Psychological well-being over time among informal caregivers caring for persons with dementia living at home

Lethin, Connie; Renom-Guiteras, Anna; Zwakhalen, Sandra; Soto-Martin, Maria; Saks, Kai; Zabalegui, Adelaida; Challis, David J.; Nilsson, Christer; Karlsson, Staffan

Published in:
Aging & Mental Health

DOI:
10.1080/13607863.2016.1211621

2017

Document Version:
Peer reviewed version (aka post-print)

Link to publication

Citation for published version (APA):
Lethin, C., Renom-Guiteras, A., Zwakhalen, S., Soto-Martin, M., Saks, K., Zabalegui, A., Challis, D. J., Nilsson, C., & Karlsson, S. (2017). Psychological well-being over time among informal caregivers caring for persons with dementia living at home. *Aging & Mental Health*, *21*(11), 1138-1146. https://doi.org/10.1080/13607863.2016.1211621

Total number of authors:
9

LUND UNIVERSITY

PO Box 117
221 00 Lund
+46 46-222 00 00

Aging and Mental Health 2016 Jul 27:1-9. [Epub ahead of print]

Title: Psychological well-being over time among informal caregivers caring for persons with dementia living at home

Connie Lethin, PhD student, MSc, RN [a,*], Anna Renom Guiteras, PhD, Geriatrician[b], Sandra Zwakhalen, PhD, RN, Assistant Professor[c], Maria Soto Martin, MD, Gérontopôle[d], Kai Saks, MD, PhD, Professor[e], Adelaida Zabalegui, PhD, RN, FEANS[f], David J Challis, Professor[g], Christer Nilsson, MD, PhD[h], Staffan Karlsson, PhD, RNT, Associate Professor[a,i].

[a*]Faculty of medicine, Department of Health Sciences, Lund University, Box 157, 221 00 Lund, Sweden. [b]University of Witten/Herdecke, Alfred-Herrhausen-Straße 50 D – 58448, Witten, Germany. [c]Department of Health Services Research, Maastricht University, Maastricht, The Netherlands.[d]Alzheimer´s disease Research and Clinical Centre in Toulouse, University Hospital, Pr Vellas CHU Toulouse, France. [e]Department of internal medicine, University of Tartu, Tartu, Estonia.[f]Director of Nursing, Hospital Clínic de Barcelona, Villarroel, 170, Es.1, 7ª pl., 08036 Barcelona, Spain.[g]Director PSSRU, 2nd Floor, Crawford House, University of Manchester, Oxford Road, Manchester, M13 9PL, England United Kingdom.[h]Clinical Memory Research Unit, Department of Clinical Sciences, Lund University, Sweden.[a] Faculty of medicine, Department of Health Sciences, Lund University, Box 157, 221 00 Lund, Sweden. [i] Halmstad University, School of Health and Wellfare, PO 823, SE-30118, Halmstad, Sweden.
CONTACT: Connie Lethin, e-mail: connie.lethin@med.lu.se

Abstract

Objectives: To investigate informal caregivers' psychological well-being and predicted increase in psychological well-being, when caring for persons with dementia (PwDs) living at home, related to caregiver, PwD and formal care (FC) factors.
Method: A cohort study, at baseline and 3 months´ follow-up in eight European countries. Caregivers included (*n*=1,223) were caring for PwDs aged $\geq$ 65 years at home. Data on caregivers, PwDs and FC were collected using standardized instruments. Regression analysis of factors associated with caregiver psychological well-being at baseline and 3 months later was performed.
Results: Factors associated with caregiver psychological well-being at baseline were positive experience of caregiving, low caregiver burden, high quality of life (QoL) for caregivers, male gender of PwD, high QoL of PwD, few neuropsychiatric symptoms and depressive symptoms for the PwD. At follow-up, caregivers with increased psychological well-being experienced of quality of care (QoC) higher and were more often using dementia specific service. Predicting factors for caregivers' increased psychological well-being were less caregiver burden, positive experience of caregiving, less supervision of the PwD and higher caregiver QoL, if PwD were male, had higher QoL and less neuropsychiatric symptoms. Furthermore, higher QoC predicted increased caregivers' psychological well-being.
Conclusion: Informal caregiving for PwDs living at home is a complex task. Our study shows that caregivers' psychological well-being was associated with, among other things, less caregiver burden and higher QoL. Professionals should be aware of PwD neuropsychiatric symptoms that might affect caregivers' psychological well-being, and provide proper care and treatment for caregivers and PwDs.

Keywords: Dementia, caregivers, health professionals, home care services, adaptation; psychological

Introduction

Informal caregivers (hereafter,´caregivers´) are the main care providers for persons with dementia (PwDs) aged 65 years and more living at home. Caregiving for a PwD can be experienced as positive (The National Board of Health and Welfare, 2010) but can negatively influence caregivers´ psychological well-being. Impaired psychological well-being is associated with increased risk for poor health, including depression and life stress leading to chronic disorders (Steptoe, 2006). Therefore it is important to identify factors in caregivers, PwDs and formal care, which might be associated with the psychological well-being of caregivers and predict factors that might improve their psychological well-being.

Informal care is defined by the Organization for Economic Co-operation and Development (OECD, 2004) as care provided by caregivers who can be the spouse/partner, other members of the household, relatives, friends, neighbours or others, usually with an existing social relationship to the person they are providing care for. Informal care at home for PwDs may imply assistance in activities in daily living (ADLs), finances and supervision tasks (Schulz 2004). Caregivers provide approximately 80% of the care for PwDs living at home (Alzheimers' Association, 2010) and can have support from formal care e.g. providing instrumental ADLs (IADLs, personal ADLs (PADLs), day care for the PwD, and other forms of support. As the dementia disease progresses with increased cognitive impairment of the PwD, there is an increase in caregiving needs.

Health is defined by the World Health Organization (1948), as ´a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity´. Health is a multidimensional construct, part of which one is psychological well-being with core dimensions such as self-acceptance, environmental mastery, purpose in life, personal growth, positive relationships and autonomy (Ryff and Singer, 2008). Caring for a PwD can burden caregivers and reduce their physical and psychological well-being (Pinquart & Sörensen 2006). Caregiver burden is an important reason for institutionalization of PwD (Afram 2014; Sansoni 2013) which makes it essential to promote psychological well-being of caregivers.

Psychological well-being may therefore be a facilitating factor for health (Luybomirsky et al., 2005; Segerstrom 2012; Steptoe 2015) and improved health and reduced mortality can be predicted by higher levels of psychological well-being (Chida & Steptoe, 2008; Pressman & Cohen 2005). Few studies have focused on positive factors of psychological well-being (Luybomirsky et al., 2005) as studies of caregivers to PwDs mostly focus on factors that negatively impact the caregiver's well-being. A previous study on both caregivers to Pwd and caregivers to persons without dementia showed that well-being for the caregivers was directly affected by four factors (Chappell and Colin Reid, 2002); perceived social support, burden, self-esteem and hours of caregiving. It is therefore important to investigate factors associated with increased caregivers´ psychological well-being involving the caregiver, PwD and formal care. To understand what factors preserve and improve caregiver psychological well-being over time, it is important to investigate factors predicting an increase in psychological well-being, thus enabling individualized support to caregivers as well as PwD. This knowledge can be used to develop quality indicators for caregivers´ psychological well-being when caring for a PwD living at home. The primary aim of the present study was to investigate which caregiver, PwD and formal care-related factors are associated with psychological well-being of caregivers´ caring for older PwDs living at home. The secondary aim was to investigate which factors might predict an increase in the caregivers´ psychological well-being over time (3months).

