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Trajectories of relationship quality in dementia: a longitudinal study in eight European countries

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ABSTRACT

Objectives: Relationship quality (RQ) between a person with dementia and a family carer may influence their health and quality of life. However, evidence regarding its course and influencing factors is limited. We aimed to explore RQ trajectories in dementia, and identify predictors of change.

Methods: We analysed longitudinal data from a cohort of 350 community-dwelling people with dementia and their informal carers, participating in the Actifcare study in eight European countries. The Positive Affect Index, rated separately by both people with dementia and their carers, assessed RQ. Other measures included the Neuropsychiatric Inventory Questionnaire (regarding persons with dementia), and the Relative Stress Scale, Sense of Coherence Scale and Lubben Social Network Scale (for carers). Trajectories and influencing factors were explored applying a latent growth model (LGM).

Results: RQ in the group of carers declined over 1 year, but RQ scores for the persons with dementia did not change. Higher stress in carers negatively influenced their baseline RQ ratings. Carer sense of coherence and being a spouse were associated with more positive baseline RQ carer assessments. Higher levels of neuropsychiatric symptoms were linked to decline in carers' RQ, whereas social support was associated with more positive RQ trajectories.

Conclusion: This study provides a valuable insight into the course of RQ. LGM proved useful to explore the factors that influence RQ trajectories and variability within- and between-persons. Our findings emphasise the importance of carer-perceived social support and sense of coherence, and of reducing neuropsychiatric symptoms, in maintaining a good RQ.

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Introduction

Relationship quality (RQ) between persons with dementia and their supporters, mostly family carers, may influence quality of life (QoL) in both (Martyr et al., 2018; Menne et al., 2009; O'Shea et al., 2020; Quinn et al., 2009; Rippon et al., 2020; Woods et al., 2014).

Some studies also suggest worse RQ is associated with outcomes such as challenging behaviours, cognitive and functional decline or institutionalization (Edwards et al., 2018; Norton et al., 2009). Research indicates that RQ is a dynamic process and may change, especially from the perspective of carers, as dementia severity increases (Bruinsma et al., 2020; Clare et al., 2012; Spector et al., 2016). It is therefore important to determine which factors protect RQ over time.

A review of qualitative studies found that persons with dementia and their family carers try to maintain a sense of 'togetherness' (Wadham et al., 2016), despite the challenges and uncertainties accompanying dementia. However, the presence of difficulties such as behavioural problems may have a negative impact on RQ (Quinn et al., 2009).

Person with dementia and carer perspectives on RQ are particularly affected by factors such as carer stress (Marques et al., 2019), depression and anxiety (Watson et al., 2019), social isolation (Livingston et al., 2020) and neuropsychiatric symptoms of the person with dementia (Edwards et al., 2018). Our previous cross-sectional study of baseline data from a large European cohort study of people with dementia and their primary carers supported these findings (Marques et al., 2019). It also highlighted sense of coherence (SOC) and spouse/partner relationship type as potential protective factors of RQ meriting further evaluation. There is clearly scope for identifying other RQ predictors: in our study (Marques et al., 2019), as in other

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studies (Clare et al., 2012) a fair amount of variance in predictive models remained unexplained.

Evidence from longitudinal studies analysing the course and determinants of RQ is sparse. In young-onset dementia, RQ, as perceived by spouses, deteriorated over time (Bruinsma et al., 2020). Multiple factors were associated with lower RQ, including symptom duration, hyperactivity, apathy and less initiative toward performing daily living activities. Other longitudinal studies also found that carer RQ ratings declined (Clare et al., 2012) and that RQ is influenced by stress, depression and anxiety in the carer, and neuropsychiatric symptoms and self-reported QoL of the person with dementia (Clare et al., 2012; Spector et al., 2016).

However, the few available longitudinal studies relied on relatively small convenience samples (Clare et al., 2012; Spector et al., 2016), short follow-up periods (6 months) (Spector et al., 2016) or participants with particular profiles, such as higher anxiety in dementia (Spector et al., 2016) and young-onset dementia, or focused mainly on RQ outcomes and not determinants (Clare et al., 2014; Fauth et al., 2012; Norton et al., 2009; Springate & Tremont, 2014).

