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## **Informal Dementia Care: Consequences for Caregivers' Health and Health Care Use in 8 European Countries**

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### **Abstract**

**Background:** Informal (dementia) care has economic consequences throughout the health care system. Whilst the health and wellbeing of the care recipient might improve, the health of the caregiver might also change, typically for the worse. Therefore, this analysis aims to examine the association between caregiving intensity and caregivers' health and health care utilization.

**Data and Methods:** The empirical analysis is based on cross-sectional survey data generated by the European Project "RightTimePlaceCare" (RTPC). RTPC was a prospective cohort study conducted in eight European countries (Estonia, Finland, France, Germany, Netherlands, Sweden, Spain and the United Kingdom). The health status of 1029 informal caregivers was assessed by measures of psychological wellbeing (GHQ-12) and self-rated overall health (EQ-VAS). Health care utilization was measured by i) the self-stated proportion of health care use influenced by caregiving and ii) the probability of at least one visit to a general practitioner within in the last 30 days. The association between caregiving intensity and caregivers' health and health care utilization was assessed by descriptive analysis and multivariate OLS- and probit-models.

**Results:** A higher amount of informal care was significantly related to negative health outcomes for informal caregivers. On average, one additional hour of informal caregiving per day was associated with a decrease of psychological wellbeing and self-rated overall health by 0.16 and 0.42 index points respectively. Furthermore, one more hour of informal caregiving corresponded with increased self-stated proportion of health care use by 0.56 percentage points. However, the claim of increased health care demand due to caregiving as measured by GP visits was only partly confirmed.

**Conclusion:** When evaluating the full economic effect of informal care, the impact of providing care on caregivers' health and health care utilization has to be taken into account.

**Keywords:** Dementia, Informal Care, Caregivers' Health, Health Care Utilization, Europe

## 1. Introduction

Dementia is a complex, progressively debilitating disorder which typically causes a general loss of cognitive, functional and mental capabilities [1]. Currently, an estimated 35.6 million people worldwide are affected by this disease, the prevalence of which increases almost exponentially with older age [1]. Due to aging populations in all industrialized countries, the number of individuals afflicted by dementia will increase significantly over the next decades.

Compared to other diseases which impose a large burden on society, dementia is a relatively new area of policy focus. A core policy principle within Europe is to encourage home and community-based services in order to delay institutionalization [2, 3]. As a result, informal caregiving (defined as unpaid care provided by relatives or friends) is playing an increasingly vital role in delivering care for people with dementia (PwD). Although family members caring for their impaired relatives are not remunerated by direct payments, providing informal care is associated with different economic effects (cf. [4] for an overview about the economic effects of informal care and [5] for an overview about economic valuation of informal care).

Besides a considerable amount of opportunity costs, which occur when informal caregivers (ICG) quit their jobs or reduce their working hours due to caring for their relatives, it is well documented that informal care has an impact on formal care expenditures by influencing care recipients' (CR) formal care use [e.g. 6]. Although informal care can be both a substitute and a complement to formal care, van Houtven and Norton found, that on net, informal care is cost-saving by reducing formal care expenditures [4]. However, in order to quantify the net savings on formal care expenditures, it has to be taken into account that informal caregiving might influence caregivers' health and health care utilization as well.

Dementia caregiving is often perceived as stressful and extremely challenging by many caregivers [7, 8]. Even though providing care to a relative or a close friend can also be accompanied by positive aspects such as feeling useful or experiencing pride in one's own abilities to cope with crisis [9], past studies have shown that dementia caregiving has been linked to a number of adverse health conditions.

Compared with non-caregivers, caregivers showed significantly higher rates of depressive disorders [7, 10], they experienced decrements in immunity measures relative to controls [11, 12], and (to a smaller extent) reported more physical morbidity [7]. The findings regarding the extent to which bad health can be explained by the amount of assistance provided on the one hand and moderator variables like CRs' physical and cognitive impairment or the presence of behavioral problems on the other hand are not consistent across studies. For example,

investigating the determinants of caregiver burden and depressive mood, Pinquart and Sörensen found in their meta-analysis a (small) positive relationship between the amount of provided care, depression and caregiver burden [13], whereas other studies didn't find such a relationship [e.g. 14, 15].