Methods

Design

This study was a cohort study. Data were collected at baseline to investigate factors associated with caregivers´ psychological well-being. The study included a follow up after 3 months to investigate changes in caregiver psychological well-being.

Context

The study was a part of the European project ´RigthTimePlaceCare´ (RTPC; the EU 7th Framework programme for research, contract number 24 21 53) including eight participating countries; England, Estonia, Finland, France, Germany, the Netherlands, Sweden and Spain (Appendix 1). The aim of the RTPC project was to describe the health services for European citizens with dementia and to develop best practice strategies for the transition from professional home care to institutional long-term nursing care facilities. The present study followed the same methods and procedures used by the RTPC project without modification (Verbeek et al., 2012).

Sample

Caregivers and PwDs living in the community were recruited by the RTPC study, one county council or province in each country, in total 1,223 dyads (England *n*=81, Estonia *n*=172, Finland *n*=182, France *n*=175, Germany *n*=116, the Netherlands *n*=177, Sweden *n*=146 and Spain *n*=174). A contact person with knowledge about PwDs in the municipality, contacted probable participants. The contact person could be from different health care disciplines and contacts were made most commonly in the home care and in one hospital. Inclusion criteria for the PwD were age ≥ 65 years, official diagnosis of dementia, Standardized Mini-Mental State Examination (SMMSE) score ≤ 24 (Molloy et al., 1991; Folstein et al., 1975), living at home and receiving home care from health care or the social services. PwDs had to be judged to be at risk for institutionalization within 6 months by a professional caregiver responsible for their care. The caregiver had to be visiting the PwD at least twice a month and included both paid and non-paid caregivers. Recruitment in each country was performed by a contact person; these contact persons could be from different disciplines. The contact person informed the caregiver and PwD dyad about the study and the interviews, and asked for permission for researchers to contact them for a face-to-face interview.

Data collection

The study was conducted between November 2010 and April 2012. Standardized measuring instruments used for collecting data are described in detail in Table 1. The caregiver answered all questions except for the SMMSE questions, which were answered by the PwD, as well as a part of the quality of life (QoL) for the PwD. Caregiver data collected that had a potential impact on the caregivers´ psychological well-being included; age, gender, and cohabiting with the PwD, or duration and number of visits to the PwD during the last two weeks. Data on the PwDs included age, gender and dementia symptoms. Data concerning formal care regarded caregivers´ experiences of QoC provided by formal care at home. Information about specialized dementia care regarding respite care and day care was collected with a single item question: ´Are you or your relative using any dementia specific service?´ The response alternatives were ´yes´ or ´no´. Satisfaction with specialized dementia care for the PwD was measured with a single item question: ´How satisfied are you with the care provided by the dementia-related service?´ which was rated on a 5-point Likert scale, where; 1 = very dissatisfied; 2 = dissatisfied; 3 = neither satisfied, nor dissatisfied; 4 = satisfied and 5 = very satisfied.

Table 1. Instruments used for data collection, and measured factors, items, score ranges, interpretation and handling of missing data. The Table also provides references for validity and reliability.

Subject	**Instrument, and outcomes measured**	
Caregiver	GHQ12	General Health Questionnaire, measuring psychological well-being. Score range: 0- 36, a higher score indicating less psychological wellbeing. Handling of missing data: mean score if <10% missing (Goldberg, 1972; Goldberg, 1978).
	CRA	Caregiver Reaction Assessment Scale, measuring caregiver experiences of care giving in chronic patients. 24 items in five domains: *Caregiver esteem*: seven items with a possible score range of 7–35; *Lack of family support*: five items with a score range from 5 to 25, *Impact on finances*: three items with a score range from 3 to15, *Impact on schedule*: five items with a score range of 5–25; and *Impact on health*: four items with a score range from 4 to 20. A higher score on Caregiver esteem indicates positive impact on caregiver experience; for the other domains, a higher score indicates a negative impact on caregiver experience. When one item was missing, no total score was calculated (Given et al., 1992).
	ZBI	Zarit Burden Interview measuring caregiver burden. 22 items in five domains: *Burden in the relationship*, six items; *Emotional wellbeing*, seven items; *Social and family life*, four items; *Finances*, one item; and *Loss of control over one's life*, four items. Score range: 0- 88 with a higher score indicating higher perceived burden. Handling of missing data: mean score if <10% missing. (Zarit et al. 1980; Herbert et al., 2000).
	RUD	Resource Utilization in Dementia, measuring informal care provision and amount of care required from caregivers. *Personal ADLs:* hours per day of caregiving and occasions during the last 30 days of caregiving. *Instrumental ADLs:* hours per day of caregiving and occasions during the last 30 days of caregiving. *Supervision:* hours per day of caregiving and occasions during the last 30 days of caregiving. Handling of missing data: imputed data. (Wimo et al., 1998; Wimo & Nordberg, 2007).
	EQ-5D-3L EQ-VAS	EuroQoL, measuring health related quality of life (QoL) and self-rated health-related quality of life. Five descriptive questions about five health dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Score range: -0.594- 1 with a higher score indicating higher health-related QoL. EQ-VAS, measuring self-rated health. Score range: 0- 100 with a higher score indicating higher self-rated health. No total score if one item was missing. (TheEuroQolGroup, 1990; Brazier, Jones, & Kind, 1993; Oemar & Oppe 2013).
PwD	CCI	Charlson Comorbidity Index. Comorbidity of the PwD. 19 possible comorbidities. Score ranges: 0- 37 with a higher score indicating a greater risk to die from comorbid disease. Handling of missing data was not applicable. (Charlson et al., 1987; D'hoore et al., 1996).
	SMMSE	Standardized Mini-Mental State Examination, measuring cognitive function. 20 items: orientation in time and space, short term memory, short tasks on language, calculation, coordination. Score range: 0- 30 with a lower score indicating greater cognitive impairment. Handling of missing data was not applicable. (Folstein et al., 1975; Molloy et al., 1991).
	QoL-AD proxy rated	Quality of Life in Alzheimer's disease, measuring QoL of persons with dementia (Logsdon et al., 1999). Possible score: 13- 52 with a higher score indicating higher QoL (Logsdon et al., 2002).
	Katz-ADL	Katz Index of Independence in Activities of Daily Living, measuring activities of daily living (ADL). Performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Score range: 0- 6 with a higher score indicating more independence in performing ADLs (Katz et al. 1963; Wallace & Shelkey, 2008).
	NPI-Q	Neuropsychiatric Inventory Questionnaire, measuring behavioural and neuropsychiatric symptoms. 12 items: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behaviour, sleep/night-time behaviour disorders, appetite and eating disorders. 1) Screening presence the past four weeks; 2) Severity; 3) Caregiver distress. Severity score range: 0- 36 with a higher score indicating presence of more (severe) neuropsychiatric symptoms. Distress score range: 0 to 60 with a higher score indicating more distress for the caregiver (Cummings, 1994; Kaufer, et al., 2000).
	CSDD	Cornell Scale for Depression in Dementia. The CSDD contains 19 items covering five dimensions: mood-related signs (four items); behavioural disturbance (four items); physical signs (three items); cyclic functions (four items); and ideational disturbance (four items). Score range: 0- 38 with a higher score indicating more depressive symptoms. Handling of missing data: mean score if a maximum of three missing items. The answer option "unable to evaluate" = missing value (Alexopoulos et al., 1988).
FC	CLINT	CLient INTerview Instrument – Home Care, measuring subjective experiences of quality of care in the home. Right amount of food (portions), enjoying meals, personal hygiene, same care workers, things care workers do, perceiving care workers as honest and trustworthy, clean home, garden maintenance, general satisfaction with FC. Score range: 9- 45 with a higher score indicating lower quality of care. Exception: if missing or not applicable in the question about gardening, the mean score was imputed. Mean score if a maximum of one missing item. No total score if >1 item missing (Vaarama, 2009; Beerens et al., 2014).

