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Research paper

Sense of coherence, subjective burden, and anxiety and depression symptoms in caregivers of people with dementia: Causal dynamics unveiled by a longitudinal cohort study in Europe

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ABSTRACT

Background: Sense of coherence (SOC) is a disposition to perceive things as comprehensible, manageable and meaningful. Lower SOC is associated with subjective burden and psychological morbidity in family caregivers, including in dementia. However, the evidence-base mainly comprises small-scale or cross-sectional studies. More should be known about SOC stability, causal relationships, and international contexts. We aimed to study longitudinal links between dementia caregivers' SOC, subjective burden, and anxiety and depression symptoms in a multinational sample.

Methods: We analyzed the EU-Actifcare cohort (451 dyads of community-dwelling people with mild-moderate dementia and their caregivers). Caregivers' assessments included: SOC scale, Relatives' Stress Scale, Hospital Anxiety and Depression Scale. A cross-lagged panel model was used to investigate associations between these measures at baseline, 6 and 12-month follow-ups, controlling for covariates.

Results: Caregivers' subjective burden, anxiety and depression symptoms increased over time, SOC remaining overall stable. Considering the first six-month follow-up, we found bidirectional relationships between SOC and

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subjective burden, and SOC and anxiety symptoms, while lower SOC predicted depression symptoms but not vice versa. For the remaining follow-up period, both anxiety and depression symptoms predicted lower SOC but not vice versa.

Limitations: Convenience sampling precludes full generalizability.

Conclusions: This large longitudinal study shed more light on interplays between SOC, subjective burden and mental health outcomes in dementia caregivers. Findings were consistent with SOC potential protective role against burden and psychological morbidity. However, they also supported reverse causality regarding part of the associations. Caregivers' SOC levels may be directly influenced by subjective burden and psychological morbidity.

1. Background

Sense of coherence (SOC), defined as a personal disposition to view the world as comprehensible, manageable, and meaningful, develops in young adulthood and theoretically remains stable thereafter, perhaps slightly decreasing with retirement (Antonovsky, 1987). Closely associated with mental health (Huber et al., 2011), SOC may protect and promote health overall, as emphasized by salutogenic perspectives (Eriksson and Lindström, 2006; Mittelmark et al., 2017).

Providing care to someone with a chronic health condition is the daily experience of many people worldwide. The majority of informal (unpaid) caregivers are family members, whom we call 'caregivers' in this paper. Caregiving experiences may include subjective burden or stress specific to caregiving (henceforth 'caregiver burden', despite the limitations of the term 'burden') and psychological morbidity, particularly anxiety and depression symptoms, syndromes or disorders. Associations between caregiver burden and depression symptoms are uncontentious (Pinquart and Sörensen, 2003), while links between caregiver burden and anxiety symptoms are also recognized e.g., among dementia caregivers (Cooper et al., 2007; Li and Loke, 2013). For those caring for older relatives, their subjective burden is a risk for depression symptoms and may precipitate clinical depression (del-Pino-Casado et al., 2019b). Addressing caregivers' burden may plausibly foster psychological well-being.

There is a rationale for the putative protective role of SOC regarding caregivers' burden and mental health outcomes: internal resources empower individuals to face life's challenges through the ability to find meaning in difficult, longstanding situations. A systematic review and meta-analysis reported that higher levels of SOC are associated with less caregiver burden and better mental health outcomes, suggesting SOC safeguards caregiver well-being (del-Pino-Casado et al., 2019a). A longitudinal analysis of caregivers of older people (a minority of whom were cognitively impaired) (López-Martínez et al., 2021) found that SOC was inversely associated with anxiety and depression symptoms, mediating both the relationship between caregiver strain and anxiety, and strain and depression symptoms. SOC remained relatively stable, apparently buffering the impact of caregivers' strain on psychological morbidity.

Dementia, including Alzheimer's disease, poses particular challenges to caregivers. Despite the relationship of motivations for caregiving with wellbeing (Quinn et al., 2010), SOC remains under-researched in dementia caregiving (Marques and Gonçalves-Pereira, 2014). Only 12 of the 38 studies reviewed by del-Pino-Casado et al. regarded dementia caregivers and findings are inconsistent: a recent study reported inverse associations between SOC and psychological distress, as expected, but associations with caregiver burden and positive aspects of caregiving were not significant (Gonçalves-Pereira et al., 2021).

Most studies have been cross-sectional; for a better understanding of the role of SOC in dementia caregiving, emphasis must be given to longitudinal research. A study of spouses of persons with mild Alzheimer's dementia in Finland reported a significant decrease of SOC over time, predicted by caregivers' depression symptoms at baseline (Välimäki et al., 2014). Another group, in Spain, examined the longitudinal effect of SOC on the burden of care in Alzheimer's dementia. SOC generally decreased but was stable among high scorers. The low-SOC group reported a higher caregiver burden, and vice versa (Turró-Garriga et al., 2022).

In summary, lower SOC has been proposed as a risk factor for caregiver burden and psychological morbidity in caregivers of older people with chronic conditions, in general, but the evidence is limited in relation to dementia. As López-Martínez et al. (2021) pointed out, most studies do not account for other variables that may be important in affecting resilience and predicting well-being e.g., unmet needs, access to resources. We need to know more about dementia caregivers' SOC stability, causal relationships regarding caregiver burden and mental health, and the cross-national or cross-dementia subtype generalizability of findings, so that caregiver needs can be more effectively addressed. The EU-Actifcare cohort study can contribute to bridge part of these gaps, with its large multinational sample of people with dementia and their primary caregivers, followed over one year, and comprehensive, high-quality data on multiple variables of interest (Kerpershoek et al., 2016).

Research on SOC - as moderator (influencing) or mediator (explaining the relationships) of caregiver burden and mental health outcomes - acknowledged the possibility of reverse causality. However, this has been rarely examined. Indeed, the relative stability of SOC has been confirmed only in part: it may be not as stable as Antonovsky postulated (Eriksson and Mittelmark, 2017), and divergent findings include two dementia caregiving reports (Turró-Garriga et al., 2022; Välimäki et al., 2014). Rethinking the construct, as operationalized, high levels of caregiver burden, anxiety and/or depression symptoms could influence how caregivers report their SOC (Gonçalves-Pereira et al., 2021). Accordingly, it is debatable whether low SOC influences the probability of falling ill or vice versa. This hypothesis does not contradict the salutogenic theory, proposing reciprocal and dynamic relationships between SOC and 'generalized resistance resources' that include the individual's coping strategies and state of mind (Idan et al., 2017). Advanced statistical methods like cross-lagged analysis provide opportunities to clarify the nature and direction of relationships between these variables, using longitudinal designs.

