

# Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study

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## Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health

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## Caregiver profiles in dementia related to quality of life, depression and perseverance time in the European Actifcare study: the importance of social health

Eveline P.C.J. Janssen <sup>a,b</sup>, Marjolein de Vugt<sup>a</sup>, Sebastian Köhler <sup>a</sup>, Claire Wolfs<sup>a</sup>, Liselot Kerpershoek<sup>a</sup>, Ron L.H. Handels <sup>a</sup>, Martin Orrell<sup>c</sup>, Bob Woods<sup>d</sup>, Hannah Jelley<sup>d</sup>, Astrid Stephan<sup>e</sup>, Anja Bieber<sup>e</sup>, Gabriele Meyer<sup>e</sup>, Knut Engedal<sup>f</sup>, Geir Selbaek<sup>f</sup>, Anders Wimo<sup>g</sup>, Kate Irving<sup>h</sup>, Louise Hopper<sup>h</sup>, Maria Marques<sup>i</sup>, Manuel Gonçalves-Pereira<sup>i</sup>, Elisa Portolani<sup>j</sup>, Orazio Zanetti<sup>j</sup> and Frans R. Verhey <sup>a</sup>

<sup>a</sup>Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience, Alzheimer Center Limburg, Maastricht University Medical Center, Maastricht, The Netherlands; <sup>b</sup>Department of Old Age Psychiatry, Mondriaan, Heerlen, The Netherlands; <sup>c</sup>Department of Psychiatry and Applied Psychology, Faculty of Medicine & Health Sciences, Institute of Mental Health, University of Nottingham, Nottingham, United Kingdom; <sup>d</sup>Dementia Services Development Centre Wales, Bangor University, Bangor, United Kingdom; <sup>e</sup>Medical Faculty, Institute for Health and Nursing Science, Halle-Wittenberg, Germany; <sup>f</sup>Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway; <sup>g</sup>Department of Neurobiology, Care sciences and Society, Karolinska Institutet, Stockholm, Sweden; <sup>h</sup>School of Nursing and Human Sciences, Dublin City University, Dublin, Ireland; <sup>i</sup>CEDOC – Chronic Diseases Research Center, Nova Medical School, Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Lisbon, Portugal; <sup>j</sup>Alzheimer Unit, IRCCS Centro San Giovanni di Dio, Fatebenefratelli, Brescia, Italy

### ABSTRACT

**Objectives:** To identify caregiver profiles of persons with mild to moderate dementia and to investigate differences between identified caregiver profiles, using baseline data of the international prospective cohort study Actifcare.

**Methods:** A latent class analysis was used to discover different caregiver profiles based on disease related characteristics of 453 persons with dementia and their 453 informal caregivers. These profiles were compared with regard to quality of life (CarerQoL score), depressive symptoms (HADS-D score) and perseverance time.

**Results:** A 5-class model was identified, with the best Bayesian Information Criterion value, significant likelihood ratio test ( $p < 0.001$ ), high entropy score (0.88) and substantive interpretability. The classes could be differentiated on two axes: (i) caregivers' age, relationship with persons with dementia, severity of dementia, and (ii) tendency towards stress and difficulty adapting to stress. Classes showed significant differences with all dependent variables, and were labelled 'older low strain', 'older intermediate strain', 'older high strain', 'younger low strain' and 'younger high strain'.

**Conclusion:** Differences exist between types of caregivers that explain variability in quality of life, depressive symptoms and perseverance time. Our findings may give direction for tailored interventions for caregivers of persons with dementia, which may improve social health and reduce health care costs.

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Dementia; social health; well-being; quality of life; caregivers

## Introduction

The concept of health is changing. In the late 40s of the past century, the World Health Organization defined health as 'a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity' (World Health Organisation, 1948). During the past decades, the concept of health has changed to become more dynamic and includes the ability to adapt and to self-manage in daily life (Huber et al., 2011). Recent research in chronic diseases, e.g. diabetes mellitus, sickle cell disease, chronic obstructive pulmonary disease and epilepsy, has shown that self-management improves quality of life (Ahmadi et al., 2014; Benzo, Abascal-Bolado, & Dulohery, 2016; Chen, Tsai, Hsi, & Chen, 2016; Sugiyama, Steers, Wenger, Duru, & Mangione, 2015). Research on self-management in neurodegenerative disorders such as dementia lags behind and has not yet received proper attention. In dementia, as well as self-management for the person with dementia (PWD), consideration must also be given to the self-management of the informal caregivers as the disease progresses (Huis In Het Veld, Verkaik, Mistiaen, van Meijel, & Francke, 2015). Self-management may entail the

search for a dynamic balance between opportunities and limitations to live with a challenging disease such as dementia. This can be addressed by the concept of social health (Vernooij-Dassen & Jeon, 2016). According to this concept, a state of well-being can be achieved if one is able to adapt to the changes and challenges of the disease (Huber et al., 2011). Several dimensions of social health can be identified including people's capacity to fulfil their potential and obligations, the ability to manage their life with some degree of independence despite a medical condition and the ability to participate in social activities including work (Huber et al., 2011).

The adaptive ability of caregivers in the context of dementia is probably not related to a single characteristic but to the interaction of internal and external factors. In that sense, disease-related characteristics, e.g. severity of the dementia, cognitive impairment and neuropsychiatric symptoms of the PWD, as well as individual characteristics of informal caregivers, e.g. age, sex, education, caregiving-related stress, stress-mediators, duration of caregiving, time spent with PWD and caregiver-patient relationship, may influence quality of life of the caregiver (Bergvall et al., 2011; Chiao, Wu, & Hsiao,

2015; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Although caregiving in general is associated with apparently negative outcomes (Gaugler, Kane, Kane, Clay, & Newcomer, 2005; Koyama et al., 2016; Srivastava, Tripathi, Tiwari, Singh, & Tripathi, 2016; Torti et al., 2004), compared with the general population, individual differences could be informative regarding adaptation and social health.