ADLs = activities of daily living; Caregiver = informal caregiver; EQ-5D-3L = EuroQoL-5 dimensions questionnaire with three levels of answers; FC = formal care; PwD = person with dementia; RTPC = RightTimePlaceCare; QoL = quality of life.

Data analysis

To identify factors that influenced increased psychological well-being we analysed data collected at two different time-points; at baseline and after 3 months. Handling of missing data is described in Table 1. Psychological well-being of the caregiver at baseline as measured by the General Health Questionnaire (GHQ12) (Goldberg, 1972; Goldberg et al., 1978), was the dependent variable for the first analysis and was dichotomized as ´1 = psychological well-being´ (0-12; better/same as usual) and ´0=low psychological well-being´ (13-36; less/much less than usual). Cut-off was decided based on the median value for psychological well-being. For the analysis at follow-up, a new variable was created indicating ´increase in GHQ12 score´, and dichotomized as: ´0 = no increase´ (no change/worse score) and ´1 = increase´ (better score). For each independent variable, a bivariate logistic regression model was applied for the caregiver, the PwD and the formal care respectively, for comparison among caregivers with psychological well-being and low psychological well-being at baseline and increased psychological well-being and no increase of psychological well-being after 3months. Changes were regarded as statistically significant if $p < 0.05$. To identify factors associated with psychological well-being and factors predicting increased psychological well-being, three multivariate logistic regression models were performed backward for the caregiver, the PwD and the formal care respectively. The software program SPSS, version 22.0, was used for statistical analyses (IBM Corp., Armonk, NY, USA).

Ethical considerations

Each participating country obtained ethical approval from country specific legal authority and permission for data collection was obtained for each country, as described in detail elsewhere. Informed consent was obtained from participating caregivers and PwDs for the RTPC study (Verbeek et al., 2012). PwDs, not able to sign the informed consent were asked to assent, and the informal caregiver signed the informed consent for the PwD, if agreed.

Results

Informal caregivers

Psychological well-being was reported by 55% of the caregivers at baseline (median 9; Q1- 7; Q3- 11). At follow up, 58% of the caregivers reported increased psychological well-being (median 10; Q1-7; Q3- 12). Caregivers with psychological well-being were more often male and not living with the PwD; they were predominantly adult children of the PwD and were providing care to the PwD less frequently compared with caregivers with low psychological well-being (Table 2). Table 2 presents results of the bivariate regression analysis for factors associated with the caregivers´ psychological well-being. Caregivers with psychological well-being reported less caregiver burden and more positive experiences of caregiving in all domains compared with caregivers with low psychological well-being. Health-related QoL was higher for caregivers reporting psychological well-being compared with caregivers with low psychological well-being. The same factors were associated with caregiver increased psychological well-being at follow-up were associated with psychological well-being at baseline, except for age.

Influence of persons with dementia on caregiver psychological well-being

Table 3 presents the results of the bivariate regression analysis for PwD-related factors associated with the caregivers´ psychological well-being. Caregivers with psychological well-being at baseline, cared for PwDs who were mostly women, and PwDs with higher comorbidity and less cognitive impairment, higher QoL and less dependency in ADLs compared with caregivers reporting low psychological well-being. Caregivers reporting

Tabel 2. Association between informal caregiver factors and caregiver psychological well-being at baseline at follow-up.

Home care	**Psychological well-being at baseline**					**Increased psychological well-being at follow up**				
Caregivers [a]	**PWB**	**Low PWB**	**OR**	**CI 95%**	***p* value**	**Increase**	**No increase**	**OR**	**CI 95%**	***p* value**
	n=667	*n*=550				*n*=545	*n*=401			
Age, yrs; median (Q1; Q3)	63 (54; 77)	64 (55; 76)	0.993	0,986- 1.000	**0.046**	63 (54; 76)	64 (54; 75)	0.996	0.987- 1.005	0.353
Female gender, %	64	74	0.611	0.504- 0.740	<**0.001**	64	75	0.637	0.486- 0.834	**0.001**
Living with the PwD, %	55	69	0.560	0.442- 0.710	<**0.001**	56	70	0.508	0.392- 0.657	<**0.001**
No. of visits in the last 2weeks (range)	6 (4- 14)	7 (5- 14)	0.988	0.974- 1.001	0.074	6 (4- 12)	8 (4- 14)	0.995	0.980- 1.010	0.503
Length of average visit, min (range)	90 (60- 180)	115 (60- 180)	0.999	0.998- 1.000	**0.011**	90 (60- 165)	120 (60- 180)	1.000	0.999- 1.001	0.975
Relation to PwD, %										
Husband	19	16			<**0.001**	19	15			<**0.001**
Wife	20	29	0.620	0.454- 0.847	**0.003**	19	31	0.535	0.364- 0.786	**0.001**
Child	45	45	1.088	0.836- 1.418	0.529	46	44	0.924	0.657- 1.298	0.649
Friend	2	1	1.861	0.743- 4.663	0.185	1	-	6.387	0.801- 50.900	0.080
Other	14	9	1.511	1.075- 2.123	**0.017**	15	10	1.373	0.856- 2.203	0.189
Experiences of care giving (CRA) score, median (Q1; Q3)										
Esteem 7-35	27 (24; 30)	24 (21; 28)	1.080	1.060- 1.100	<**0.001**	27 (24; 30)	24 (21; 28)	1.083	1.056- 1.112	<**0.001**
Support 5-25	10 (8; 14)	13 (10; 17)	0.916	0.899- 0.934	<**0.001**	11 (8; 14)	13 (10;17)	0.920	0.896- 0.944	<**0.001**
Finances 3-15	6 (4; 7)	7 (6; 11)	0.846	0.821- 0.871	<**0.001**	6 (4; 8)	7 (6; 11)	0.856	0.822- 0.891	<**0.001**
Schedule 5-25	13 (10; 18)	19 (15; 21)	0.836	0.819- 0.854	<**0.001**	14 (10; 18)	19 (16; 21)	0.851	0.828- 0.875	<**0.001**
Health 4-20	8 (6; 10)	12 (9; 15)	0.743	0.720- 0.766	<**0.001**	8 (6; 10)	12 (9; 15)	0.774	0.744- 0.805	<**0.001**
Caregiver burden (ZBI), 0-88	24 (15; 33)	41 (31; 50)	0.923	0.916- 0.930	<**0.001**	23 (14; 34)	41 (30; 52)	0.937	0.928- 0.947	<**0.001**
Informal care provision (RUD) median (Q1; Q3)										
PADLs, hours per day of caregiving	1 (0; 3)	2 (1; 4)	0.957	0.934- 0.981	<**0.001**	1 (0; 3)	2 (1; 4)	0.931	0.905- 0.959	<**0.001**
PADLs, occasions, last 30 days of caregiving	24 (0; 30)	30 (8; 30)	0.975	0.966- 0.983	<**0.001**	30 (0; 30)	30 (15; 30)	0.975	0.966- 0.984	<**0.001**
IADLs, hours per day of caregiving	2 (1; 4)	3 (2; 5)	0.945	0.919- 0.972	<**0.001**	2 (1; 4)	3 (2; 5)	0.906	0.876- 0.938	<**0.001**
IADLs, occasions, last 30 days of caregiving	30 (10; 30)	30 (22; 30)	0.975	0.964- 0.986	<**0.001**	30 (12; 30)	30 (26; 30)	0.973	0.961- 0.985	<**0.001**
Supervision, hours per day of caregiving	1 (0; 10)	4 (1; 14)	0.966	0.953- 0.980	<**0.001**	1 (0; 10)	5 (1; 14)	0.955	0.940- 0.970	<**0.001**
Supervision, occasions, last 30 days of caregiving	30 (0; 30)	30 (15; 30)	0.972	0.964- 0.981	<**0.001**	29 (0; 30)	30 (16; 30)	0.966	0.956- 0.975	<**0.001**
Health related quality of life (EQ-5D-3L), -0.594-1	0.8 (0.7; 1.0)	0.7 (0.6; 0.8)	18.635	12.085-28.735	<**0.001**	0.9 (0.8; 1.0)	0.7 (0.6; 0.9)	9.591	5.639- 16.313	<**0.001**
EQ5D Visual analog scale (VAS), 0-100	78 (65; 85)	60 (50; 75)	1.046	1.040- 1.052	<**0.001**	80 (69; 85)	60 (50; 71)	1.032	1.025- 1.040	<**0.001**