We therefore aimed to investigate how levels of SOC in caregivers of community-dwelling people with mild-moderate dementia might change over one year. By using cross-lagged analysis, we also aimed to uncover the dynamic relationships between caregiver SOC, caregiver burden, anxiety and depression symptoms, controlling for covariates to increase the precision of our findings.

2. Methods

We conducted a secondary analysis of the EU-Actifcare longitudinal study of people with dementia and their caregivers in eight European countries (Germany, Ireland, Italy, Norway, Portugal, Sweden, The Netherlands, and United Kingdom). Details on methods, including design, sampling, variables, measures and procedures, were published elsewhere (Kerpershoek et al., 2016).

2.1. Population and sample

The EU-Actifcare sample comprised 451 dyads of people with DSM-IV-TR dementia (American Psychiatric Association, 1994) and their primary (main) family caregivers. According to inclusion criteria, participants should have mild or moderate dementia (Clinical Dementia Rating – CDR) (Morris, 1993) or scores below 25 on the Mini Mental State Examination (MMSE) (Folstein et al., 1975), no relevant formal assistance with personal care relating to dementia (e.g., paid home caregiver) for the previous 6 months, and a clinical impression that such formal care would be needed within one year. People with significant comorbidities (severe somatic/mental disorders or sensory impairments) were excluded (Kerpershoek et al., 2016).

In each country, dyads were recruited from different regions, and clinical and social settings (primary care, neurology and psychiatry outpatient clinics, memory clinics, and the third sector, including Alzheimer associations). Assessments took place at baseline, and at 6 and 12-month timepoints (T0, T1 and T2, respectively).

2.2. Variables and measures

Our main variables were SOC, caregiver burden, and anxiety and depression symptoms. SOC was assessed using the 13-item Orientation to Life Scale (Antonovsky, 1993), commonly named the SOC scale, adapted from the 29-item version. These 13 items, measuring comprehensibility, manageability and meaningfulness, were rated on a seven-point Likert scale (1 to 7) for agreement or disagreement. The 7-response options change between questions; five items are negatively worded and are reverse coded when summing the items. A total score was calculated, ranging from 13 to 91, with higher scores indicating a stronger SOC. In this study, the Cronbach's α for SOC at T0, T1 and T2 were 0.80, 0.82, and 0.83, respectively. Caregiver burden was assessed using the Relative Stress Scale (RSS) (Greene et al., 1982). It consists of 15 items scored on five levels of intensity, ranging from 0 = 'not at all' to 4 = 'to a high degree'. A total score was calculated, ranging from 0 to 60. In this study, the Cronbach's alpha for RSS ranged from 0.90 to 0.91 across different timepoints. Anxiety and depression symptoms were measured using the 14-item Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). It consists of seven-item scales, one for anxiety (HADS-A) and the other for depression (HADS-D), each scale score ranging from 0 to 21. In this study, the HADS-A Cronbach's alpha ranged from 0.81 to 0.84 and, for the HADS-D, from 0.78 to 0.81.

Several covariates were considered: caregivers' demographics (gender, age), co-residence with the person with dementia, and perceived support of the social network (*Lubben Social Network Scale* - LSNS-6) (Lubben et al., 2006), together with clinical-functional variables of persons with dementia: the *Clinical Dementia Rating Scale* (CDR) (Morris, 1993) for dementia severity; the *Lawton Instrumental Activities of Daily Living scale* (IADLS) (Lawton and Brody, 1969) and the *Physical Self-Maintenance Scale* (PSMS) (Lawton and Brody, 1969) for functionality; the *Neuropsychiatric Inventory* (NPI-Q) (Cummings et al., 1994) for neuropsychiatric symptoms. The *Camberwell Assessment of Need for the Elderly* (CANE) interview (Reynolds et al., 2000) measured the needs of people with dementia (non-existent, met or unmet) and help (received and needed) across 24 biopsychosocial domains. The sum of unmet needs according to interviewers' ratings was used. Finally, the *Resource Utilization in Dementia* (RUD) instrument (Wimo et al., 2013) was used to estimate the extent of informal care in personal and instrumental activities of daily living (in hours).

2.3. Procedures

Participants were seen, mostly at home, by trained interviewers. One to two visits of up to two hours were typically required to complete all assessments. Ethical approval was granted by ethics committees in each country and procedures followed the Helsinki Declaration of the World Medical Association. Persons with dementia and caregivers provided written informed consent according to national regulations (Kerpershoek et al., 2016).

2.4. Data analysis

Descriptive and inferential analyses were carried out. Pearson correlation coefficients were estimated to examine relationships between main variables. Repeated measures ANOVA tests assessed changes between the three timepoints for main variables. The invariance of the measures was assessed using multiple confirmatory factor analyses in a four-step process. Using the step-up approach, the fit of the basic model was judged to be good for all constructs. Subsequent tests for configural, metric and scalar invariance showed the models still fit well under restrictive conditions (Supplementary Table-A); this indicated that factor models for all scales remained invariant over time, fulfilling the requirements for autoregressive models (Little et al., 2007). Intraclass correlation coefficients were also calculated for main variables and varied between 0.87 and 0.90, indicating a very high level of consistency and reliability in the measurements taken.

A cross-lagged panel model with two variables was used to test the predictive relationships between SOC and the other main variables (caregiver burden, anxiety and depression symptoms) and also between caregiver burden and anxiety, and depression symptoms at all timepoints, resulting in three types of relationships: synchronous relationships, indicating cross-sectional associations between variables at the same timepoints; autoregressive relationships, indicating e.g., the longitudinal prediction of SOC_T1 by SOC_T0 or RSS_T1 by RSS_T0; and cross-lagged relationships, indicating e.g., the longitudinal prediction of RSS_T1 by SOC_T0 or SOC_T1 by RSS_T0. A strength of this approach is the ability to analyze both time-lagged directions simultaneously, identifying potential bidirectional associations between SOC and caregiver burden, and anxiety and depression symptoms over time (Anderson and Kida, 1982).