Caregivers differ in their characteristics in terms of, for example, care management strategies, caregiving-related stress or coping styles (de Vugt et al., 2004; Etters, Goodall, & Harrison, 2008; Hinrichsen & Niederehe, 1994). An adaptive care management strategy (i.e. the caregiver's acceptance of the caregiving situation and dementia-related problems) is related to more positive caregiver outcomes in terms of depression and caregiver competence than a non-adaptive care management strategy (de Vugt et al., 2004). Several other variables of caregivers have been identified, for example, closer kinship ties, less social support and being a female caregiver are associated with increased subjective burden (Aadil Jan Shah & Latoo, 2010; Etters et al., 2008; Torti et al., 2004).

Also of interest is the question how long caregivers can provide their current care, i.e. perseverance time (Kraijo, Brouwer, de Leeuw, Schrijvers, & van Exel, 2014). A desire to institutionalize can be derived from this (Kraijo et al., 2014). A higher desire to institutionalize is previously linked to higher symptoms of burden and depression in caregivers (Gallagher et al., 2011). Perseverance time is an instrument that integrates the aspect of perceived burden and the caregiver's capacity to cope with this burden and allows informal caregivers to give a reasonable indication how long they will be able to continue with the care, wherefore support can be tailored in, for example, extra support or transition to a nursing home care (Kraijo et al., 2014; Richters, Olde Rikkert, van Exel, Melis, & van der Marck, 2016).

Current evidence does not offer an integrated view of combined caregiver characteristics of demographics, stress and disease-related characteristics that contribute to different underlying latent caregiver profiles. The relevance of identifying such caregiver profiles lies in their potential to explain differential caregiver variables in terms of experienced quality of life, depression and perseverance time. Moreover, it may lead to more targeted and personalized interventions for improving caregivers' and patients' social health.

Hence, the aims of the present study were (1) to identify different profiles of caregivers of people with mild to moderate dementia and (2) to investigate differences between the identified caregiver profiles in quality of life, in depression and in perseverance time.

## Methods

### Study population

In this study, we used cross-sectional baseline data from the Actifcare (Access to Timely Formal Care) study. Actifcare is a European prospective cohort study aiming at best-practice development in finding timely access to formal care for community-dwelling PWD and their informal caregivers in eight European countries (Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Sweden and United Kingdom). Participation was restricted to people with mild to moderate dementia according to DSM-IV-TR criteria and their informal caregivers. Patients were asked for informed consent in case they were

able to give consent themselves. When a patient was not able to give informed consent, the legal procedures in the specific country were followed. The PWD did not yet receive regular assistance from a professional carer worker with regard to dementia-related personal care, but a healthcare professional judged that such additional assistance was likely to be considered or required within one year. The PWD had an informal caregiver who was in contact with the PWD at least once a week and was able to participate in the study. Participants were recruited from various settings, including general practices, memory clinics, case managers, community mental health teams and through mass media campaigns in local and national newspapers. The present report includes data from the 453 dyads (453 PWD and 453 corresponding caregivers). The participants completed the baseline survey between November 2014 and July 2015. The study protocol was approved by national ethic committees.

### Measures of people with dementia

Several disease-related characteristics of the PWD were used to identify caregiver profiles. Clinical measures of the PWD included a diagnosis of dementia according to DSM-IV-TR criteria, cognitive functioning measured by the Mini-Mental State Examination (MMSE), dementia severity assessed with the Clinical Dementia Rating scale (CDR, rating by the interviewer) and neuropsychiatric symptoms measured by the Neuropsychiatric Inventory (NPI, proxy rating of the informal caregiver).

MMSE scores range from 0 to 30, with higher scores indicating better cognitive function (Folstein, Folstein, & McHugh, 1975).

The CDR is a global numeric rating scale used to quantify the severity of symptoms of dementia in six areas: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care (Hughes, Berg, Danziger, Coben, & Martin, 1982).

The NPI is a numeric scale measuring the presence of 12 neuropsychiatric symptoms. The continuous score for each symptom is obtained by multiplying severity (1–3) by frequency (1–4) (Cummings, 1997). A score > 3 per symptom indicates the presence of clinically relevant symptoms (Aalten, van Valen, Clare, Kenny, & Verhey, 2005).

All three scales are commonly used in clinical and research areas of dementia. All scales were used as measures, not for including or excluding PWD.

### Measures of informal caregivers

Caregiver characteristics that were used to identify profiles were demographics and measures of stress and stress mediators. Demographics included gender, age, years of education, living situation, working situation and time spent with PWD.

Time spent with PWD consisted of the hours of time per day spent for basic and instrumental activities of daily living and supervision.

Caregiving-related stress was assessed by use of the Relative Stress Scale (RSS) (Greene, Smith, Gardiner, & Timbury, 1982). The scale consists of 15 items scored on five levels of intensity, from 0 = 'not at all' to 4 = 'to a high degree'. A total mean score is calculated (Ulstein, Wyller, & Engedal, 2007).