Caregiver = informal caregiver; CI = confidence interval; CRA = Caregiver Reaction Assessment Scale; EQ-5D-3L = EuroQoL-5 dimensions questionnaire with three levels of answers; IADL = instrumental activities of daily living (ADLs); PADLs = personal activities of daily living (ADLs); OR = odds ratio; PWB = psychological well-being; RUD = Resource Utilization in Dementia instrument; ZBI = Zarit Burden Interview.

$P < 0.05$ was regarded as significant; significant p-values are marked in bold.

Underlining of values indicates a positive result, e.g., 0- 36.

Missing cases at baseline = 0, missing cases at follow up = 3.

[a] PwD moved to nursing home by follow up, n=274.

[b] Imputation of data: PADL last 30 days caregiving n=1- 2, Supervision last 30 days of caregiving n=1- 2, [c] Imputation of data: PADL last 30 days of caregiving n=19- 20, Supervision hours per day n=77, Supervision last 30 days of caregiving n=19- 20.

Table 3. Association between person with dementia (PwD)-related factors and informal caregivers´ psychological well-being at baseline and at follow-up.

Home care	**Psychological well-being at baseline**					**Increased psychological well-being at follow up**				
Persons with dementia[a]	**PWB** *n*=667	**Low PWB** *n*=550	**OR**	**CI 95%**	***p* value**	**Increase** *n*=545	**No increase** *n*=401	**OR**	**CI 95%**	***p* value**
Age, yrs; median (Q1; Q3)	83 (79; 87)	83 (74; 86)	1.008	0.995- 1.022	0.231	83 (79; 87)	82 (78; 86)	1.013	0.994- 1.032	0.174
Symptoms, yrs (range)	4 (2– 6)	4 (2– 7)	0.986	0.960- 1.012	0.296	4 (2– 6)	4 (2- 7)	0.984	0.949- 1.021	0.388
Female gender, %	68	58	1.480	1.226- 1.787	<**0.001**	70	57	1.740	1.348- 2.246	<**0.001**
Dementia diagnosis (%)										
Alzheimers disease (AD)	57	51			0.190	56	53			0.578
AD/ Vascular dementia (VaD)	5	7	0.637	0.391- 1.039	0.071	7	5	1.246	0.720- 2.156	0.431
VaD	15	18	0.709	0.516- 0.975	**0.034**	15	18	0.790	0.561- 1.112	0.176
Frontotemporal dementia	1	1	1.004	0.223- 4.523	0.995	1	1	0.937	0.208- 4.226	0.933
Lewy Body dementia	2	2	1.507	0.636- 3.569	0.352	2	2	1.305	0.513- 3.321	0.576
Unknown	16	16	0.948	0.686- 1.311	0.748	14	17	0.798	0.560- 1.136	0.211
Other	4	5	0.753	0.432- 1.313	0.317	5	4	1.093	0.591- 2.022	0.776
Comorbidity (CCI), median (Q1; Q3), 0-37	2 (1; 3)[b]	2 (1; 3)[c]	0.909	0.856- 0.966	**0.002**	2 (1; 3)[d]	2 (1; 3)[e]	0.921	0.842- 1.006	**0.067**
Cognitive function, (SMMSE), 0-30	16 (11; 20)	15 (9; 19)	1.023	1.008- 1.038	**0.003**	16 (11; 20)	15 (9; 19)	1.031	1.011- 1.052	**0.003**
Quality of life (QoL-AD, proxy), 13-52	29 (26; 33)	26 (23; 30)	1.089	1.070- 1.108	<**0.001**	29 (26; 33)	26 (23; 31)	1.082	1.055- 1.110	<**0.001**
Activities of daily living (Katz ADL), 0-6	4 (2; 5)	3 (2; 5)	1.096	1.047- 1.148	<**0.001**	3 (2; 5)	3 (1; 4)	1.101	1.033- 1.174	**0.003**
Neuropsychiatric symptoms (NPI)[f] median (Q1; Q3)										
Severity, 0- 36	7 (3; 11)	11 (6; 15)	0.941	0.927- 0.955	<**0.001**	6 (3; 11)	8 (4; 12)	0.952	0.933- 0.971	<**0.001**
Distress, 0- 60	7 (2; 13)	13 (7; 20)	0.931	0.918- 0.944	<**0.001**	6 (2; 12)	10 (5; 14)	0.952	0.939- 0.966	<**0.001**
Depression in dementia (CSDD), 0- 38	6 (2; 10)	9 (5; 14)	0.917	0.901- 0.934	<**0.001**	5 (2; 9)	8 (5; 17)	0.938	0.916- 0.960	<**0.001**

CCI = Charlson Comorbidity Index; CI = confidence interval; CSDD = Cornell Scale for Depression in Dementia; NPI = Neuropsychiatric Inventory; OR = odds ratio; PWB = Psychological well-being; QoL-AD = quality of life in Alzheimer's disease; Q1 = first quartile; Q3 = third quartile; SMMSE = Standardized Mini-Mental State Examination.