Four models were tested for SOC and each other main variable, following guidelines (Martens and Haase, 2006). Picking the example of SOC and caregiver burden, a first model (M1) included only autoregressive correlations of the variables. A measure of SOC predicted subsequent SOC, and caregiver burden predicted subsequent caregiver burden. The second model (M2) included autoregressive paths plus the path from SOC_T0 to RSS_T1 and SOC_T1 to RSS_T2. The third model (M3) included autoregressive paths plus the path from RSS_T0 to SOC_T1 and RSS_T1 to SOC_T2. Finally, the fourth model (M4) was fully cross-lagged, with autoregressive effects and both cross-lagged pathways. The same logic was used to test the caregiver burden models with anxiety and depression symptoms. Additionally, we conducted the same analyses using only two timepoints (T0 and T2), such as M2 (SOC_T0 to RSS_T2) and M3 (RSS_T0 to SOC_T2) (Supplementary Table-B).

According to standards for model fit and data, CFI (Comparative Fit Index) > 0.90, TLI (Tucker-Lewis Index) > 0.90, RMSEA (Root Mean Square Error of Approximation) < 0.08 and SRMR (Standardized Root Mean Square Residual) < 0.08 are the basic criteria that should be met (Bentler and Bonett, 1980). Missing data were handled using maximum likelihood estimation due to varying participant numbers across measurement points. Once these conditions were met, the difference between the χ^2 for each model and the χ^2 given by the previously well-fitted model was used to select the best model. We report only the three best models for SOC and each of the other main variables. A p value < 0.05 was considered statistically significant. The data were analyzed using JASP (version 0.18.0) performed with lavaan syntax.

3. Results

3.1. Descriptive and preliminary inferential analyses

Table 1 displays the demographic characteristics of caregivers and

Table 1
Characteristics of people with dementia and their caregivers at baseline.

People with dementia	$n = 451$
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	
Alzheimer's type, *n* (%)	218 (48.6)
Vascular, *n* (%)	52 (11.6)
Lewy Body, *n* (%)	6 (1.3)
Mixed (Alzheimer's and vascular), *n* (%)	56 (12.5)
Not known, *n* (%)	90 (20)
Other, *n* (%)	27 (6)
Missing	2 (0.4)
Dementia severity (CDR)	
Category 1, n (%)	354 (78.2)
Category 2, n (%)	87 (19.7)
Missing	10 (2.2)
Comorbidity (Charlson index), mean (SD)	5.7 (15.6)
None, *n* (%)	108 (23.9)
Low comorbidity, *n* (%)	108 (23.9)
High comorbidity, *n* (%)	235 (52.1)
Lawton IADL function (range: 0–8), mean (SD)	3.4 (1.97)
Basic ADL function (PSMS) (range: 0–6), mean (SD)	3.65 (1.86)
Neuropsychiatric symptoms (NPI-Q) (range: 0–30), mean (SD)	7.82 (5.53)
Camberwell Assessment of Need for the Elderly (CANE): Unmet needs, mean (SD)	1.75 (1.99)

Caregiver	$n = 451$
Women, *n* (%)	299 (66.4)
Age (years), mean (SD)	66.4 (13.3, range 25–92)
Marital status	
Single (never married), *n* (%)	30 (6.7)
Married, *n* (%)	398 (88.2)
Other (separated, divorced, widowed), *n* (%)	56 (12.3)
Education (years), mean (SD)	11.9 (4.4)
Relationship to the person with dementia	
Spouse/partner, *n* (%)	288 (63.9)
Adult children, *n* (%)	137 (30.4)
Other (e.g., son/daughter in law, sibling, other relative, friend, and neighbour), *n* (%)	26 (5.8)
Occupation	
Retired, *n* (%)	287 (63.8)
Employed, *n* (%)	125 (27.8)
Other (for example, homemaker, unemployed/unable to work, student, …), *n* (%)	38 (8.4)
Living with person with dementia, *n* (%)	323 (71.6)
Social support (LSNS-6) (range: 0–5), mean (SD)	2.77 (0.92)
Resource Utilization in Dementia (RUD): informal care in personal and instrumental activities of daily living (hours), mean (SD)	3.56 (3.16)

Note: ADL – activities of daily living; CDR - Clinical Dementia Rating; Charlson index (number of comorbidities) – none: 0–1 conditions; low comorbidity: 2 conditions; high comorbidity: ≥ 3 conditions; IADL – instrumental activities of daily living; LSNS-6 - Lubben Social Network Scale; NPI-Q – Neuropsychiatric Inventory Questionnaire; SD – standard deviation.

their relatives, along with baseline clinical and functional data. T0 assessments were completed by 451 dyads, T1 by 398 and T2 by 368. Given the number of participants lost to follow-up (T1, $n = 53$; T2, $n = 83$), potential selection bias was examined. Baseline differences in the main variables were tested between participants at T2 and those lost to this follow-up, using Student's *t*-test. No differences were found in SOC [$t(443) = -0.61$, $p > .05$] and anxiety symptoms (HADS-A) levels ($t(442) = -0.678$, $p > .05$). However, participant dropouts had higher levels of caregiver burden [$M = 22.9 \pm 11.4$; $t(444 = -2.173$, $p < .05$] and depression symptoms (HADS-D) [$M = 5.5 \pm 3.8$; $t(442) = -2.571$, $p < 0.05$] at baseline compared to completers ($M = 20.5 \pm 10.6$; M = 4.5 ± 3.5, respectively).

The means, standard deviations, Cronbach's alphas and correlations of the main variables are presented in Table 2. Caregiver burden increased significantly from T0 to T2 [*F(2,602) = 4.6, p = 0.01)*], as did anxiety [*F(2,638) = 2.997, p = 0.05)*] and depression symptoms [*F(2,626) = 14.877, p < 0.001]*. There were no statistically significant differences in SOC levels from T0 to T2 [*F(2,646) = 2.285, p = 0.103)*]. Correlations between T0, T1 and T2 assessments on each main variable ranged from 0.683 to 0.727 for SOC, 0.699 to 0.796 for caregiver burden, 0.678 to 0.709 for anxiety symptoms and 0.679 to 0.760 for depression symptoms, indicating high constancy. All these main variables were significantly correlated with each other at each timepoint. At baseline, SOC was negatively correlated with caregiver burden, anxiety and depression symptoms (all $rs \leq -0.44$, all $ps < 0.001$), while caregiver burden, anxiety and depression symptoms were positively correlated with each other (all $rs \geq 0.49$, all $ps < 0.001$).