Besides negative mental and physical health effects, it has been revealed that informal caregiving might also lead to higher health care utilization. For example, former studies showed that outpatient visits [16, 17] and rates of drug use [6, 18] have been significantly higher among caregivers relative to non-caregivers. This additional resource utilization has to be considered when calculating the total costs of informal caregiving.

Studies investigating the relationship between informal caregiving and ICG's health status and health care utilization predominantly come from the US. Results from Europe are rare and particularly comparisons between different European countries are to the best of our knowledge not available. However, as European countries differ with respect to several factors (e.g. health care structures, dementia care policy or cultural values), which may all contribute to the amount of informal care and its consequences on ICG's health and health care utilization, a comprehensive comparison among different European countries is required in order to derive adequate policy implications for Europe.

It has been shown for other areas in the context of health care provision for people suffering from dementia that outcomes differ tremendously within Europe. For example, a large variation between European countries was found regarding the quality of life and quality of care for people with dementia [19], for the reasons contributing to their institutionalization [20] and for care and service activities in general [21].

In the particular context of informal caregiving, previous findings point to a significant north-south gradient within Europe. For example, Bolin, Lindgren and Lundborg found that the relationship between informal caregiving and labor market outcomes differ significantly between northern and southern regions within Europe [22]. Furthermore a higher support for filial norms and a preference for receiving informal long-term care from their families were reported in southern countries (Spain and Israel). In general, southern European countries are often described as countries where family loyalties and intra-generational support are more pronounced, whereas Nordic countries and Central Europe are referred to as countries with less distinct family ties [23].

In this study, we focus on the association between informal caregiving and caregivers' health and health care utilization in eight European countries. Special emphasis is put on i) the

determinants potentially influencing the impact of caregiving intensity on caregivers' health and health care utilization, i.e. factors that are strongly related to CRs' care needs, such as illness severity characteristics and ii) differences among European countries regarding the association between informal caregiving and caregivers' health and health care utilization.

Until now, comparative analyses among European countries have been exacerbated by a lack of comparable data. In this analysis we are taking advantage of an unique primary dataset generated by a large European Project called "RightTimePlaceCare" (RTPC). The dataset contains information about more than 1000 people with dementia living at home together with their informal caregivers and was collected in a consistent manner across eight European countries.

The study includes countries from various geographical areas of Europe. Specifically, participating countries can be assigned to the north of Europe (Estonia, Finland and Sweden), to central Europe (France, Germany, the Netherlands and the United Kingdom (UK)) and to the south of Europe (Spain). This enables us to explore the existence of the north-south gradient in relation to the research questions mentioned before.

The remainder of this paper is organized as follows: in section two a brief overview of the study design of "RightTimePlaceCare" is given and the empirical strategy is described. In section three the regression results are presented and the final section discusses the results and draws some conclusions.

## **2. Data and methods**

### *2.1 Data source*

The empirical analysis is based on survey data generated by the European Project "RightTimePlaceCare". RTPC was a prospective cohort study conducted in eight European countries (Estonia, Finland, France, Germany, Netherlands, Sweden, Spain and the UK). The UK data for the current study were gathered solely in England. Data were collected by face-to-face interviews at baseline between November 2010 and April 2012 and follow-ups were performed after three months. RTPC provides a wide range of outcome measures for both people with dementia (e.g. health characteristics and resource utilization) and their informal caregivers (e.g. caregiving intensity and caregiver burden).