P < 0.05 was regarded as significant; significant p-values are marked in bold.

Missing cases at baseline = 0; missing cases at follow-up = 3.

Underlining of values indicates a positive result, e.g., 0–36.

[a] PwDs who had moved to a nursing home at follow-up, n=274.

[b] Mean 2.24, standard deviation (SD) =1.8; [c] mean 2.00, SD=1.28; [d] mean 2.18, SD=1.50; [e] mean 2.01, SD=1.25.

[f] Imputation of data for NPI, severity and burden, respectively, n=1.

Table 4. Association between formal care-related factors and informal caregivers´ psychological well-being at baseline and at follow-up.

Home care	**Psychological well-being at baseline**[h]					**Increased psychological well-being at follow up**[i]				
Formal care[a]	**PWB** *n*=667	**Low PWB** *n*=550	**OR**	**CI 95%**	***p* value**	**Increase** *n*=545	**No increase** *n*=401	**OR**	**CI 95%**	***p* value**
Quality of care at home (CLINT)										
median (Q1; Q3)										
Total score, 9- 45	15.0 (12.0; 18.0)	16.1 (13.1; 18.1)	0.948	0.919- 0.978	**0.001**	14.0 (12.0; 17.1)	16.1(13.1; 18.1)	0.947	0.916- 0.980	**0.002**
Food portions, 1- 5	1.0 (1.0; 1.9)	1.0 (1.0; 1.2)	0.975	0.895- 1.063	0.571	1.0 (1.0; 1.0)	1.0 (1.0; 2.0)	1.042	0.922- 1.177	0. 510
Enjoy meals, 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2. 0)	0.875	0.799- 0.958	**0.004**	1.0 (1.0; 2. 0)	2.0 (1.0; 2. 0)	0.848	0.742- 0.970	**0.016**
Personal hygiene, 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.867	0.790- 0.952	**0.003**	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.895	0.787- 1.019	0.094
Same care workers, 1- 5	2.0 (1.0; 3.0)	2.0 (1.0; 2.0)	1.150	1.026- 1.288	**0.016**	2.0 (1.0; 2.0)	2.0 (1.0; 2.0)	1.128	0.996- 1.277	0.058
Things care workers do 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.837	0.719- 0.975	**0.023**	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.815	0.689- 0.965	**0.018**
Honest care workers, 1- 5	1.0 (1.0; 1.0)	1.0 (1.0; 2.0)	0.766	0.629- 0.933	**0.008**	1.0 (1.0; 1.0)	1.0 (1.0; 2.0)	0.783	0.631- 0.970	**0.025**
Home clean, 1- 5	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.718	0.627- 0.822	<**0.001**	1.0 (1.0; 2.0)	2.0 (1.0; 2.0)	0.719	0.620- 0.833	<**0.001**
Garden maintenance, 1- 5	2.0 (2.0; 2.0)	2.1 (2.1; 2.1)	0.773	0.662- 0.904	**0.001**	2.0 (2.0; 2.0)[d]	2.0 (2.0; 2.0)[f]	0.741	0.625- 0.879	**0.001**
General satisfaction, 1- 5	2.0 (1.0; 2.0)[b]	2.0 (1.0; 2.0)[c]	0.826	0.710- 0.961	**0.013**	2.0 (1.0; 2.0)[e]	2.0 (1.0; 2.0)[g]	0.842	0.715- 0.990	**0.037**
Service to the PwD										
Use of specific dementia service %	43	49	0.736	0.614- 0.881	**0.001**	46	51	0.898	0.702- 1.148	0.389
Satisfaction with dementia specific care, %										
Satisfied, 1- 5	75	71	1.168	0.868- 1.571	0.305	74	68	1.329	0.928- 1.902	0.121

CI = confidence interval; CLINT = CLient INTerview Instrument–Home Care; OR = odds ratio; PWB = psychological well-being; PwD = person with dementia; Q1 = first quartile; Q3 = third quartile.

P < 0.05 was regarded as significant; significant p-values are marked in bold.

Underlining of values indicates a positive result, for CLINT 9–45 and 1-5; for satisfaction with dementia specific care 1– 5.

Missing cases at baseline = 0; missing cases at follow-up = 3.

[a] PwD moved to nursing home at follow-up, n=274.

[b] Mean 1.71, standard deviation (SD)=0.75; [c] mean 1.82, SD=0.80; [d] mean 1.89, SD=0.59; [e] mean 1.72, SD=0.77; [f] mean1.98, SD=0.69; [g] mean 1.77, SD=0.71.

[h] Imputation of data for the CLient INTerview Instrument–Home Care (CLINT), Food portions, n =155, Enjoy meals, n =4, Personal hygiene, n =4, Same care workers, n =4, Things care workers do, n =6, Honest care workers, n =1, Home clean, n =3, Garden maintenance, n =814, General satisfaction, n =3.

[i] Imputation of data for CLINT follow-up: Food portions, n =4; Enjoy meals, n =294; Personal hygiene, n =2; Same care workers, n =1; Things care workers do, n =1; Honest care workers, n =1; Home clean, n =2; Garden maintenance, n =670

psychological well-being cared for PwDs with fewer neuropsychiatric symptoms and symptoms of depression on the depression scale compared with caregivers reporting low psychological well-being. The same factors were associated with increased caregiver psychological well-being at follow-up as with psychological well-being at baseline, except for PwD comorbidity. Type of dementia diagnosis was not associated with caregivers´ psychological well-being at baseline, except for vascular dementia. Neither was it associated with increase in the caregivers´ psychological well-being at follow-up.

The impact of formal care on caregiver psychological well-being

In Table 4 the results of the bivariate regression analysis are presented for formal care-related factors associated with caregiver psychological well-being. Overall, caregivers reporting psychological well-being at baseline, reported higher QoC generally, and explicitly regarding enjoyment of meals, personal hygiene for the PwD, continuity in care workers, tasks care workers do, honesty in care workers, having a clean home, help with garden maintenance and general satisfaction compared with caregivers reporting low psychological well-being. Caregivers reporting psychological well-being at baseline also reported higher use of dementia specific care. The same factors as with psychological well-being at baseline were associated with caregiver increased psychological well-being at follow-up, except for personal hygiene for the PwD, continuity in care workers, and use of dementia specific care.

Factors associated with and predicting caregiver psychological well-being

Table 5 shows the factors that were both associated with, and predicted caregiver psychological well-being, according to the multivariate regression analysis. Caregiver-related factors, in this category were: a positive experience of caregiving in the dimension of health; and less caregiver burden. The PwD-related factors were male gender of the PwD; and the PwD had higher QoL, and fewer neuropsychiatric symptoms causing distress to the caregiver. Finally, formal care-related factors in this category were: a positive experience of QoC concerning having a clean home; garden maintenance and general satisfaction.

Factors solely associated with caregiver psychological well-being at baseline were the caregivers own experience of less caregiver burden; and higher health-related QoL. Regarding the PwD, factors in this category were fewer depressive symptoms on the depression scale. Formal care-related factors in this category were higher rated experience of QoC regarding continuity in formal care workers; and a positive experience of the use of dementia-specific care. On the other hand, caregiver-related factors solely predicting caregiver increased psychological well-being at follow-up were informal care provision concerning less supervision in the last 30 days; and higher health-related QoL. In this category, PwD-related factors were presence of neuropsychiatric symptoms with less severity. Formal care-related factors in this category were experience of QoC: continuity in formal care workers; having a clean home; and general satisfaction.