The first stress mediator is sense of coherence and was measured with the Sense of Coherence scale (SOC-13). It

contains items on stressors, coping and health, and is built upon three components: comprehensibility (to which five items contribute), manageability (four items) and meaningfulness (four items) (Antonovsky, 1993; Holmefur, Sundberg, Wettergren, & Langius-Eklof, 2015). These 13 items rate agreement or disagreement on a seven-point Likert scale. Total scores can range from 13 to 91. Following Holmefur et al. (2015), a higher score indicates a successful adaptation to a stressful situation which leads to better health and well-being.

Another stress mediator of the informal caregiver is locus of control and was assessed with the Locus of Control of Behaviour Scale (Craig, Franklin, & Andrews, 1984). The questionnaire comprises 17 items rated on a six-point scale, ranging from 0 = 'strongly disagree' to 5 = 'strongly agree'. Response options are used to calculate a continuous total score with higher score reflecting greater perceived external-ity of control (Guitar, 2005).

Sense of coherence and locus of control can be perceived as a way to adapt to stress, i.e. adaptability.

### Dependent variables

Primary dependent variables were quality of life, depressive symptoms and perseverance time.

Quality of life of the caregiver was measured by use of the Care-related Quality of Life scale (CarerQoL), which was developed to measure and value the impact of informal care on caregivers (Brouwer, van Exel, van Gorp, & Redekop, 2006). The CarerQoL consists of two parts: the CarerQoL-7D and the CarerQoL-VAS (visual analogue scale). The CarerQoL-7D comprises seven dimensions (fulfilment, relation, mental health, social, financial, perceived support and physical), which can be answered in three possible responses ('no', 'some' and 'a lot'). Total scores can be calculated using a scoring system, ranging from 0 to 14, with higher score indicating better quality of life. A VAS measures well-being in the caregiver, ranging from 0 'completely unhappy' to 10 'completely happy'.

Symptoms of anxiety and depression were measured by the 14-item Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The HADS consists of two seven-item scales for anxiety and depression, each with a score ranging from 0 to 21. Only the HADS-depression subscale is used in this research. A mean score  $\geq 8$  shows the most optimal balance between sensitivity and specificity for the presence of a possible mood disturbance (Bjelland, Dahl, Haug, & Neckelmann, 2002).

Perseverance time was measured with a single question how long the caregiver could continue caring if the situation remained, ranging from 1 'less than one week' to 6 'more than two years'. This simple measure of perseverance time has been shown to have good content validity (Kraijjo et al., 2014).

Measures that were not available in all languages were translated and back-translated via a translation protocol to ensure validity.

### Statistical analysis

Statistical analyses were performed with IBM SPSS Statistics version 20.0 (IBM Statistics for Windows, Armonk, NY, USA) and Mplus 7.4 (Muthén & Muthén, Los Angeles, CA, USA). Dichotomous data were analysed with chi-square test and continuous data with independent samples *t*-test.

A latent class analysis for continuous and categorical indicators was conducted to discover different caregiver subgroups using a robust maximum likelihood estimator. As described, latent class indicators included individual characteristics of the informal caregivers (i.e. gender, age, years of education, living situation, working situation and time spent with PWD), measures of caregiver functioning that assess aspects of stress and stress-mediators (i.e. RSS, SOC-13 and locus of control of behaviour) and disease-related characteristics of PWD (i.e. diagnosis, MMSE score, severity of dementia and NPI score). Latent class analysis with increasing number of classes was fitted until the most parsimonious and clinically relevant model was identified, based on comparison of Bayesian Information Criterion (lower is better), classification entropy (preferably  $\geq .80$ ) and Lo-Mendel-Rubin adjusted likelihood ratio testing comparing models with  $k$  classes to the model with  $k - 1$  classes (Muthen & Asparouhov, 2012; Schwarz, 1978). Bayesian Information Criterion and likelihood ratio testing were *a priori* considered most important in the comparison. While the former is generally considered the best indicator, likelihood ratio testing can be used to detect an upper limit of the number of potential classes to be considered useful (Nylund, Asparouhov, & Muthén, 2007). For completeness, we also report the model log-likelihood and Akaike Information Criterion.

After deciding on the maximum number of classes, differences in quality of life, depressive symptom scores and perseverance time between latent classes were tested using CarerQoL-7D and CarerQoL-VAS score, HADS depression score and perseverance time as dependent variables in the final latent class analysis. For this, we used an automatic three-step modified Bolck-Croon-Hagenaars approach embedded in Mplus 7.4 (Bakk, Tekle, & Vermunt, 2013; Muthen & Asparouhov, 2015). In simulation studies, the Bolck-Croon-Hagenaars method performs best in analysing continuous dependent variables and is most robust for non-normally distributed variables (e.g. HADS scores) or differences in variance of dependent variables between classes, and is particularly useful in models with high entropy (Bakk et al., 2013; Muthen & Asparouhov, 2015).

### Results

In this study, 453 patient-caregiver dyads were included. Baseline demographic and clinical characteristics are presented in Table 1. More than half of PWD were female (54.3%) and most had a diagnosis Alzheimer's disease (48.3%). Median MMSE score was 19.00 (SD  $\pm$  4.48). Total NPI score was 7.82 (SD  $\pm$  5.60). The caregivers of the PWD had a mean age of 66 years (SD  $\pm$  7.82), of whom two-thirds were female (66.6%). Seventy-two per cent of the informal caregivers lived together with the PWD, and 64% were spouses. Mean time spent with PWD was 5.7 hours per day (SD  $\pm$  5.6). Depression scores were mean HADS-D score 4.80 (SD  $\pm$  3.67) in the caregiver group, and the RSS revealed a mean score of 21.22 (SD  $\pm$  11.02). SOC-13 showed a mean score of 67.13 (SD  $\pm$  10.97). Locus of control of behaviour was 48.42 (SD  $\pm$  10.08).