As RTPC focuses on the transition from professional home care towards institutional nursing care, two groups of people were included: 1) People with dementia (PwD) newly admitted to

institutional long-term care facilities (i.e. within one to three months after admission) and their informal caregivers, and 2) PwD receiving professional home care, who were at risk of institutionalization (criterion was a health care professional who judged institutionalization as probable within three to six months) along with their informal caregivers. In the present study, we focused on health effects and health care utilization of informal caregivers and thus merely considered group 2) in the analysis. To ensure that country-specific samples were comparable among each other, the general inclusion criteria for PwD in group 2) were applied: 1) a formal diagnosis of dementia; 2) a maximum score of 24 on the Mini Mental State Examination (MMSE) measure of cognitive functioning (in order to exclude cases of mild cognitive impairment); 3) the availability of an informal caregiver who visited at least twice a month and 4) a minimum age of 65 years. People with primary psychiatric disease or Korsakoff's syndrome were excluded, since they usually differ from other PwD (e.g. have a better mobility and are younger). Further information about RTPC's rationale and its methodology can be found in Verbeek et al. [24].

Overall, the present study was based on data from 1029 caregivers providing informal care in the home care setting. The analysis was restricted to baseline data in order to avoid problems of panel attrition. 194 (15.9%) observations were excluded from the original sample because of missing values in one or more variables. The main reason for missing values was due to incomplete scores on the MMSE for individuals with more severe dementia.

## *2.2 Outcome measures*

We used two different self-reported measures of caregivers' wellbeing: 1) the General Health Questionnaire – 12 (GHQ-12) to assess psychological wellbeing (range from 0 to 36, with higher values indicating less psychological wellbeing, cp. [25]) and 2) EQ-VAS, which is the second part of the health-related quality of life questionnaire EQ-5D. EQ-VAS is a visual analogue scale which records the caregivers' self-rated health on a 20 cm vertical scale and ranges from 0 to 100 (with 0 indicating the worst and 100 the best imaginable health status, cp. [26, 27]). The EQ-VAS and EQ-5D are widely used for health economic evaluation and in many areas of health research and its psychometric properties have been demonstrated in populations with different diseases and disorders [28] as well as in the context of informal caregiving [29]. In our study we decided to use the VAS instead of the categorized EQ-5D index as it was shown for some diseases that EQ-VAS scores were more responsive than EQ-5D index scores.

Caregivers' health care utilization was assessed by the probability of at least one GP visit within the last month. Furthermore, caregivers' subjective rating about the proportion of their use of health and social care resources which is influenced by caregiving was considered. Therefore, after completing the Resource Utilization in Dementia (RUD) questionnaire, caregivers had to specify if 0, 25, 50, 75 or 100 % of their total use of health and social care resources (e.g. doctor visits, medication or hospitalization) was related to their caregiving tasks.

### *2.3 Caregiving intensity*

The amount of care was assessed by the total numbers of hours per day caregivers spent on assisting their relatives with activities of daily living (ADL) such as eating or dressing and instrumental activities of daily living (IADL) such as shopping or housekeeping. Assistance on ADL and IADL was measured using the Resource Utilization in Dementia (RUD) instrument [30] which has been validated for assessing informal care in several previous studies [31]. For the descriptive statistics (Table 1), the intensity of care was divided into three groups: a low level of care was coded for 0 – 3 hours of daily care, a medium level for 4 – 8 hours and a high level of care for more than 8 hours of care per day. In the multivariate analysis, caregiving intensity was included as continuous variable. Total hours of caregiving were restricted to a daily maximum of 16 hours as we assumed a minimum of 8 hours non-caregiving per day.