Discussion

Caring for a PwD living at home is a continuous responsibility for caregivers. To maintain and facilitate caregivers´ psychological well-being it is crucial to support the caregiver. This study has identified several factors associated with caregiver psychological well-being. Positive experiences of caregiving and less burden concerning their own health were associated with the presence of caregiver psychological well-being. Caregivers with psychological well-being reported higher self-esteem, more support from family, and less impact on finances, their own spare time and health compared with caregivers with both low psychological well-being and no increase in psychological well-being. These results are similar to the results of the study by Chapell and Colin Reids (2002) who showed that the psychological well-being for caregivers of PwDs and caregivers of persons without dementia

Table 5. Factors associated with informal caregivers´ psychological well-being and predicting factors for increased psychological well-being.

Associated factors for psychological well-being		**Adjusted R^{2*}**	**OR**	**CI 95%**	***p* value**
Caregiver factors	**Experiences of care giving (CRA)**	0.428			
	Health		0.899	0.856 - 0.944	<**0.001**
	Caregiver burden (ZBI)		0.932	0.920 - 0.945	<**0.001**
	Health related QoL				
	EQ5D Visual analogue scale (VAS)		1.025	1.016 - 1.034	<**0.001**
PwD factors	Gender (male)	0.208	1.562	1.192 - 2.046	**0.001**
	QoL (QoL-AD, proxy)		1.096	1.064 - 1.128	<**0.001**
	Neuropsychiatric symptoms (NPI)				
	-Distress		0.952	0.935 - 0.970	<**0.001**
	Depression in dementia (CSDD)		0.965	0.937 - 0.995	**0.023**
FC factors	**Experiences of quality of care (CLINT**)	0.063			
	-Same care worker		1.270	1.109 - 1.453	**0.001**
	-Having a clean home		0.750	0.647 - 0.870	<**0.001**
	-Garden maintenance		0.840	0.709 - 0.994	**0.043**
	-General satisfaction		0.790	0.659 - 0.949	**0.012**
	Service to the PwD				
	Use of dementia specific care		0.721	0.556 – 0.936	**0.014**
Predicting factors for increased psychological well-being					
Caregiver factors	**Experiences of care giving (CRA)**	0.306			
	Health		0.882	0.838 - 0.928	<**0.001**
	Caregiver burden (ZBI)		0.961	0.949 - 0.973	<**0.001**
	Informal care provision (RUD)				
	Supervision in the last 30 days of caregiving		0.983	0.971 - 0.994	**0.003**
	Health related QoL, EQ-5D-3L		2.684	1.430 - 5.038	**0.002**
PwD factors	Gender (male)	0.119	1.771	1.355 - 2.316	<**0.001**
	QoL (QoL-AD, proxy)		1.073	1.043 - 1.103	<**0.001**
	Neuropsychiatric symptoms (NPI)				
	-Severity		1.069	1.024 - 1.116	**0.002**
	-Distress		0.926	0.899 - 0.953	<**0.001**
FC factors	**Experiences of quality of care (CLINT)**	0.045			
	-Same care worker		1.209	1.048 - 1.396	**0.009**
	-Having a clean home		0.721	0.617 - 0.842	<**0.001**
	-General satisfaction		0.825	0.682 - 0.998	**0.048**

Caregiver = informal caregiver; CI = confidence interval; CLINT = CLient INTerview Instrument–Home Care; CRA = Caregiver Reaction Assessment Scale; CSDD = Depression Scale in Dementia; EQ-5D-3L = EuroQoL-5 dimensions questionnaire with three levels of answers; FC = formal care; NPI = Neuropsychiatric Inventory; OR = odds ratio; PwD = person with dementia; QoL = Quality of life; QoL-AD = Quality of life in Alzheimer's disease; RUD = Resource Utilization in Dementia instrument; ZBI = Zarit Burden Interview.
$p < 0.05$ was regarded as significant; significant p-values are marked in bold.

was directly affected by their perception of social support, self-esteem and burden. Another study including caregivers to older people in general showed that less contact with colleagues and friends was associated with high psychological distress suggesting that it is important to keep social contacts (Yiengprugsawan et al., 2012). For health care and social services, this indicates the need to identify vulnerable caregivers in order to be able to provide them with support, such as respite care or day care for the person cared for (in our case the PwD) and encourage families to support each other and share the caregiver responsibility. Such support has been suggested to facilitate caregiver psychological well-being and relieve caregiver burden. By enabling caregivers to maintain their social network and self-esteem, it enables them to continue caring for the PwD at home.

As the dementia disease progresses the care needs of the PwD increase. With support from formal care, caregiver psychological well-being may remain unaffected and may even increase. The present study shows that caregivers with psychological well-being cared for

PwDs who experienced fewer neuropsychiatric symptoms and less dependency in ADLs. Further, the amount of informal care provision regarding IADLs and PADLs and supervision affected caregiver with psychological well-being. This is similar to results reported in a study by Chappell and Colin Reid (2002) showing that the psychological well-being of caregivers to PwDs and caregivers to persons without dementia was directly affected by hours of informal care, while caregiver burden was directly affected by neuropsychiatric symptoms. A previous study reporting spousal caregiving showed that wives reported higher well-being when providing care to their husbands compared with when carrying out chores such as doing the laundry, preparing dinner and cleaning. For husbands, neither the spouse disability nor her care needs were associated with experienced well-being (Freedman et al., 2014). In the present study, fewer neuropsychiatric symptoms in the PwD were both an associated factor for caregiver psychological well-being and a predicting factor for increased caregiver psychological well-being. It is important for health care and social services to have knowledge about what factors affect caregiver psychological well-being. This enables formal care to provide individualized support to caregivers to promote their psychological well-being.

The way formal care is performed including dementia specific care for the PwD may be important for caregivers and may have an impact on their psychological well-being. The result of our study show that factors associated with caregiver psychological well-being were, positive experiences of QoC overall, and specifically the experience of continuity of care workers and having a clean home. In addition, caregivers with psychological well-being were using dementia specific care. In a previous study, caregivers´ dissatisfaction with formal care was reported to occur when the caregivers did not know which professionals to call for complaints, emergencies and other problems (Janse et al., 2014). In addition, dissatisfaction might relate to other factors such as behavioral and psychiatric symptoms as shown in a previous study included in cognitively impaired patients in hospital settings (Whittamore et al., 2014). Other factors that can affect the caregiver psychological well-being are the caregivers´ levels of self-esteem, mastery and neuroticism (Brodaty, 2009). As shown in this study important factors that influence the psychological well-being of caregivers are their experiences of caregiving and informal care provision; the PwDs neuropsychiatric symptoms and dependency in ADLs, and the caregivers experience of QoC.