Moreover, these studies used variable-centred methodologies such as multiple regression, factor analysis and analysis of variance (Clare et al., 2012; Fauth et al., 2012; Norton et al., 2009; Spector et al., 2016; Springate & Tremont, 2014). To the best of our knowledge, the application of a statistical method such as latent growth model (LGM) to the understanding of RQ in dementia is novel. LGMs consist of variable based analyses that takes into account both within-person changes and between-person differences in individuals' change trajectories (Berlin et al., 2014; Duncan et al., 2006; Muthén, 2001; Preacher, 2008). Therefore, the present study aims to employ LGM to understand the course of RQ and its determinants in a large cohort of dementia caregiving dyads, examining a broader range of influences than considered in previous studies. These include RQ risk factors potentially amenable to intervention. Specifically, the influence of SOC, type of relationship and psychological and social unmet needs are evaluated alongside other recognised potentially modifiable risk factors, including neuropsychiatric symptoms, and carer stress, depression and anxiety.

The linkage between RQ perspectives of carers and people with dementia (interdependence) also merits further research. Some studies have explored the reciprocal influence of RQ, regarding specific outcomes. For example, higher perceived RQ among carers was positively associated with better ratings of QoL by people with dementia (Martyr et al., 2018). Findings from a cross-sectional analysis (Rippon et al., 2020) revealed that for each member of the dyad, their perceptions of RQ were significantly related to their own life satisfaction and well-being (an 'actor effect', Kenny et al., 2006) but had no significant impact on the wellbeing and life satisfaction of the other member of the dyad (a 'partner effect', Kenny et al., 2006). To our knowledge, no study has explored yet how the RQ perspectives of each member of the dyad impact on the perceived RQ of the other, although this information could inform timely psychosocial interventions, with a relationship focus.

Accordingly, we aimed firstly to examine changes in RQ longitudinally over a 12-month period in persons with dementia and carers, and to describe individual differences in these trajectories over time. Secondly, we aimed to consider the influence of a broad range of variables on RQ levels and trajectories.

Materials and methods

We studied a community-dwelling sample of people with mild-to-moderate dementia and their informal (family) carers participating in the Actifcare (ACcess to TImely Formal Care) EU-JPND project. Actifcare was a 1-year prospective cohort and multimethod study focusing on dementia formal care in the community in eight European countries: Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden and United Kingdom. Our previous study on RQ analysed baseline data from this cohort (Marques et al., 2019).

In the present study we used longitudinal data (three assessments: baseline, 6 and 12-month follow-ups), collected between November 2014 and August 2016, from people with dementia and their family carers (451 dyads). The Actifcare cohort study protocol is detailed elsewhere (Kerpershoek et al., 2016).

Participants

Participants were people with mild-to-moderate dementia according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) and the Clinical Dementia Rating (CDR) (Morris, 1993), and their informal carers (being in contact at least once a week). Clinicians in charge assessed the participants' severity of dementia, also confirmed by researchers (Kerpershoek et al., 2016). Exclusion criteria included alcohol-related dementia or Huntington's disease, and receipt of significant (personal) care from formal services at baseline because of dementia. Participants were recruited from various settings, including general practices, memory clinics and Alzheimer's Associations (Kerpershoek et al., 2016). Demographic and clinical characteristics of the Actifcare cohort at baseline are also detailed elsewhere ($n = 451$ dyads) (Kerpershoek et al., 2017; Marques et al., 2019).

Measures

Comprehensive assessments were conducted by trained staff (Kerpershoek et al., 2016), mostly at the participants' homes. Only the main measures used here are outlined below. Baseline variables possibly influencing carer and person with dementia RQ ratings were chosen based on the literature, including our previous findings (Marques et al., 2019).

When validated national versions were not available, instruments were translated and careful translation-back translation procedures helped to ensure validity and reliability.

The Positive Affect Index (PAI) (Bengston & Schrader, 1982) assessed current perceived RQ, and was rated separately by both persons with dementia and their carers. This 5-item scale comprises five questions addressing closeness, communication, similar views, shared activities and generally getting along. An example of an item is 'how is communication between yourself and your relative/friend, how well can you exchange ideas or talk about things that really concern you?'. Responses are rated on a 6-point scale from 1 (not well) to 6 (extremely well), with a total sum score ranging from 5 to 30 (higher scores reflecting better RQ). This scale has been used with people with dementia (Clare et al., 2012; Quinn et al., 2009), showing good internal consistency (Cronbach α .81) and reasonable test-retest reliability over 12 weeks ($r = .66$) (Woods, 2009). In the present study, Cronbach's α's were .82 (people with dementia) and .79 (carers).