### Latent class analysis

Different models with one to seven latent classes were analysed. Model fit and substantive interpretation suggested that

**Table 1.** Baseline characteristics of people with dementia (PWD) and their caregivers.

Person with dementia <i>n</i> = 453	
Age (years)	77.8 ± 7.8
Sex, female	246 (54.3%)
Years of education	9.9 ± 4.5
Type of dementia	
Alzheimer's disease (AD)	217 (48.3%)
Vascular	52 (11.6%)
Mixed vascular/AD	56 (12.5%)
Lewy body	6 (1.3%)
Unknown	91 (20.3%)
Other	27 (6.0%)
MMSE	19.0 ± 5.0
NPI total score	7.8 ± 5.6
CDR score 0.5/1/2/3	2.0%/77.7%/20.1%/0.2%
Informal caregiver <i>n</i> = 453	
Age (years)	66.4 ± 13.3
Sex, female	302 (66.6%)
Years of education	11.9 ± 4.4
Lives together with PWD	326 (72.1%)
Relationship with PWD	
Spouse	290 (64.0%)
Son/daughter (in law)	144 (31.7%)
Sibling	5 (1.1%)
Other relative	9 (2.1%)
Other	5 (1.1%)
Time spent with PWD (hours/day)	5.7 ± 5.6
HADS-D	4.8 ± 3.7
SOC-13	67.1 ± 11.0
LOC	48.4 ± 10.1
RSS	21.2 ± 11.0

Note: Continuous data is presented as: mean ± SD. Dichotomous data is presented as: N (%)

MMSE: Mini Mental State Examination; NPI: neuropsychiatric inventory; CDR: clinical dementia rating scale; HADS-D: Hospital Anxiety Depression rating Scale-depression; SOC-13: sense of coherence scale-13; LOC: locus of control of behaviour; RSS: relative stress scale

**Table 2.** Fit statistics for different latent class models.

	1 Class	2 Classes	3 Classes	4 Classes	5 Classes	6 Classes	7 Classes
Log likelihood	-13,926.241	-13,410.476	-13,260.037	-13,187.753	-13,103.726	-13,042.889	-13,008.070
AIC	27,900.483	26,902.952	26,636.074	26,525.505	26,391.452	26,303.778	26,268.140
BIC	27,999.264	27,071.704	26,874.796	26,834.197	26,770.114	26,752.411	26,786.743
Entropy	1.00	0.948	0.922	0.871	0.879	0.886	0.898
LMR LRT	-	<0.0001	<0.0001	0.0506	0.0021	0.3676	0.1063

AIC: Akaike Information Criterion; BIC: Bayesian Information Criterion;

LMR LRT: Lo-Mendel-Rubin adjusted likelihood ratio test for model with *k* classes versus model with *k* - 1 classes

**Table 3.** Characteristics of 5-class model.

Label	Class				
	3	5	1	4	2
	Older low strain	Older intermediate strain	Older high strain	Younger low strain	Younger high strain
Number caregivers (%)	106 (23.4%)	97 (21.4%)	88 (19.4)	100 (22.1%)	62 (13.7%)
Age (SE)	73.8 (1.0)	72.2 (1.1)	75.6 (0.8)	52.5 (1.1)	53.7 (1.5)
Female sex (%)	52.0 (5.8)	65.3 (5.1)	63.5 (6.5)	80.3 (4.3)	74.4 (6.5)
Living together (%)	100.0 (0.0)	95.0 (2.6)	100.0 (0.0)	13.1 (5.0)	46.4 (8.4)
Spouse/partner (%)	99.0 (1.0)	88.1 (3.9)	100.0 (0.0)	2.5 (2.5)	16.2 (6.5)
Time spent with PWD in hours/day (SE)	2.9 (0.4)	15.1 (0.4)	4.9 (0.5)	1.6 (0.2)	3.3 (0.5)
Education years (SE)	11.3 (0.6)	12.2 (0.4)	9.7 (0.6)	13.7 (0.3)	12.9 (0.6)
Paid work (%)	15.4 (4.6)	3.3 (1.9)	0.0 (0.0)	78.3 (4.5)	55.2 (8.3)
RSS (SE)	13.1 (1.0)	26.7 (1.1)	28.2 (1.4)	13.1 (1.0)	29.9 (1.5)
LOC (SE)	44.6 (1.1)	50.1 (1.2)	56.5 (1.0)	40.6 (1.0)	53.2 (1.3)
SOC-13 (SE)	73.9 (1.1)	67.4 (1.4)	61.0 (1.5)	71.0 (0.2)	58.0 (2.0)
Moderate/severe dementia (%)	5.7 (3.3)	38.9 (5.5)	19.0 (5.1)	10.5 (3.6)	32.6 (8.2)
Diagnosis					
AD (%)	52.0 (5.7)	47.4 (5.5)	45.4 (6.7)	47.3 (5.5)	49.6 (7.3)
VaD (%)	11.8 (3.7)	13.8 (3.8)	13.3 (4.2)	11.0 (3.2)	6.1 (3.6)
Other/unknown (%)	4.2 (2.4)	7.3 (2.8)	24.4 (5.2)	9.8 (3.7)	21.5 (5.9)
MMSE (SE)	20.1 (0.6)	18.1 (0.6)	18.4 (0.8)	20.0 (0.5)	17.6 (0.8)
NPI (SE)	5.5 (0.5)	11.6 (0.7)	8.3 (0.7)	5.1 (0.4)	9.5 (0.7)