The main strengths of our study were the large size of the cohort and the comprehensive approach that is data were gathered on many different factors potentially associated with caregivers´ psychological well-being, including data on all involved parties, namely the caregiver, PwD and formal care. Since the PwDs were at risk for institutionalization within 6 months, we supposed that caregiver burden and psychological well-being would be negatively affected. Examining caregiver psychological well-being both at baseline and after 3 months allowed us to determine the stability of psychological well-being over time, as well as factors that could predict increased or worsened well-being. The gender effect on caregiver psychological well-being and increased psychological well-being shows different results depending on the analysis. The bivariate regression analysis shows that most PwDs cared for were female and the multivariate regression analysis shows male gender, affecting the caregiver psychological well-being and increased psychological well-being. The main limitation of this study was that the study design (cross-sectional at baseline) did not allow us to establish any causal relationships, and therefore the results should be interpreted cautiously, with further prospective studies needed. The caregivers caring for PwDs living in the community receiving home care and being at risk for institutionalization, might differ from the PwDs who do not receive such services and who would not be judged as being at risk for institutionalization. This would mean that the result may not be representative for caregivers to PwD in general. Another limitation might be that the follow-up after 3 months was probably too short to see significant changes, and therefore the changes in caregiver psychological well-being within this short time frame should be interpreted very carefully. However, more caregivers at follow-up than at baseline rated psychological well-being (58% vs 55%). This was due to some PwDs (*n*=274) having been admitted to institutional care during the follow-up period, which may have affected the results, with higher perceived psychological well-being at follow-up. Caregivers in this study come from different European countries that differ with regard to care and support systems. There may have been some variations in the recruitment process. Nevertheless, to ensure internal validity the same guidelines and procedures were used by the countries participating in the RTPC project. External validity was promoted by including countries representing northern, southern, central, western and eastern Europe. Each country's sample was n=81- 182 which was assessed to be sufficient for the provided analysis (Verbeeck, 2012). In the bivariate regression analysis, several factors at baseline showed large differences in values with little, or no, overlap but with significance (p=<0.05) due to the large sample (n=1,223). Mean value was calculated for equal confidence interval between baseline and follow-up values to show differences (QoC). However, the 95% confidence interval was small for several factors which shows precision of this study. This study used QoL for the PwD (Quality of life in Alzheimer's disease, QoL-AD), as rated by caregivers. Previous studies have shown that the PwDs QoL is rated lower by caregivers than by the PwDs themselves (Logsdon 1999; Thorgrimsen, 2003), and it may be possible that caregivers´ perception of low PwD QoL has an impact on their own psychological well-being. In one study, this may have affected the associated factors in caregivers to perceive low psychological well-being in connection to whether QoL-AD rated by the PwD had been selected. The PwDs QoL can be rated by the PwD even with a very low Mini Mental State Examination (MMSE) score ≤3 (Thorgrimsen et al., 2003). Knowledge about how PwDs experience their own QoL may increase caregivers´ psychological well-being.

Conclusion

Informal caregiving for an older PwD living at home is a complex task that could be influenced by factors associated with the caregiver, the PwD and the formal care. Our study showed that caregiver psychological well-being was associated with less caregiver burden and higher QoL. A higher number of neuropsychiatric symptoms in the PwD was associated with caregivers´ decreased psychological well-being. Higher rated QoC was associated with caregivers´ increased psychological well-being. Professionals should consider the possibility that PwDs neuropsychiatric symptoms may affect their caregivers´ psychological well-being, and provide appropriate care and treatment for both the caregiver and the PwD. Maintaining their social network, and retaining their self-esteem to continue caring for the PwD at home may help caregivers increase their psychological well-being.

Acknowledgements

We are grateful for the informal caregivers participating in the RightTimePlaceCare project and who made this study possible. We are also grateful for the statistical advices given by Anna Axmon, Associate professor, Occupational and Environmental Medicine, Lund University, Sweden.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the EU 7th Framework programme under grant number 242153.

References

Afram, B., Stephan, A., Verbeek, H., Bleijlevens, M.H., Suhonen, R., Sutcliffe, C., … Hamers, J.P. (2014). Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *J Am Med Dir Assoc,* 15(2), 108-116. doi: 10.1016/j.jamda.2013.09.012.

Alexopoulos, G.S., Abrams, R.C., Young, R.C., & Shamoian, C.A. (1988). Cornell Scale for Depression in Dementia. *Biological Psychiatry, 23*, 271-284.

Alzheimer's Association. 2010 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 2010;6*, 159-194. Retrieved from http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf

Beerens, H.C., Sutcliffe, C., Renom-Guiteras, A., Soto, M.E., Suhonen, R., Zabalegui, A., … Hamers, J.P. (2014). Quality of life and quality of care for people with dementia receiving long term institutional care or professional home care: the European RightTimePlaceCare study. *Journal of the American Medical Directors Association, 15*, 54-61. doi: 10.1016/j.jamda.2013.09.010.

Brazier, J., Jones, N., & Kind, P. (1993). Testing the validity of the EuroQol and comparing it with the SF-36 health survey questionnaire. *Quality of Life Research, 2*(3), 169-180. http://www.jstor.org.ludwig.lub.lu.se/stable/4034500

Brodaty H, Donkin M. (2009). Family caregivers of people with dementia. *Dialogues Clin Neurosci*, 11, 217-228.

Chappell NL, Reid RC. (2002). Burden and well-being among caregivers: examining the distinction. *Gerontologis*,42, 772-780.

Charlson, M.E., Pompei, P., Ales, K.L., & MacKenzie, C.R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Disorders, 40*, 373-383.

Chida, Y., & Steptoe, A. (2008). Positive psychological well-being and mortality: a quantitative review of prospective observational studies. *Psychosomatic Medicine,70,* 741-756. doi: 10.1097/PSY.0b013e31818105ba.

Cummings, J.L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D.A., & Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology, 44*, 2308-2314.

D'hoore, W., A. Bouckaert, & Tilquin, C. (1996). Practical Considerations on the Use of the Charlson Comorbidity Index with Administrative Data Bases. Journal of Clinical Epidemioly, *49*, 1429-1433.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Researc*h, *12*, 189-198.

Freedman, V.A., Cornman, J.C., & Carr, D. (2014). Is spousal caregiving associated with enhanced well-being? New evidence from the panel study of income dynamics. *The Journals* of *Gerontology Series B*: *Psychological Sciences* and *Social Sciences, 69*, 861-869. doi: 10.1093/geronb/gbu004. Epub 2014 Feb 5.

Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairment. *Research of Nursing Health*, *15*, 271-283.

Golberg, D.P. (1972). *The detection of psychiatric illness by questionnaire*. London: Oxford University Press.

Goldberg, D.P. (1978). *Manual of the General Health Questionaire*. Windsor, England, NFER.

Hebert, R., Bravo, G., & Preville, M. (2000). Reliability, Validity and Reference Values of the Zarit Burden Interview for Assessing Informal Caregivers of Community-Dwelling Older Persons with Dementia. *Canadian Journal on Aging, 19*, 494-507.

Janse, B., Huijsman, R., & Fabbricotti, I.N. (2014). A quasi-experimental study of the effects of an integrated care intervention for the frail elderly on informal caregivers' satisfaction with care and support. *BMC Health Services Research, 29*, 14, 140. doi: 10.1186/1472-6963-14-140.