Person with dementia measures

Measures for people with dementia included: CDR (Morris, 1993), Mini Mental State Examination (MMSE) (Folstein et al., 1975), a version of the Neuropsychiatric Inventory Questionnaire (NPI-Q), with symptom count and separate scores for severity and carer distress (Kaufer et al., 2000), Instrumental Activities of Daily Living (IADL) and Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969). The NPI-Q, IADL and PSMS were completed from the carer's report. The Camberwell Assessment of Need (CANE) was used to assess 24 areas of individual needs (environmental, health, social and psychological) and to record separately the perspectives of the people with dementia, carer and researcher (Reynolds et al., 2000). For each specific area (e.g. Does the person have difficulty in looking after their home?), responses are rated on a three point scale: 0 – no need, 1 – met need (problem receiving appropriate intervention or assessment) and 2 – unmet need (problem not receiving appropriate assessment or intervention). We considered the researcher's perspective (based on both person and carer's perspectives and all other information gathered though the assessment) regarding the total number of needs judged to be unmet.

Carer measures

Carers completed the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) and the Relative Stress Scale (RSS) (Greene et al., 1982). Carer's perceived social network was measured with the Lubben Social Network Scale (LSNS-6) (Lubben & Gironda, 2000). The 13-item version of the SOC scale was used to assess carer's sense of coherence (Antonovsky, 1987, 1993). Two CANE items evaluate carers' needs: information and psychological distress (Reynolds et al., 2000).

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.

Statistical analysis

For this longitudinal analysis, only dyads providing sufficient data on the PAI scale at all three time points were considered (350 dyads). Conditional Latent Growth Models (LGM) for both persons with dementia and carers were fitted to the data with the *lavaan* package (Rosseel, 2012) from the R Statistical Software System (R Core Team, 2019).

Missing data for variables with less than 10% missing were imputed using the Full Information Maximum Likelihood (*FIML*) method present in the lavaan package. No severe deviations to normality were observed in PAI scores ($|Sk|<3$ and $|ku|<7$) and thus Maximum Likelihood methods were appropriate for LGM (Marôco, 2018).

LGM assumes that the observed variations can be explained by two latent factors – the intercept (in this analysis, the initial level of RQ) and the slope (change rate of RQ) – that quantify the variation both at group level (fixed effects, the mean of the latent factor) and at individual level (random effects, the variance of the latent factor that estimates interindividual heterogeneity around the mean and the intraindividual variability over time) (Marôco, 2014). The analysis of individual effects versus group effects is conducted with significance tests on the means and variances of the intercept and slope.

Models were fitted using maximum likelihood and goodness of fit was assessed with the statistic, Goodness of Fit Index (*GFI*), Tucker Lewis Index (*TLI*) and Standardized Root Mean Square Residual (*SRMR)*. Since LGM have generally reduced degrees of freedom, the use of Root Mean Square Error of Approximation (*RMSEA)* is not recommended (Marôco, 2018). Non-significant , *GFI* and *TLI* larger than 0.95 and *SRMR* smaller than 0.05 were considered indicative of good model fit (Kline, 2015).

Results

Table 1 provides details of the demographics of the included sample ($n=350$ dyads) and their scores on measures at baseline. Table 2 provides descriptive statistics for the PAI at the three time points.

Relationship quality trajectories among persons with dementia and carers

The overall LGM for persons with dementia (Figure 1) had a good fit to the longitudinal data at the three time points $\chi^2(1)$

Table 1. Characteristics and summary of measures of people with dementia and their carers at baseline.