SE: standard error; %: percentage

RSS: Relative Stress Scale; LOC: Locus Of Control of behaviour; SOC-13: Sense Of Coherence scale-13;

MMSE: Mini Mental State Examination of person with dementia; NPI: Neuropsychiatric Inventory of person with dementia

Female sex: female sex of the caregiver; Moderate/severe dementia measured by use of the Clinical Dementia Rating scale of person with dementia;

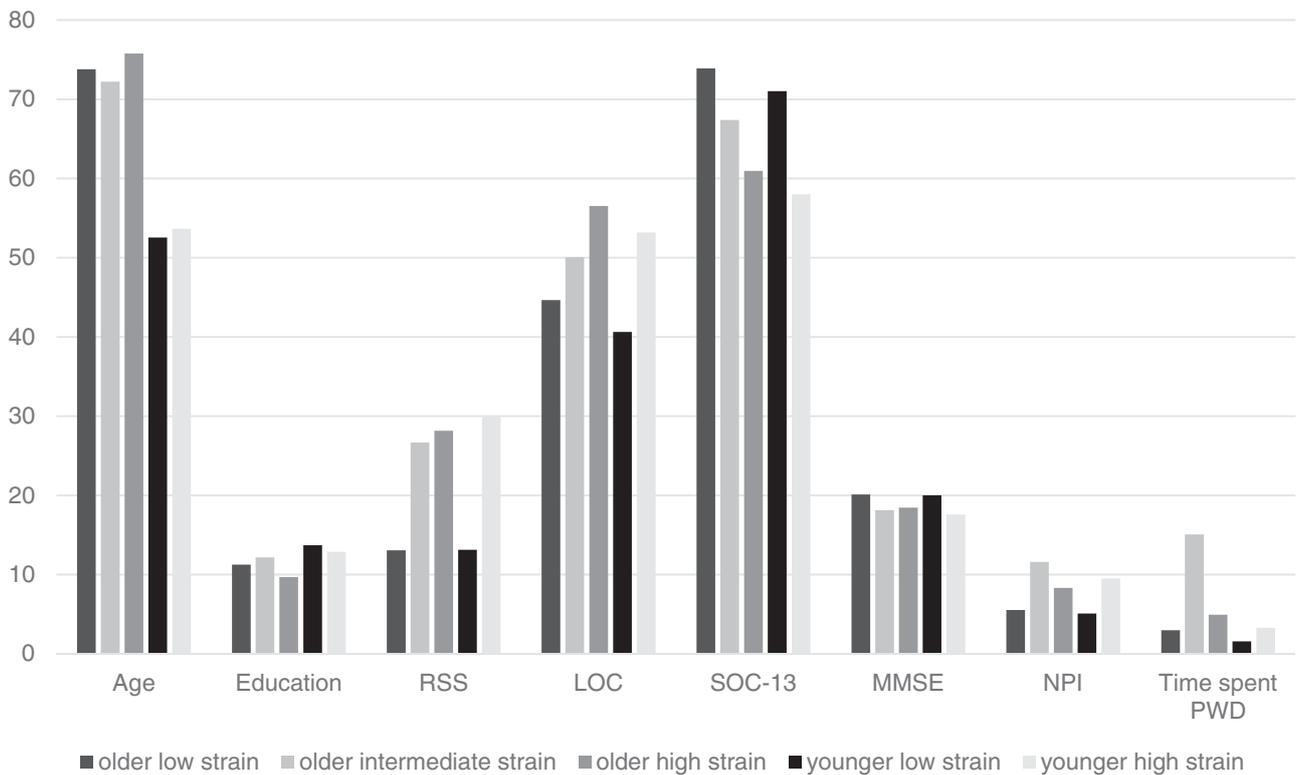
Diagnosis of person with dementia; AD: Alzheimer's disease; VaD: vascular dementia

five classes represented the most parsimonious solution (Table 2). The 5-class model showed the best Bayesian Information Criterion value in combination with a significant likelihood ratio test compared with the 3-class model and a high entropy score (0.88). A 6-class model did not improve model fit further.

Differences between caregiver classes are shown in Table 3, and in Figures 1 and 2. Most noticeably, classes 2 and 4 were comparable in caregiver age, years of education and were mostly offspring and employed. Classes 1, 3 and 5 were also similar to each other, but different from classes 2 and 4 in caregiver age and years of education, and they were mostly spouses or partners who did not perform paid work.

Alzheimer's disease was the most common aetiology of dementia in all classes. Classes 2 and 5 had the highest percentage of moderate/severe PWD and also had the highest neuropsychiatric symptom scores on the NPI. These caregivers experienced more caregiving-related stress and were less successful in adapting to stressful situations. Next to this, time spent with PWD was the highest in class 5 compared to classes 1, 2, 3 and 4.

Classes 2 and 4 were comparable in caregiver age, but differed in adaptability and severity of dementia and neuropsychiatric symptoms of the PWD. Therefore, class 2 was labelled as 'younger high strain' and class 4 as 'younger low strain'. Classes 1, 3 and 5 were comparable in age, but differed in adaptability and severity of the PWD too, and were therefore labelled 'older high strain', 'older low strain' and 'older intermediate strain', respectively.



**Figure 1.** Characteristics of 5-class model, continues variables

RSS: Relative Stress Scale; LOC: Locus Of Control of behaviour; SOC-13: Sense Of Coherence scale-13; MMSE: Mini Mental State Examination of person with dementia; NPI: Neuropsychiatric Inventory of person with dementia. Note: Due to one scale on the Y-axis differences between variables are difficult to interpret in this graph. However, the graph is designed to show the differences between profiles per variable.