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A. & Jaffe, M.W. (1963). Studies of illness in the aged. The Index of ADL: A standarized measure of logical and psychosocial function. *Journal of the American Medical Association, 21*, 914-919.

Kaufer, D. I. Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., … DeKosky, S.T. (2000). Validation of the NPI-Q: a brief clinical form of the Neuropsychiatric Inventory. *Journal of Neuropsychiatry and Clinical Neurosciences, 12,* 233–239.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer´s disease: Patient and caregiver reports. *Journal of Mental Health & Aging, 5*(1), 21-32.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64,* 510-519.

Lyubomirsky, S. King, L., & Diener, E. (2005). The benefits of frequent positive affect: does happiness lead to success? *Psychological Bulletine, 131*, 803-855.

Molloy, D.W., Alemayehu, E., & Roberts, R. (1991). Reliability of a Standardized Mini-Mental State Examination compared with the traditional Mini-Mental State Examination. *American Journal of Psychiatry, 148*, 102-105.

OECD: The OECD Health Project. *Long-term Care for Older People Paris: The Organisation for Economic Cooperation and Development*; 2005.

Oemar, M., & Oppe, M. *EQ-5D-3L User Guide: Basic Information on how to use the EQ-5D-3L instrument*, 2013, EuroQol Group: Rotterdam. p. 7.

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychological Aging, 18*, 250-267.

Pressman, SD., & Cohen, S. (2005). Does positive affect influence health? *Psychological Bulletine, 131*, 925-971.

Ryff, C.D. & Singer, B.H. (2008). Know thyself and become what you are: A eudaimonic approach to psychological well-being. *Journal of Happiness Studies*, 9, 13–39. doi: 10.1007/s10902-006-9019-0

Sansoni, J., Anderson, K.H., Varona, L.M., & Varela, G. (2013). Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. *Ann Ig.* 25(3), 235-246. doi: 10.7416/ai.2013.1926.

Schulz, R., Belle, S.H., Czaja, S.J., McGinnis, K.A., Stevens, A., & Zhang, S. (2004) Long-term Care Placement of Dementia Patients and Caregiver Health and Well-being. *Journal of the American Medical Association*, *292*, 961-967.

Segerstrom C. ed. *The Oxford Book of Psychoneuroimmunology.* Oxford: Oxford University Press; 2012.

Steptoe A, ed. *Depression and physical illness.* Cambridge: Cambridge University Press; 2006.

Steptoe, A., Deaton, A., & Stone, A.A. (2015). Subjective wellbeing, health, and ageing. *Lancet, 14*, 640-8. doi: 10.1016/S0140-6736(13)61489-0. Epub 2014 Nov 6.

TheEuroQolGroup. (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health policy, 16*, 199-208.

The National Board of Health and Welfare (2010). *Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010 – stöd för styrning och ledning.* [in Swedish]. (National Guidelines for Care in cases of Dementia),Västerås, Edita Västra Aros.

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R.T., & Orrell, M. (2003). Whose quality of life is it anyway? The validity and reliability of the

Quality of Life-Alzheimer's Disease (QoL-AD) scale. *Alzheimer Disease and Associated Disorders, 17*, 201-208.

Vaarama, M. (2009). Care-related quality of life in old age. *European Journal of Ageing,* 6, 113-125.

Verbeek, H., Meyer, G., Leino-Kilpi, H., Zabalegui, A., Rahm Hallberg, I., Saks, K., … Hamers, J.P.H. (2012). A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. *BMC Public Health*, 12(68), 1-10. doi: 10.1186/1471-2458-12-68.

Wallace M & Shelkey M. (2008). Monitoring functional status in hospitalized older adults. *American Journal of Nursing, 108*, 64-71; quiz 71-2. doi: 10.1097/01.NAJ.0000314811.46029.3d.

Whittamore, K.H., Goldberg, S.E., Bradshaw, L.E., Harwood, R.H. (2014). Medical Crises in Older People Study Group. Factors associated with family caregiver dissatisfaction with acute hospital care of older cognitively impaired relatives. *Journal of American Geriatric Sociaty*, *62*, 2252-60. doi: 10.1111/jgs.13147.

Wimo, A., Jönsson, B., Karlsson, G., & Winblad, B. (1998). *Health economics of dementia*. New York, USA. John Wiley & Sons.

Wimo, A. & Nordberg, A. (2007). Validity and reliability of assessments of time. Comparisons of direct observations and estimates of time by the use of the resource utilization in dementia (RUD)-instrument. *Archives of Gerontology and Geriatrics*, *44*, 71-81.

World Health Organization (1948). WHO definition of health. http://www.who.int/about/definition/en/print.html

Yiengprugsawan, V., Seubsman, S.SA., Sleigh, A.C. (2012). Psychological distress and mental health of Thai caregivers. *Psychological Well Being*, *2,* 1-11.

Zarit, S.H., Reever K.E., & Bach-Peterson., J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *The Gerontologist, 20*, 649-655.

Appendix 1

Consortium partners for the RightTimePlaceCare are as follows:

Coordinator:
University of Witten/Herdecke (DE): Gabriele Meyer, PhD, RN; Astrid Stephan, PhD, RN; Anna Renom Guiteras, PhD, MD; Dirk Sauerland, PhD; Ansgar Wübker, PhD; Patrick Bremer.

Consortium Members:
Maastricht University (NL): Jan P.H. Hamers, PhD, RN; Basema Afram, PhD, MD; Hanneke C. Beerens, PhD, RN; Michel H.C. Bleijlevens, PhD, PT; Hilde Verbeek, PhD; Sandra M.G. Zwakhalen, PhD, RN; Dirk Ruwaard, PhD, MD; Ton Ambergen, PhD.

Lund University (SE): Ingalill Rahm Hallberg, PhD; Ulla Melin Emilsson, PhD; Staffan Karlsson, PhD; Christina Bökberg, MSc; Connie Lethin, MSc.

University of Manchester (UK): David Challis, PhD; Caroline Sutcliffe, MSc; David Jolley, PhD; Sue Tucker, MSc, RN; Ian Bowns, PhD; Brenda Roe, PhD; Alistair Burns, PhD.

University of Turku (FI): Helena Leino-Kilpi, PhD, RN; Jaana Koskenniemi, MSc, RN; Riitta Suhonen, PhD, RN; Matti Viitanen, PhD, MD; Seija Arve, PhD, RN; Minna Stolt, PhD; Maija Hupli, PhD, RN.

University of Tartu (EE): Kai Saks, PhD, MD; Ene-Margit Tiit, PhD; Jelena Leibur, MD; Katrin Raamat, MA; Angelika Armolik, MA; Teija Tuula Marjatta Toivari, MA, RN.

Fundació Privada Clinic per la Recerca Biomedica, Hospital Clinic of Barcelona (ES): Adelaida Zabalegui, PhD, RN; Montserrat Navarro, PhD, RN; Esther Cabrera, PhD, RN (Tecnocampus Mataró); Ester Risco, MSc, RN; Carme Alvira, MSc, RN; Marta Farre, MSc, RN; Susana Miguel, MSc, RN.

Gerontôpole, University of Toulouse (FR): Maria Soto, MD; Agathe Milhet; Sandrine Sourdet, MD; Sophie Gillette; Bruno Vellas, PhD.