***Person with dementia* ($n=350$)**	
Sex, women, n (%)	169 (52.6)
Age, years, mean (SD, range)	76.8 (7.8, 47-94)
Education, years, mean (SD)	10.1 (4.5)
Living alone, n (%)	81 (25.2)
Type of dementia, n (%)	
Alzheimer's disease	176 (50.3)
Vascular	35 (10.0)
Mixed vascular/Alzheimer's disease	42 (12.0)
Lewy Body	4 (1.1)
Other	24 (6.9)
Unspecified/unknown type of dementia	69 (19.7)
Cognitive impairment (MMSE), mean (SD)	19.2 (5.0)
Dementia severity (CDR), n (%)	
1 (Mild)	342 (97.7)
2 (Moderate)	8 (2.3)
Neuropsychiatric symptoms (NPI-Q), mean (SD)	7.3 (5.4)
Severity (NPI-Q), mean (SD)	7.8 (5.1)
IADL function, mean (SD)	3.5 (1.9)
Basic ADL function (PSMS), mean (SD)	3.9 (1.8)
Unmet needs (CANE), mean (SD, range)	1.6 (1.8, 0-10)
***Carer* ($n=350$)**	
Sex, female, n (%)	209 (65.1)
Age, years, mean (SD, range)	66.7 (13.2, 28-92)
Education, years, mean (SD)	12.0 (4.5)
Relationship to the person with dementia, n (%)	
Spouse/partner	235 (67.1)
Adult children	96 (27.4)
Other (e.g. son/daughter in law; sibling; other relative; friend; neighbour)	19 (5.4)
Depression (HADS), mean (SD)	4.3 (3.5)
Anxiety (HADS), mean (SD)	5.9 (3.9)
Distress (NPI-Q), mean (SD)	8.7 (7.0)
Perceived social support (LSNS-6)	16.6 (5.6)
Stress (RSS), mean (SD)	20.31 (10.5)
Sense of coherence (SOC), mean (SD)	67.6 (10.9)
Psychological distress unmet needs (CANE), mean (SD, range)	1.0 (2.1, 0-9)
Information unmet needs (CANE), mean (SD, range)	1.1 (1.9, 0-9)

CANE, Camberwell Assessment of Need for the Elderly; CDR, Clinical Dementia Rating Scale; HADS, Hospital Anxiety and Depression Scale; IADL, Instrumental Activities of Daily Living; LSNS-6, Lubben Social Network Scale; MMSE, Mini Mental State Examination; NPI-Q, Neuropsychiatric Inventory Questionnaire; PSMS, Physical Self-Maintenance Scale; RSS, Relatives' Stress Scale; SD, Standard Deviation; SOC, Sense of Coherence.

Table 2. Descriptive statistics for Relationship Quality (PAI).

Variable	n participants	n missing participants	Completeness rate of PAI scale	*M*	*SD*	*Sk*	*Ku*	Histogram
PwD RQ (T0)	350	5	0.99	22.85	3.94	−0.78	1.28	
PwD RQ (T1)	350	29	0.92	22.40	3.86	−0.83	1.20	
PwD RQ (T2)	350	52	0.85	22.60	3.74	−0.58	0.73	
Carer RQ (T0)	350	6	0.98	21.31	4.42	−0.36	−0.14	
Carer RQ (T1)	350	15	0.96	20.71	4.31	−0.26	−0.29	
Carer RQ (T2)	350	9	0.97	19.82	4.55	−0.11	−0.34	

Ku, Kurtosis; M, Mean; PAI, Positive Affect Index; PwD, Person with dementia; RQ, Relationship Quality; SD, Standard Deviation; Sk, Skewness; T0, baseline; T1, follow-up at 6 months; T2, follow-up at 12 months.