3.2. Cross-lagged panel analysis

As seen in Table 3, the M4 models significantly improved the fits over the previous models. The cross-lagged correlations of the M4 models involving SOC are presented in Fig. 1.

The first model links **SOC and caregiver burden** (Fig. 1a). In this model, the path from SOC at T0 to burden at T1 ($\beta = -0.177$, $p < 0.001$) and the reverse path (burden at T0 to SOC at T1) were both statistically significant ($\beta = -0.117$, $p < 0.01$) These results revealed a bidirectional relationship between SOC and caregiver burden levels, albeit restricted to the first follow-up period: in fact, neither the path from SOC at T2 to burden at T1 nor from burden at T2 to SOC at T1 were significant.

The second model describes the associations between **SOC and anxiety symptoms** (Fig. 1b). In this model, the path from SOC at T0 to anxiety symptoms at T1 ($\beta = -0.225$, $p < 0.001$) was statistically significant, but not the one from SOC at T1 to anxiety symptoms at T2 ($\beta = -0.026$, $p > 0.05$). The reverse paths were both significant: from anxiety symptoms at T0 to SOC at T1 ($\beta = -0.159$, $p < 0.001$) and from anxiety symptoms at T1 to SOC at T2 ($\beta = -0.1$, $p < 0.05$).

Fig. 1c shows the third model linking **SOC and depression symptoms**. SOC at T0 negatively predicted depression symptoms at T1 ($\beta = -0.251$, $p < 0.001$), while SOC at T1 did not predict depression symptoms at T2 ($\beta = 0.002$, $p > 0.05$). On the other hand, depression symptoms at T0 did not predict SOC at T1 ($\beta = -0.074$, $p > 0.05$) but at T1 they predicted SOC at T2 ($\beta = -0.139$, $p < 0.01$).

Regarding the relationship between **caregiver burden and anxiety symptoms**, the best model fit was M3 (Fig. 2a). Caregiver burden at T0 predicted anxiety symptoms at T1 ($\beta = 0.222$, $p < 0.001$), and similarly, caregiver burden at T1 predicted anxiety symptoms at T2 ($\beta = 0.1$, $p < 0.05$). Model M4 provided the best fit for the relationship between **caregiver burden and depression symptoms**: these symptoms at T0 predicted caregiver burden at T1 ($\beta = 0.162$, $p < 0.001$) and, vice versa, caregiver burden at T0 predicted depression symptoms at T1 ($\beta = 0.154$, $p < 0.01$). Furthermore, depression symptoms at T1 predicted caregiver burden at T2 ($\beta = 0.122$, $p < 0.01$), although the reverse relationship was not statistically significant ($\beta = 0.041$, $p > 0.05$) (Fig. 2b).

In the cross-lagged model considering only T0 and T2, SOC at T0 predicted caregiver burden ($\beta = -0.215$, $p < 0.001$), anxiety ($\beta = -0.124$, $p < 0.05$) and depression symptoms ($\beta = -0.208$, $p < 0.001$) at T2. This link was bidirectional only for anxiety symptoms ($\beta = -0.171$, $p < 0.001$). Anxiety ($\beta = 0.132$, $p < 0.05$) and depression symptoms ($\beta = 0.153$, $p < 0.001$) at T0 influenced caregiver burden at T2, yet this relationship was not bidirectional (Supplementary Table-C).

4. Discussion

4.1. Main results

Findings of this large-scale and multinational longitudinal study shed more light on the intricate interplay between SOC, caregiver burden and mental health outcomes in dementia caregivers. Our first aim was to

Table 2
Descriptive and correlation statistics for main variables: caregivers' sense of coherence, subjective burden, anxiety and depression symptoms.

Variables	α	*M*	*SD*	*F*	1	2	3	4	5	6	7	8	9	10	11
1. SOC T0	0.799	67.13	10.96	2.285	1										
2. SOC T1	0.823	68.62	11.48		0.733**	1									
3. SOC T2	0.831	67.8	11.37		0.684**	0.726**	1								
4. RSS T0	0.895	21.3	10.91	4.6*	−0.504**	−0.469**	−0.4**	1							
5. RSS T1	0.902	20.88	10.8		−0.475**	−0.566**	−0.453**	0.761**	1						
6. RSS T2	0.905	21.89	10.92		−0.467**	−0.48**	−0.554**	0.704**	0.799**	1					
7. HADS-A T0	0.81	6.17	3.82	2.997*	−0.526**	−0.523**	−0.501**	0.626**	0.513**	0.489**	1				
8. HADS-A T1	0.826	6.29	3.99		−0.493**	−0.638**	−0.534**	0.524**	0.646**	0.486**	0.679**	1			
9. HADS-A T2	0.843	6.6	4.09		−0.442**	−0.524**	−0.617**	0.504**	0.555**	0.669**	0.698**	0.71**	1		
10. HADS-D T0	0.775	4.78	3.63	14.877**	−0.522**	−0.45**	−0.431**	0.67**	0.571**	0.526**	0.617**	0.494**	0.472**	1	
11. HADS-D T1	0.808	4.99	3.81		−0.53**	−0.604**	−0.561**	0.559**	0.661**	0.568**	0.494**	0.66**	0.53**	0.727**	1
12. HADS-D T2	0.807	5.41	3.91		−0.479**	−0.479**	−0.597**	0.493**	0.577**	0.669**	0.491**	0.506**	0.631**	0.698**	0.767**

Note: SOC - Sense of Coherence scale; RSS – Relative Stress Scale (subjective burden); HADS-A – Hospital Anxiety and Depression Scale, anxiety symptoms; HADS-D – Hospital Anxiety and Depression Scale, depression symptoms; * $p < 0.05$; ** $p < 0.001$.

investigate the temporal evolution of SOC in caregivers of people with mild-moderate dementia. Following Antonovsky's theory, we could have hypothesized that SOC would be relatively stable, despite different findings in two previous studies in similar populations (Turró-Garriga et al., 2022; Välimäki et al., 2014). SOC levels indeed remained stable after twelve months, while caregiver burden and anxiety and depression symptoms increased. SOC consistently showed an inverse association with these variables across three timepoints, supporting its protective role against caregiver burden and psychological morbidity.

