.176		-.096		.170
Negative feelings (RSS)		-.209**		-.276*		-.221*		-.321**
Distress (NPI)		-.023		.050		.014		.097
Anxiety (HADS)		-.045		.022		-.014		.147
Depression (HADS)		-.172*		.033		.030		-.009
Block 3: Caregiving context variables	.014		.021		.015		.031	
Living together with person with dementia		-.110		.015		-.114		-.149
Time spent with person with dementia		-.015		.149		-.002		-.037
Proportion of time spent by primary carer among all carers		.013		.044		.049		.185
Number of other carers involved in care		-.031		.081		.011		.139
Total R^2	.334		.264		.133		.210	
	F (21, 219) = 5.223***		F (21, 124) = 2.114**		F (21, 216) = 1.579		F (21, 102) = 1.293	

* $p \le .05$ ** $p \le .01$ *** $p \le .001$