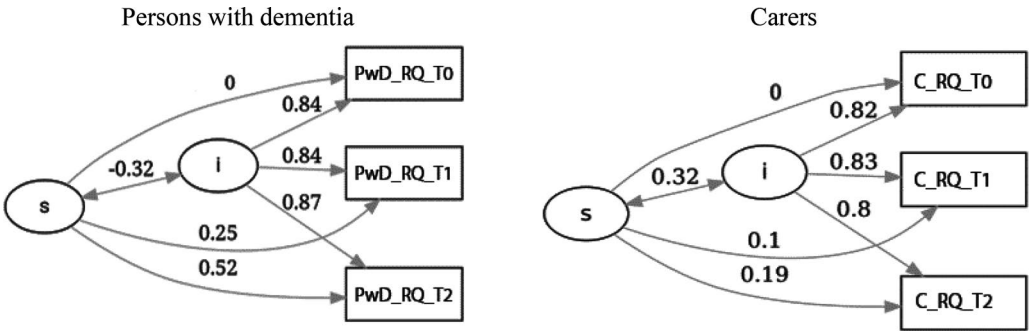

Figure 1. Path diagram for persons with dementia and carers' latent growth curve model (LGM). C, Carer; i, Intercept; PwD, Person with dementia; RQ, Relationship Quality; s, Slope; T0, baseline; T1, follow-up at 6 months; T2, follow-up at 12 months. By convention, circles (or ellipses) represent unobserved/latent variables (intercept and slope), squares (or rectangles) represent observed/measured variables (here RQ at T0, T1 and T2 are equally spaced repeated measures). The double-headed arrow represents the covariance between the latent intercept and slope, and single-headed arrows represent regression weights. The intercept is the initial level of RQ, measured by PAI scale, and the slope represents the rate in change of RQ over time. Each participant has an estimated intercept and slope, and these are allowed to vary across individuals. Latent variables also have means, reflecting the average of all participants' intercepts and slopes.

Table 3. Summary of LGM analysis for the baseline variables predicting Relationship Quality (PAI) trajectories among persons with dementia (factor loadings).

Latent factor	Indicator	Beta	SE	Z	Sig
i	Carer Relationship Quality (PAI)	0.431	0.050	6.546	0.000***
i	Relative Stress Scale (RSS)	0.084	0.022	1.185	0.236
i	Perceived social support of carer (LSNS-6)	0.027	0.036	0.451	0.652
i	PwD unmet needs (CANE)	−0.120	0.115	−1.950	0.051
i	Carer psychological distress unmet needs (CANE)	−0.001	0.537	−0..023	0.982
i	Spouse/partner relationship to the PwD	0.062	0.426	1.031	0.303
s	Carer Relationship Quality (PAI)	0.052	0.026	0.444	0.657
s	Relative Stress Scale (RSS)	0.164	0.012	1.306	0.191
s	Perceived social support of carer (LSNS-6)	0.023	0.019	0.221	0.825
s	PwD unmet needs (CANE)	0.111	0.061	1.007	0.314
s	Carer psychological distress unmet needs (CANE)	−0.038	0.282	-.0.325	0.745
s	Spouse/partner relationship to the PwD	−0.037	0.218	−0.351	0.726

CANE, Camberwell Assessment of Need for the Elderly; i, Intercept; LSNS-6, Lubben Social Network Scale; PAI, Positive Affect Index; PwD, Person with Dementia; RSS, Relatives' Stress Scale; s, Slope.

= 3.74, *CFI* = 0.99, *NFI* = 0.99, *TLI* = 0.97, *SRMR* = 0.02). The mean RQ at baseline was $\beta_0 = 22.745$; $p < .001$ and the mean RQ growth rate $\beta_1 = -0.159$; $p = 0.116$. Although the RQ growth trajectory for the entire group of persons with dementia did not change significantly over the 12-month period, there was a degree of individual variation within the group in their baseline RQ levels (Var(β_0) = 10.902, $p < .001$)). However, no significant variation in individual RQ growth trajectories over time was observed (Var(β_1) = 0.993; $p = 0.123$) (see appendix A1 published as supplementary material online).

Regarding carers, the overall LGM (Figure 1) had a good fit to the longitudinal data at T0, T1 and T2 ($\chi^2(1) = 1.07$, *CFI* = 1, *NFI* = 1, *TLI* = 1, *SRMR* = 0.01). The mean RQ baseline level was $\beta_0 = 21.370$; $p < .001$ and the mean RQ growth rate $\beta_1 = -0.762$; $p < .001$. Carer RQ ratings declined significantly over time. There were significant interindividual differences among the carers in their baseline RQ levels (Var(β_0) = 13.099, $p < .001$)) but no individual variation in the growth curve within the group was observed (Var(β_1) = 0.191; $p = 0.780$) (see appendix A2 published as supplementary material online).