Pursuing our second aim, cross-lagged analysis allowed us to further explore temporal dynamics and reciprocal influences among the main variables. We were interested in the nature and strength of relationships between caregiver SOC and important caregiver outcomes (caregiver burden, and symptoms of anxiety and depression), and any causal directions. It could be that besides SOC's protective role on the negative impact of caregiving, caregiver burden and mental health outcomes would influence SOC self-reports over time.

We found bidirectional relationships between SOC and caregiver burden, and SOC and anxiety symptoms, considering the first six months of follow-up. However, this was not so regarding SOC and depression symptoms for any of the follow-up periods, nor regarding SOC and caregiver burden, or SOC and anxiety symptoms, for the last six months of follow-up. In other words, displaying a higher SOC at T0 predicted lower caregiver burden at T1 and vice versa, whereas neither SOC at T1 predicted caregiver burden at T2, nor did caregiver burden at T1 predict SOC at T2. SOC at T0 predicted less anxiety symptoms at T1, but not from T1 to T2. However, significant paths were observed in the opposite direction, i.e. anxiety symptoms at T0 predicted lower SOC at T1, and anxiety symptoms at T1 predicted lower SOC at T2. Regarding the paths in which SOC levels related to symptoms of depression, higher SOC at baseline predicted lower levels of depression symptoms at six months but not the contrary, while at six months higher levels of depression symptoms predicted lower SOC at 12 months, but not the contrary.

We were also interested in reciprocal relations between caregiver burden and mental health outcomes, expecting that higher caregiver burden would predict more anxiety and depression symptoms, while admitting a reverse causality effect. We found a bidirectional relationship between caregiver burden and depression symptoms, considering the first six months of follow-up. However, this was not so regarding the subsequent six months, nor the relationship between caregiver burden and anxiety symptoms over both six-month follow-ups. In other words, caregiver burden at baseline predicted symptoms of depression at the first follow-up, and vice versa. Then, depression symptoms at six months predicted caregiver burden at twelve months, but the inverse relationship was not significant. In addition, caregiver burden at baseline predicted anxiety symptoms at the first follow-up, and this unidirectional relation was similar at T1-T2, according to the best model fit.

In sum, these prediction analyses yielded divergent results depending on timepoints considered. For the first six-month follow-up, we found bidirectional relationships between SOC and caregiver burden, and SOC and anxiety symptoms, while lower SOC predicted depression symptoms but not vice versa; bidirectional relationships existed between caregiver burden and depression symptoms, but while caregiver burden predicted anxiety symptoms the reverse did not occur. For the second six-month follow-up, both anxiety and depression symptoms predicted lower SOC but not vice versa; surprisingly, higher caregiver burden did not predict depression symptoms. Overall, our findings underline the complexity underlying both nature and direction of the associations between these main variables, and that reverse causality must be considered.

What if we had not conducted the intermediate follow-up? The complementary cross-lagged T0-T2 analyses suggested a predictive effect of baseline SOC on caregiver burden, anxiety and depression symptoms at the final timepoint. Here, only for anxiety symptoms was this relationship bidirectional. Additionally, baseline anxiety and depression symptoms predicted caregiver burden, but again this

Table 3
The goodness-of-fit statistics (chi square) for the nested SEM models on the predictive relationships between caregivers' sense of coherence, subjective burden, anxiety and depression symptoms.

Tested Models	χ^2 values	*df*	*p*	TLI	CFI	RMSEA	SRMR	Model Comparisons	χ^2 diference test[b]	*df*	*p*
SOC-RSS											
M1	70.794	42	0.004	0.936	0.961	0.057	0.047				
M2	79.654	44	<0.001	0.958	0.976	0.046	0.033	M1 vs M2/M3	8.86	2	0.012
M3	79.654	44	<0.001	0.958	0.976	0.046	0.033	M2 vs M3	0	0	
M4[a]	103.666	46	<0.001	0.965	0.98	0.042	0.026	M2/M3 vs M4	24.012	2	<0.001
SOC-HADS-A											
M1	56.389	42	0.068	0.928	0.956	0.058	0.055				
M2	73.835	44	0.003	0.962	0.987	0.042	0.034	M1 vs M2	17.466	2	<0.001
M3	77.792	44	0.001	0.957	0.975	0.045	0.034	M2 vs M3	3.958	0	
M4[a]	105.971	46	<0.001	0.981	0.989	0.03	0.025	M3 vs M4	28.178	2	<0.001
SOC-HADS-D											
M1	68.518	42	0.006	0.919	0.95	0.064	0.055				
M2	79.167	44	<0.001	0.958	0.976	0.046	0.037	M1 vs M2	10.649	2	0.005
M3	101.585	44	<0.001	0.932	0.96	0.059	0.04	M2 vs M3	22.417	0	
M4[a]	117.748	46	<0.001	0.967	0.982	0.041	0.031	M3 vs M4	16.164	2	<0.001
RSS- HADS-A											
M1	80.503	42	<0.001	0.941	0.964	0.057	0.046				
M2	97.27	44	<0.001	0.943	0.967	0.056	0.039	M1 vs M2	16.767	2	<0.001
M3[a]	82.298	44	<0.001	0.959	0.976	0.048	0.026	M2 vs M3	−14.972	0	
M4	103.973	46	<0.001	0.957	0.976	0.049	0.026	M3 vs M4	21.675	2	0.449
RSS- HADS-D											
M1	82.337	42	<0.001	0.929	0.956	0.065	0.054				
M2	92.011	44	<0.001	0.951	0.971	0.053	0.036	M1 vs M2	9.674	2	0.008
M3	99.127	44	<0.001	0.944	0.967	0.057	0.034	M2 vs M3	7.116	0	
M4[a]	119.6	46	<0.001	0.957	0.976	0.05	0.028	M3 vs M4	20.474	2	<0.001

Note: SOC - Sense of Coherence scale; RSS – Relative Stress Scale (subjective burden); HADS-A – Hospital Anxiety and Depression Sympt oms Scale, anxiety symptoms; HADS-D – Hospital Anxiety and Depression Symptoms Scale, depression symptoms; CFI - Comparative Fit Index; TLI - Tucker-Lewis Index; RMSEA - Root Mean Square Error of Approximation; SRMR - Standardized Root Mean Square Residual; [a] The model which best fits the data; [b] The model is improved if χ^2 difference (1) >3.84, $p < 0.05$.

relationship was not bidirectional. Overall, this supports SOC being a useful predictor of key caregiver outcomes over an extended period (one year). It also reinforces that mental health outcomes may, at least in part, influence how SOC is self-rated.