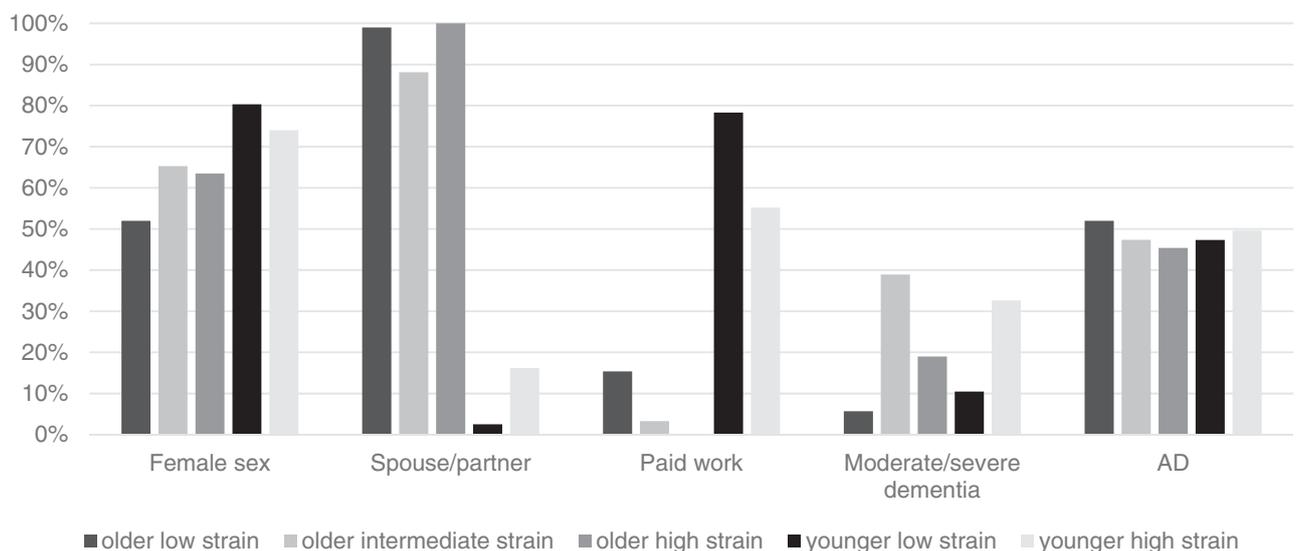
### Associations with dependent variables

The five classes showed significant differences in all dependent variables, i.e. CarerQoL-7D ( $\chi^2 = 167.76$ ,  $df = 4$ ,  $p < .001$ ), CarerQoL-VAS ( $\chi^2 = 110.30$ ,  $df = 4$ ,  $p < .001$ ), perseverance time ( $\chi^2 = 31.74$ ,  $df = 4$ ,  $p < .001$ ) and HADS-D ( $\chi^2 = 245.0$ ,  $df = 4$ ,  $p < .001$ ) (Table 4). The 'younger low strain' and 'older low strain' classes (classes 4 and 3, respectively) experienced a higher quality of life on the CarerQoL-7D and Care-rQoL-VAS than the 'older high strain', 'older intermediate strain' and 'younger high strain' classes (classes 1, 5 and 2, respectively). Depressive symptoms were more often

reported in the 'older high strain', 'older intermediate strain' and 'younger high strain' classes. Perseverance time did significantly differ between the classes on the continuous scale, but classes' mean scores fell in the same perseverance time category, i.e. 'continue caring in the current situation between one and two years'.

### Discussion

In the current multicentre study, we identified five different profiles of informal caregivers of persons with dementia:



**Figure 2.** Characteristics of 5-class model, dichotomous variables.

Note: Moderate/severe dementia measured by use of the Clinical Dementia Rating scale of person with dementia. AD: Alzheimer's disease of person with dementia.

**Table 4.** Dependent variables of 5-class model.

Class	Label	Dependent variable			
		CarerQoL-7D	CarerQoL-VAS	Perseverance time	HADS-D
3	Older low strain	11.06 ± 0.22 <sup>i</sup>	7.55 ± 0.19 <sup>j</sup>	5.83 ± 0.07 <sup>i</sup>	2.65 ± 0.30 <sup>h,i</sup>
5	Older intermediate strain	8.66 ± 0.26	5.94 ± 0.22	5.32 ± 0.11	5.74 ± 0.35
1	Older high strain	8.34 ± 0.25 <sup>a,b,c</sup>	5.00 ± 0.22 <sup>a,b,c,d</sup>	5.29 ± 0.12 <sup>b,c</sup>	8.21 ± 0.45 <sup>b,c,d</sup>
4	Younger low strain	11.00 ± 0.22 <sup>j</sup>	7.22 ± 0.16 <sup>j</sup>	5.68 ± 0.08 <sup>i</sup>	1.91 ± 0.21 <sup>j</sup>
2	Younger high strain	6.81 ± 0.36 <sup>e,f,g</sup>	5.49 ± 0.26 <sup>e,f</sup>	5.11 ± 0.17 <sup>e</sup>	6.79 ± 0.51 <sup>e,f</sup>
Overall test		$p = 0.000$	$p = 0.000$	$p = 0.000$	$p = 0.000$

Note: Data presented as: mean ± SE.

<sup>a</sup>  $p < 0.001$ , versus class 2.

<sup>b</sup>  $p < 0.001$ , versus class 4.