Baseline determinants of relationship quality trajectories

We examined a number of potential baseline influences on RQ trajectories of persons with dementia and carers. For persons with dementia, we considered person with dementia unmet needs and carers' RQ perspective, stress, perceived social support, psychological distress unmet needs, and type of care relationship (i.e. spouse or adult child). Only RQ as rated by the carer showed a significant positive association with the baseline (intercept) perceived RQ of the person with dementia $\beta = 0.431$; $p < .001$ (Table 3). No statistically significant effects were

Table 4. Summary of LGM analysis for the baseline variables predicting Relationship Quality (PAI) trajectories among carers (factor loadings).

Latent Factor	Indicator	Beta	SE	Z	Sig
i	Basic ADL function (PSMS)	−0.023	0.117	−0.390	0.696
i	Neuropsychiatric symptoms (NPI-Q)	−0.062	0.042	−0.987	0.323
i	PwD Relationship Quality (PAI)	0.357	0.049	6.577	0.000***
i	Sense of Coherence (SOC)	0.190	0.022	2.807	0.005**
i	Anxiety (HADS)	0.022	0.071	0.288	0.773
i	Depression (HADS)	−0.127	0.082	−1.578	0.115
i	Relative Stress Scale (RSS)	−0.272	0.029	−3.173	0.002**
i	Perceived social support of carer (LSNS-6)	0.066	0.036	1.202	0.229
i	PwD unmet needs (CANE)	−0.072	0.116	−1.268	0.205
i	Carer psychological distress unmet needs (CANE)	0.044	0.527	0.722	0.470
i	Spouse/partner relationship to the PwD	0.198	0.427	3.509	0.000***
s	Basic ADL function (PSMS)	0.245	0.057	0.675	0.500
s	Neuropsychiatric symptoms (NPI-Q)	−0.839	0.021	−2.122	0.034*
s	PwD Relationship Quality (PAI)	−0.486	0.024	−1.423	0.155
s	Sense of Coherence (SOC)	0.263	0.011	0.619	0.536
s	Anxiety (HADS)	0.421	0.035	0.877	0.381
s	Depression (HADS)	0.634	0.040	1.257	0.209
s	Relative Stress Scale (RSS)	−0.395	0.014	−0.731	0.465
s	Perceived social support of carer (LSNS-6)	0.673	0.018	1.921	0.045*
s	PwD unmet needs (CANE)	0.916	0.056	2.561	0.010*
s	Carer psychological distress unmet needs (CANE)	0.464	0.258	1.221	0.222
s	Spouse/partner relationship to the PwD	−0.205	0.209	−0.577	0.564

CANE, Camberwell Assessment of Need for the Elderly; HADS, Hospital Anxiety and Depression Scale; i, Intercept; LSNS-6, Lubben Social Network Scale; NPI-Q, Neuropsychiatric Inventory Questionnaire; PAI, Positive Affect Index; PSMS, Physical Self-Maintenance Scale; RSS, Relatives' Stress Scale; s, Slope; SOC, Sense of Coherence.

observed for RQ change over time (slope, β_1) regressed on the conditioning variables.

Regarding the baseline factors influencing carers' rated RQ, increased levels of carer stress ($\beta = -0.262$, $p = .002$) related to lower baseline RQ (intercept) among carers (Table 4). RQ, as rated by the person with dementia ($\beta = 0.357$, $p < .001$), carer SOC ($\beta = 0.190$, $p = .005$) and being a spouse (compared to adult child carer) ($\beta = 0.198$, $p = .001$) were positively correlated with the baseline RQ level of carers. Higher levels of baseline neuropsychiatric symptoms ($\beta = -.839$, $p = .034$) influenced the decline of the carers' RQ growth curve over 1 year. Carer perceived social support ($\beta = 0.673$, $p < .045$) and person with dementia unmet needs ($\beta = 0.916$, $p < .010$) positively influenced RQ over time.

Discussion

In this one-year longitudinal study, we examined trajectories of RQ and its influencing factors in a large European sample of persons with dementia and their family carers.

Carers mean RQ scores decreased over time, whereas those of the persons with dementia did not. Partner-rated RQ was the only factor positively influencing both persons with dementia and carer RQ baseline levels. Higher levels of carer stress negatively influenced baseline RQ scores among carers. Carer SOC and being a spouse were positively correlated with the baseline RQ scores of carers. Neuropsychiatric symptoms at baseline predicted a decline in carers' RQ over time, whereas carer social support and person with dementia unmet needs were associated with more positive RQ growth curves.