4.2. Comparison with other studies

Regarding SOC evolution over time, contrary to our findings, the two previous longitudinal studies of dementia caregivers documented decreases in SOC levels over three (Välimäki et al., 2014) and two years (Turró-Garriga et al., 2022). Besides the former using the 29-item version, our follow-up was shorter, similarly to the one-year study, not dementia-specific (López-Martínez et al., 2021), that also supported SOC stability (cf. Supplementary Table-D). The differences do not appear explainable in terms of participants' characteristics, but the clinical diversity of the large international sample adds weight to our findings. Reports also favor SOC stability in caregivers of post-stroke survivors (Chumbler et al., 2008; Jaracz et al., 2015; Wu et al., 2015) and of people with schizophrenia (Chumbler et al., 2008; Gonçalves-Pereira, 2010; Wu et al., 2015). Overall, SOC research in caregiving has been limited by shorter follow-ups and no measurements prior to caregiving.

This discussion cannot ignore whether people whose SOC is being evaluated are caregivers or not. In general populations, the original postulate that an individual's SOC tends to stabilize around their thirties (Antonovsky, 1987) has been challenged. In fact, SOC may continue to develop throughout the lifecycle, possibly increasing with age (Eriksson and Mittelmark, 2017). Caregiving implies major challenges, particularly in conditions like dementia, whereby 'general resistance resources' are mobilized differently over time and clinical situation, making it more complex to interpret SOC trends.

Regarding the associations of caregivers' SOC, burden, and anxiety and depression symptoms, our findings do not contradict previous evidence indicating SOC's moderate negative impact on caregiver burden, and its moderate to large effect on anxiety and depression symptoms (del-Pino-Casado et al., 2019a). Overall, they also do not diverge with the dementia caregiving longitudinal studies subsequent to del-Pino-Casado et al.'s review (López-Martínez et al., 2021; Turró-Garriga et al., 2022). Moreover, caregiving research is consistent with findings in general populations, where SOC was associated with mental health and quality of life (Eriksson and Lindström, 2006, 2007) and longitudinal studies over the lifespan analyzed the predictive value of SOC on health and vice versa (Eriksson and Lindström, 2007; Hakanen et al., 2007; Kivimäki et al., 2000; Kouvonen et al., 2010; Langeland and Wahl, 2009; Nilsson et al., 2003).

What has become clearer is that theory (Antonovsky, 1987; Eriksson and Lindström, 2007) and evidence both suggest that the relationship between SOC and health (including mental health) may be reciprocal i. e., SOC may influence health, but health may also influence SOC. The same obviously applies to the associations between SOC and caregiver burden.

Finally, our results partially align with the literature in that caregiver burden is a risk factor for depressive symptoms, possibly precipitating clinical depression (del-Pino-Casado et al., 2019b). They also documented the risk for anxiety symptoms. However, there must be prudence in taking these associations for granted.

4.3. Strengths and limitations

The main strength of the study lies in its longitudinal design with repeated assessments to analyze how SOC, caregiver burden and psychological morbidity, and their associations, evolved over time, rather than aiming at only a cross-sectional snapshot. Furthermore, we were able to collect comprehensive data of a large cohort of family caregivers of persons with different types of dementia, from eight different countries in Europe. We had previously explored the influencing role of caregivers' SOC on caregiver profiles (Janssen et al., 2017) and relationship quality (Marques et al., 2019, 2022). The reasons that led us into this secondary analysis of the EU-Actifcare data came from a detailed comparison of the methodological aspects of ours and the previous three longitudinal explorations, summarized in Supplementary