<sup>c</sup>  $p < 0.001$ , versus class 3.

<sup>d</sup>  $p < 0.01$ , versus class 5.

<sup>e</sup>  $p < 0.001$ , versus class 3.

<sup>f</sup>  $p < 0.01$ , versus class 4.

<sup>g</sup>  $p < 0.001$ , versus class 5.

<sup>h</sup>  $p < 0.05$ , versus class 4.

<sup>i</sup>  $p < 0.05$ , versus class 4.

<sup>j</sup>  $p < 0.05$ , versus class 5.

CarerQoL-7D: Care-Related Quality of Life Scale – Seven Dimensions; CarerQoL-VAS: Care-Related Quality of Life Scale – Visual Analogue Scale; HADS-D: Hospital Anxiety and Depression Rating Scale – Depression.

namely ‘younger low strain’, ‘younger high strain’, ‘older low strain’, ‘older intermediate strain’ and ‘older high strain’. These classes differed in characteristics mainly in type of relationship with the PWD and perceived stress, next to severity of dementia and neuropsychiatric symptoms of the PWD, but age, education and time spent with PWD are also salient features. A clinically relevant and statistically significant difference was observed with regard to quality of life and depressive symptoms scores between the identified caregiver groups. Furthermore, a clinically small but highly significant statistical difference was observed for perseverance time score between these profiles.

To our knowledge, this is the first study carried out to understand profiles of caregivers using latent classes and testing associations with dependent variables among informal caregivers of PWD. This approach for identifying caregiver classes is rather new in this field and can help in understanding heterogeneity in caregiver outcomes. While the five caregiver profiles differed on several variables, they grossly consisted of two groups. On the one hand, we found three classes with older caregivers, which were mostly partners, and on the other hand, we found two classes with younger caregivers which were mostly children. Within each group, one class was characterized by higher caregiving-related stress, more external locus of control and lower sense of coherence than the other. This suggests that caregivers might be categorized along two axes concerning adaptability, i.e. age and relationship with the PWD and severity of dementia on the one hand, and tendency towards stress and difficulty in adapting to stress on the other hand. Time spent with PWD did not differ substantially between the caregiver profiles, except for the older intermediate strain caregivers. They spent more than half of the day with the PWD for basic and instrumental activities of daily living and supervision, but were intermediate in adapting to stress.

Interestingly, older and younger high strain and older intermediate strain caregivers had to deal with more severe dementia and more neuropsychiatric symptoms in PWD, but the direction of the relationship between caregiver adaptation and dementia and NPI severity cannot be confirmed in a cross-sectional analysis such as this. The older intermediate strain seems to be a profile consisting of spouses who care for the patient with more severe dementia and more neuropsychiatric symptoms, but these caregivers adapt relatively good

to their changed lives. This is in line with an earlier conducted study where no correlation was found between the time spent with PWD and depression (Bednarek et al., 2016).

Two vulnerable caregiver groups, i.e. ‘older high strain’ and ‘younger high strain’ classes, were identified (Figure 1 and 2) with the variables indicating worse quality of life and more depressive symptoms, based on disease-related characteristics and caregiver characteristics. Caregiver characteristics such as gender, burden and stress mediators are important determinants of our caregiver profiles. This is in line with a previous study where caregiver strategies were investigated (de Vugt et al., 2004). It is supposed that caregiver strategies in stress and coping influence patient behaviour and vice versa (de Vugt et al., 2004). The behaviour of the PWD can influence the variables of the PWD and the variables of the caregiver in terms of quality of life and social health.

Identification of above-mentioned profiles might help healthcare professionals in daily clinical practise to identify vulnerable dyads which need additional interventions to support the caregiver. Important distinguishing characteristics are age of the caregiver, severity of dementia and neuropsychiatric symptoms of the PWD and the relationship of the caregiver with the PWD, of which younger and older both can have poor effects on adaptability. Previous research showed that age-associated impairments in physical competence make the provision of care more difficult for older caregivers (Aadil Jan Shah & Latoo, 2010). Next to that, wives experienced higher levels of caregiver burden compared to other family members (Zarit, Reever, & Bach-Peterson, 1980). Closer kinship ties were previously associated with increased caregiver burden (Etters et al., 2008). Regarding the relationship of the caregiver with the PWD, we found that the ‘older low strain’ is the largest class, the ‘younger high strain’ the smallest class. In our study we showed that comparable vulnerable dyads come forward in the group with mostly spouses and but also in the group with mostly children.

In daily clinical practice, healthcare professionals should give extra attention to caregivers of people with moderate or severe dementia and a high score on the NPI reflecting clinically relevant neuropsychiatric symptoms, as caregivers of these PWD show lower quality-of-life scores and have higher depressive symptoms scores, irrespective of the age and kinship. In these groups, tailored interventions (Moniz Cook, Swift, & James, 2012; Olazaran, Reisberg, & Clare, 2010), e.g.

aimed at reducing neuropsychiatric symptoms, pharmacological and non-pharmacological, may improve the quality of life, depressive symptoms and perseverance time of the caregiver, and therefore may lead to a longer period of successful informal caregiver participation.