The LGM approach is invaluable in describing and explaining the development of RQ over time, offering the possibility of analysing change at the individual level and identifying influencing factors. LGM capitalises on both aspects of change over time (mean trend and individual departures from the mean trend). This combination of individual and group levels of analysis is unique. In this study, the significant mean and variance of the intercept factor indicated a considerable between-person variation in the initial levels of perceived RQ for both persons with dementia and carers. To the best of our knowledge, this is the first study using LGM to evaluate RQ in dementia. However, findings from reviews of qualitative studies demonstrated the importance of exploring the heterogeneity of individual experiences to provide a richer understanding of RQ (Evans & Lee, 2014; Wadham et al., 2016).

The decreasing carer RQ scores and the stable scores of person with dementia are in line with other studies (Bruinsma et al., 2020; Clare et al., 2012; Spector et al., 2016). Although family carers may try to maintain their previous RQ (Wadham et al., 2016), the caring process can be overwhelming and this may lead to the observed reduction in RQ (Egilstrod et al., 2019; Evans & Lee, 2014). In this study, carer stress negatively influenced baseline carer RQ scores, as in our previous baseline analysis (Marques et al., 2019) and in several other studies (Clare et al., 2012; Spector et al., 2016), although the direction of causation remains uncertain.

Social support emerged as a significant protector of carer RQ growth trajectories. This is in line with previous evidence that informal support mechanisms may reduce the burden of caregiving (Del-Pino-Casado et al., 2018) and impact positively on RQ. A study with carers of people with young-onset dementia (Bruinsma et al., 2020) showed an association between 'seeking social support' and lower RQ. The authors suggested this might be due to reverse causality. Spouses perceiving RQ as low might seek more social support from relatives or friends, using emotion-focused coping. Our results extend the findings from a meta-analysis that called for interventions that enhance carers' perceived social support, to prevent or alleviate subjective burden (Del-Pino-Casado et al., 2018). The authors called, specifically, for interventions resulting in carers 'feeling connected' rather than on 'building connections', since perceived social support was more strongly related to subjective burden than was the amount of social support actually received (Del-Pino-Casado et al., 2018). These interventions are even more relevant given the impact of COVID-19 restrictions on informal support mechanisms and social support services increasing social isolation and carer stress (Giebel et al., 2021; Tuijt et al., 2021).

The positive association between carer SOC and the initial RQ level also supports our previous baseline analysis (Marques et al., 2019). Living in a satisfactory relationship may contribute to maintain or increase one's SOC. Continuing home care does not necessarily decrease SOC and positive caregiving experiences may contribute to increasing SOC (Kuroda et al., 2007). On the other hand, a stronger SOC, as a dispositional orientation, potentially protects family carers from psychological distress and may reduce the negative impact of caregiving (Childers, 2019; Del-Pino-Casado et al., 2019; Gonçalves-Pereira et al., 2021; López-Martínez et al., 2021). In a longitudinal study, SOC appears to buffer the impact of carer strain on symptoms of depression and anxiety in informal carers (López-Martínez et al., 2021). This possible reciprocal association merits study, given previous findings outside caregiving contexts (Pokorski & Kuchcewicz, 2012; Volanen et al., 2004), and the potential for preventive interventions, namely targeting spouse carers with low SOC who seem to be a vulnerable group (Andrén & Elmståhl, 2008; Gonçalves-Pereira et al., 2021).

Being a spouse/partner (compared to adult child carer) emerged as a potential protector of initial carers' RQ but did not influence RQ trajectories over time. A systematic review found little attention accorded to characteristics such as kin-relationship of the carer that could influence RQ perceptions (Quinn et al., 2009). In one study, using a different relationship index, partner carers reported a worse relationship with the person with dementia than adult child carers or children-in-law (Spruytte et al., 2002). In contrast, in our previous baseline analysis, using a variable-centred approach (regression), findings showed that being a spouse/partner was positively associated with RQ, as rated either by the carer or the person with dementia (Marques et al., 2019). However, the current analysis, indicated that being a spouse/partner, as a potentially protective variable, loses explanatory power in the various RQ trajectories. The experience of giving and receiving care usually occurs within long-standing relationships which precede the onset of dementia and continue to evolve as it progresses. Providing support to spouses to come to terms with factors that menace their sense of couplehood might help them to adopt a more positive attitude toward their relationship and improve the RQ and care (Ablitt et al., 2009; Pozzebon et al., 2016). Aspects of prior relationship influence caregiving dynamics and on how the caregiver and care-receiver roles are experienced (Steadman et al., 2007). Concurrently, the experience of living with dementia impacts on the relationship, often causing change or loss to which it is difficult to accept or adjust (Hellstrom et al., 2007).