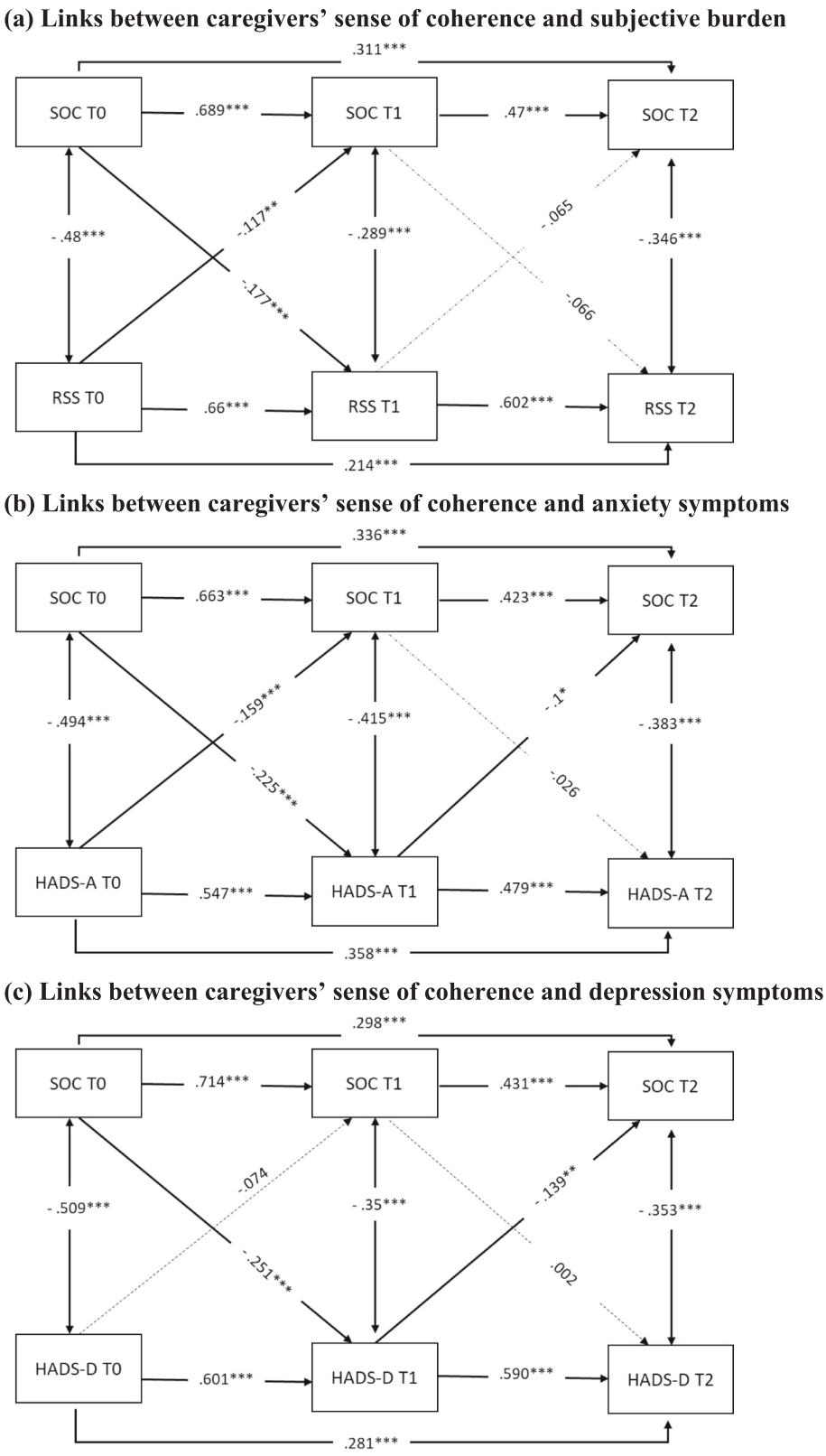

Fig. 1. Cross-lagged models linking sense of coherence (SOC) and caregiver burden (Relative Stress Scale - RSS) (a), sense of coherence (SOC) and anxiety symptoms (Hospital Anxiety and Depression Scale, anxiety subscale – .HADS-A.) (b) and sense of coherence (SOC) and depression symptoms (Hospital Anxiety and Depression Scale, depression subscale - HADS-D) (c).

Note: Standardized parameters; adjusted for all control variables, not depicted in the figure; the regression coefficient is significant when represented by the solid line, but not when represented by the dashed line. * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$.

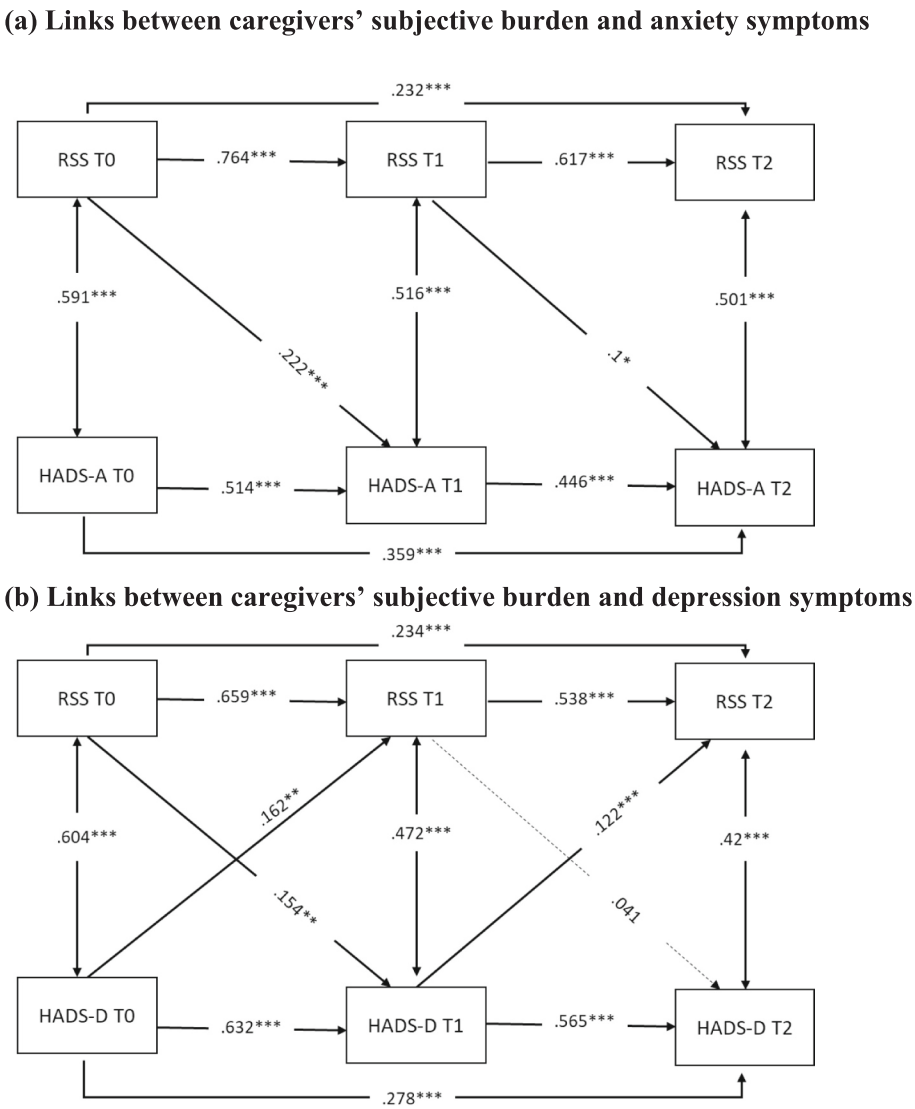

Fig. 2. Cross-lagged models linking caregiver burden (Relative Stress Scale - RSS) and anxiety symptoms (Hospital Anxiety and Depression Scale, anxiety subscale - HADS-A), and caregiver burden (Relative Stress Scale - RSS) and depression symptoms (Hospital Anxiety and Depression Scale, depression subscale - HADS-D). Note: standardized parameters; adjusted for all control variables, not depicted in the figure; the regression coefficient is significant when represented by the solid line, but not when represented by the dashed line. * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$.