Disease burden, coping strategies and their effects on quality of life are important factors in enduring chronic diseases, for both patients and caregivers (Hinrichsen & Niederhe, 1994; Sousa et al., 2016). As stated before, the concept of social health can be perceived as a state of well-being achieved if one is able to adapt to changes and challenges of the disease (Huber et al., 2011). In the current study, we framed this as related to SOC-13 and LOC, and reflected by CarerQoL. These questionnaires reflect successful adaptation to stressful situations, perceived internal control and quality of life, respectively. The pattern of differences between the caregiver classes for LOC and SOC strongly support the internal validity of these findings. In the identified caregiver groups the 'younger low strain' and 'older low strain' classes have higher score on SOC-13, lower on LOC and a higher score on CarerQoL-7D and CarerQoL-VAS (Table 3 and 4). This may indicate that caregivers who adapt to the changes and challenges of the disease of the PWD have a better social health, but certain characteristics of the PWD could influence the caregiver coping and adaptation strategies. The above-mentioned is in line with the results of a review on sense of coherence in dementia: significant associations have been reported between higher caregiver SOC and lower burden of care, and between higher caregiver SOC and better caregiver's perceived health and quality of life (Marques, 2014).

Pearlin et al. developed a stress process model of stress in caregivers in which certain primary stressors (e.g. behaviour and needs of the patient and caregivers' subjective stress) influence secondary role strains (e.g. conflict with family or social life and financial problems) and secondary intra-psychic strains (e.g. damage to self-esteem and sense of control or self-identity). These strains are mediated by coping strategies and social support leading to impact on mental well-being, physical health and giving up provision of care (Aadil Jan Shah & Latoo, 2010; Pearlin, Mullan, Semple, & Skaff, 1990). These stressors or strains could have reciprocal impact on each other as well, not seeing it as a chain reaction, but as an interactive process. For example, caregiving for a person with moderate to severe dementia might result in worsened coping and well-being of the caregiver. It subsequently could lead to more depressive symptoms and impaired quality of life. Caregiver burnout is associated with poor outcomes for the PWD as well, including early institutionalization, risk of depression and mortality (Gaugler et al., 2005; Torti et al., 2004). Monitoring caregivers' well-being and stress over time might be important in continuing care for the PWD as it may eventually influence the outcomes of the PWD.

The current study is part of the Actifcare study, a large prospective cohort study, which has several strengths. Most notably, its sample size allows studying latent classes in the caregiver groups using valid and clinically relevant measures for caregiver and patient characteristics. The study was conducted throughout eight European countries, with different care systems. Increased numbers of people living with dementia are expected in the next decades and in the context of the trend towards community care and de-institutionalization of patients, informal caregivers are increasingly relied upon to care for the PWD (Aadil Jan Shah & Latoo, 2010). In

addition, validated measures were used to assess dementia, stress and stress mediators. Actifcare is a longitudinal study, which gives the opportunity to investigate whether the demonstrated caregiver profiles can predict dependent variables in the future.

Certain limitations of the study should be acknowledged as well. The study is based on cross-sectional data and therefore determining causality is limited, particularly temporality of effects. Reverse causality might explain some of the associations, e.g. caregiver depression leading to less adaptive caregiving and higher neuropsychiatric symptoms in PWD. Furthermore, despite the large sample size the number of caregivers is limited to an average of 55 participants per country. Subsequently, cultural backgrounds of the included participants might differ between countries and could potentially influence caregiver behaviour. Next to that, perseverance time could not be interpreted well, because 70% of the caregivers in all classes fell in the same ordinal group in which the perseverance time scale is divided, i.e. 'continue caring between one and two years'. Additionally, in this particular Actifcare study, we only considered questionnaires for measuring stress and stress mediators, which might have led to the exclusion of other relevant variables for caregiver profiles, such as social support and desire to institutionalize.

Different interventions for supporting informal caregivers that targeted caregivers' mental health or quality of life have been studied previously and many were to some extent effective, but published findings are rather inconsistent (Koyama et al., 2016; Vandepitte et al., 2016), and it is unknown which intervention is most effective. Furthermore, due to large numbers of informal caregivers it is logistically difficult and would be highly costly to target all caregivers of PWD with certain interventions to support their health and perseverance time in caregiving. Therefore, it is important to identify groups or subtypes of caregivers which are characterized by lower quality-of-life scores, higher depression scores and lower perseverance time scores in order to be targeted by professional interventions, as these caregivers are most prone for burnout.

Our results show that there are five different caregiver profiles which are determined by several disease-related and caregiver characteristics as well as stress and well-being of the caregiver. These findings may give direction for tailoring interventions towards personalized needs and may improve treatment results in the future. Future perspectives include a focus on the effect of different caregiver interventions for the different caregiver groups with respect to the characteristics examined in this study, and the analysis of the effects of interventions in the groups over time with both PWD as well as caregiver-related health and perseverance time as dependent variables.

## Conclusion

This study found five different profiles of informal caregivers of persons with dementia: 'older low strain', 'older intermediate strain', 'older high strain', 'younger low strain' and 'younger high strain'. Statistically significant differences between the identified caregiver groups were observed with regard to quality of life, depressive symptoms and perseverance time. Future directions for research can include replication of the different caregiver groups as well as including other relevant characteristics and variables such as social support and desire to institutionalize. The Actifcare study longitudinal follow-up

will provide the opportunity to investigate whether the demonstrated caregiver profiles can predict effects in the future. Our findings may give direction for tailoring interventions for caregivers of persons with dementia and may improve treatment results in the future that may lead to improvement of social health of the caregiver and reduction of healthcare costs for society.

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## ORCID

Eveline P.C.J. Janssen  <http://orcid.org/0000-0002-2129-2431>

Sebastian Köhler  <http://orcid.org/0000-0002-2398-0609>

Ron L.H. Handels  <http://orcid.org/0000-0002-8663-0630>

Frans R. Verhey  <http://orcid.org/0000-0002-8307-8406>

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