Higher baseline neuropsychiatric symptoms were associated with subsequent decline in RQ. Our analyses broaden the findings of a systematic review that suggested a weak association between relationship factors and challenging behaviours in dementia (Edwards et al., 2018). However, most of the studies reviewed used a cross-sectional design and only assessed carers' RQ perspective (Edwards et al., 2018). A recent longitudinal study with spouses of people with young-onset dementia found that lower perceived RQ was also associated with longer symptom duration, namely higher levels of apathy and hyperactivity (Bruinsma et al., 2020). Other authors concluded that RQ moderated family carers' distress responses to daily neuropsychiatric symptoms (Chunga et al., 2021).

The extent of person with dementia unmet needs, as assessed at baseline by the researcher, were also linked with a positive trajectory in carers' RQ. The reasons for this are unclear and require further exploration e.g. as to whether specific domains of unmet needs impact on RQ, or whether the extent to which these needs are subsequently met is important.

Our study showed the significant reciprocal partner effect of the perception of the current RQ on the other member of the dyad. This underlines the importance of considering the perspectives of both the carer and the person with dementia and enabling each to maintain positive perceptions of RQ.

Identifying baseline determinants of RQ trajectories is helpful to develop timely interventions improving the development of health and QoL outcomes later. RQ is a key component of QoL (Edwards et al., 2018; Rippon et al., 2020; Woods et al., 2014). Understanding RQ and its influencing factors better will assist professionals in identifying how to promote QoL in dementia, namely by targeting risk factors that are amenable to intervention (e.g. neuropsychiatric symptoms, lack of social support). Hence, it can help researchers and policymakers to focus on those especially at risk. The interindividual differences at baseline, potentially influencing outcomes, suggest that further analyses could help to delineate those people with dementia and family carers most at risk of developing negative RQ trajectories. Identifying and tracking individuals at risk of pursuing worse RQ trajectories is even more relevant in light of restrictions such as the recent COVID-19 lockdown that are especially challenging for those with poor RQ (Pieh et al., 2020). As the COVID-19 pandemic and its effects continue, more research is needed to understand its impact on RQ.

Strengths and limitations

The study had several strengths. We used a longitudinal design, with repeated assessments, to analyse how relationship quality changes over time in a large, typical sample from eight countries, in different European regions. Furthermore, we were able to consider an extensive range of possible predictors of RQ longitudinally, with a potential to impact positively upon the QoL of persons with dementia and families. The LGM model, positioned at the intersection of variable- and person-centered analysis, allowed identification of intraindividual and interindividual differences and examined the effect of predictors on RQ change.

The study also had limitations. First, the sample may not be fully representative, limiting generalizability. Attrition from the baseline sample inevitably leads to some selection bias, with included people with dementia likely to be younger and less severely impaired, with carers having lower stress levels. Second, the follow-up period was 12 months; a longer follow-up period could have shown different trajectory patterns of RQ. Third, we only considered the baseline measurements of the potential predictors like stress and social support, rather than change over time. Finally, we did not consider the influence of a variety of potentially important factors including notably the RQ prior to the onset of dementia.

Conclusion

The present study offers novel insights into the course of RQ using a longitudinal design supported by LGM, a statistical method that considers intra- and inter-individual aspects.

Tackling influencing factors such as carer-perceived social support, sense of coherence and person with dementia neuropsychiatric symptoms may help maintaining a good RQ trajectory, especially among more vulnerable dyads.

These findings show the reciprocity between carer and person with dementia RQ and provide social and healthcare

professionals with a preliminary understanding of RQ trajectory patterns and determinants across one year.

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