Table-D. A different statistical approach (cross-lagged analysis) allowed us to better analyze possible bidirectional associations between the main variables. To address causality between constructs, a longitudinal cross-lagged design is recommended, involving baseline and follow-up measurements for all constructs (Zapf et al., 1996). Supporting the robustness of our findings, the main measures (SOC-13, RSS, HADS) demonstrated factorial invariance over time, consistently with other SOC-13 studies (Kivimäki et al., 2000; Veenstra et al., 2005).

Limitations must also be considered. First, the sample may not be representative, limiting generalizability. The large EU-Actifcare cohort included a relatively small-size convenience sample from each country, recruited to reflect the typical national reality of community-dwelling people with mild to moderate dementia still not in need of formal support. Attrition inevitably added to selection bias: persons with dementia lost to follow-up were likely to be older and more severely impaired, their caregivers reporting higher levels of burden and depression symptoms at baseline compared to those who remained engaged at all timepoints. Second, longer follow-ups would be needed to clarify the evolution of the main variables, including SOC. The 12-month duration potentially limited our ability to fully capture bidirectional relationships between variables. However, collecting data at two follow-ups enabled us to document aspects that could have gone unnoticed without the intermediate 6-month assessment. Third, we used self-report questionnaires, intrinsically susceptible to recall or social desirability bias. However, all measures had been validated, including at national level in most cases, and extensively used in research. Nonetheless, we avoided using the established HADS cut-offs, lacking robust evidence of cross-national validation. Additionally, SOC was measured after caregiving had commenced, a limitation acknowledged by others (López-Martínez et al., 2021), and difficult to overcome in practice. Finally, the cross-lagged analyses only included covariates at baseline, overlooking changes over time. We took this approach to streamline our final models (Liu et al., 2024). We also did not consider the influence of many potentially important factors e.g., the receipt of formal care in some persons with dementia during follow-up. These issues, and the lack of an experimental design, limit causal inference. Notwithstanding, important bidirectional relationships between the main variables were revealed using longitudinal data.

4.4. Implications

These findings add to our understanding of SOC's role in dementia caregiving by documenting its overall stability at a one-year follow-up, advancing the trait versus state debate. The theoretical assumption of SOC being relatively stable or slightly increasing with age was not contradicted by our findings in this sample of dementia caregivers, where risk factors may pose proteiform challenges. More studies are needed to clarify the picture, with larger and more representative samples, involving longer follow-ups across subsequent dementia stages.

Another point regards the SOC scale and its potential for research. It has a longstanding reputation for validity and reliability, following extensive psychometric assessments (Eriksson and Mittelmark, 2017; Stoner et al., 2015). Nevertheless, some guidance seems needed to complete the questionnaire, at least to enhance face validity in dementia research (Stansfeld et al., 2019). This aligns with our experience, especially with the 29-item version (Gonçalves-Pereira, 2010; Gonçalves-Pereira et al., 2021).

There are also implications for clinical practice. Though related to resilience (Teahan et al., 2018), SOC differs in essence and operationalization, integrating cognitive, coping and motivational components around finding meaning. This renders SOC unique within the salutogenesis 'umbrella concept', encompassing constructs such as resilience and self-efficacy (Eriksson and Mittelmark, 2017). There is heuristic value in identifying a personal disposition to remain 'well' when facing caregiving adversities (Zhang et al., 2020). It could be important to identify such subgroups of caregivers, to focus on others more in need of help. However, there are recommendations against using the SOC scale for screening (Eriksson and Mittelmark, 2017). It may be preferable to conduct clinical interviews informed by SOC dimensions (Gonçalves-Pereira et al., 2021) and to incorporate salutogenic strength-based approaches into family interventions (Yu et al., 2023). Tending to be stable overall, SOC may be considered a protective factor for clinical and psychosocial outcomes. When general resistance resources are challenged, SOC will probably benefit from adequate longstanding support.

5. Conclusion

In this large cohort of dementia caregivers from eight European countries, followed for one year, SOC remained stable while caregiver burden, anxiety and depression symptoms increased over time. Regarding the associations between these main variables, results diverged at different timepoints.

Overall, our study supports the potential protective role of SOC against caregiver burden and psychological morbidity, despite higher levels of SOC not always predicting lower levels of caregiver burden or anxiety or depression symptoms in specific periods of the follow-up. Noteworthy, and again for specific timepoints, there were indications of reverse causality, supporting the notion that SOC self-reports may sometimes be influenced by caregiver burden, anxiety or depression symptoms. The complex interplay between psychosocial and clinical variables does not always fit simplistic interpretations.

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CRediT authorship contribution statement

Manuel Gonçalves-Pereira: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Maria J. Marques:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Regina F. Alves:** Writing – review & editing, Writing – original draft, Formal analysis. **Hannah Jelley:** Writing – review & editing, Data curation. **Claire Wolfs:** Writing – review & editing, Data curation. **Gabriele Meyer:** Writing – review & editing, Data curation. **Anja Bieber:** Writing – review & editing, Data curation. **Kate Irving:** Writing – review & editing, Data curation. **Louise Hopper:** Writing – review & editing, Data curation. **Orazio Zanetti:** Writing – review & editing, Data curation. **Daniel M. Portolani:** Writing – review & editing, Data curation. **Geir Selbaek:** Writing – review & editing, Data curation. **Janne Røsvik:** Writing – review & editing, Data curation. **Anders Sköldunger:** Writing – review & editing, Data curation. **Britt-Marie Sjölund:** Data curation. **Marjolein de Vugt:** Writing – review & editing, Supervision, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Frans Verhey:** Writing – review & editing, Supervision, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Bob Woods:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

Authors' contributions

MGP, MJM and BW designed the present study and wrote a first draft of the paper, with the assistance of RA (who also specifically contributed to designing the statistical analysis and conducted it). The other authors were members of the EU-Actifcare project (coordinated by MdV and FV) and all contributed to data collection, as did MGP, MJM and BW. All authors contributed significantly to the final version of the manuscript and approved it to be submitted.

Ethics approval and consent to participate

Written informed consent was provided by all participants (persons with dementia and their family carers). Permission was granted in each of the eight participating countries by local ethics committees.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

The datasets analyzed during the current study are available from the corresponding author on reasonable request.

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