### *2.4 Covariates*

Previous studies have shown that CRs' illness severity characteristics can potentially influence health outcomes among caregivers [32]. Therefore, three aspects of care receivers' impairment were included in the regression models: a measure for physical as well as cognitive impairment and an indicator for the presence of behavior and neuropsychiatric problems. The level of physical impairment was assessed by the Katz Index of Independence in Activities of Daily Living. The index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence and feeding. The total score ranges from 0 to 6, whereby a higher score indicates a higher degree of ADL-independency [33]. Cognitive impairment was measured with the Standardized Mini-Mental State Examination (S-MMSE). The S-MMSE score runs from 0 to 30 with a lower score representing more

severe cognitive impairment [34]. The NeuroPsychiatric Inventory – Questionnaire (NPI-Q) serves as instrument to indicate behavioral and neuropsychiatric problems. The NPI-Q consists of 12 items in 10 behavioral and 2 neurovegetative areas. Two scores were calculated: a severity and a distress score [35]. In the present analysis we used the severity score which ranges from 0 to 36, with higher scores indicating the presence of more severe neuropsychiatric and behavioral problems.

Furthermore, we controlled for socio-demographic variables such as age and gender and we included a binary variable to denote whether caregiver and care recipient lived together.

### *2.5 Empirical Analysis*

First, the mean values and standard deviations of the outcome measures (GHQ-12, EQ-VAS, GP visit, subjective rating of health care utilization), the caregivers' socio-demographic characteristics and three indicators for PwD's disease severity are presented in relation to three categories of caregiving intensity (low, medium and high intensity). This provides an initial impression of the distribution of the different dependent variables and covariates in relation to the duration of daily caregiving.

Second, multivariate regression models were applied to regress the outcome measures on caregiving intensity and the covariates. Initially, pooled models including the whole sample and subsequently models for each country separately were estimated. The focus of the analysis was on the impact of caregiving intensity on ICG's wellbeing and health care utilization. As the time spent on providing informal care depends on CRs' need for care, which is determined by the disease severity, we included different indicators for patients' illness characteristics stepwise in order to ascertain how the relationship between the duration of caregiving and caregiver's wellbeing and health care utilization respectively, was moderated through different disease severity characteristics. Therefore, based on the first model which solely controls for socio-demographic characteristics, the order of the entry in the pooled models was as follows: (1) ADL-independency (Katz-Index), (2) cognitive impairments (S-MMSE), and (3) behavioral problems (NPI-severity). When estimating the country-specific models, we distinguished only between the basic isolated model and the full specified model which contains all three indicators for dementia severity.

Except for the dichotomous variable "GP visit", which was estimated by probit-models, we used ordinary least squares estimation (OLS) with robust standard errors for all models. Statistical analysis was performed using the software STATA 12.0.



### 3. Results

#### 3.1 Descriptive Statistics

Table 1 presents descriptive statistics of informal caregivers' characteristics and some disease severity measures of their care recipients, differentiated by three categories of caregiving intensity (low, medium and high intensity). Mean values and standard deviations are shown for the whole sample and for each country separately. As the last part of Table 1 shows, caregivers were primarily female (68.7 %) with an average age of 64.6 years (standard deviation: 13.6). The mean S-MMSE score was 14.3 (6.6) index points, indicating the presence of moderate dementia on average [36]. ADL-independency and NPI-severity scores averaged 3.5 (1.8) and 9.3 (6.3) index points respectively.

#### Table 1

With increasing caregiving intensity, caregivers were older (66.1 (12.6) years) and PwD displayed higher behavioral problems (10.9 (6.6) NPI-Q index points) as well as lower ADL-independency (2.6 (1.9) KATZ index points) and S-MMSE scores (11.1 (7.0)). For individuals with the lowest level of care intensity (0 – 3 hours per day), these values correspond to 61.9 (13.3) years, 8.1 (5.9) NPI-Q index points, 4.2 (1.7) KATZ index points and 16.3 (5.6) S-MMSE index points. Regarding the outcomes of interest, the following patterns were observed: caregivers with the highest caregiving intensity ( $\geq 9$  hours per day) reported less psychological wellbeing (15.5 (6.7) GHQ-12 index points), a worse overall health status (62.7 (20.1) on the EQ-VAS scale) and a higher self-rated proportion of health care use which was influenced by caregiving 25.0 % (29.2). Furthermore, a greater share of caregivers providing the most intensive care had at least one GP visit within the last month (35.4 %) compared to those providing the lowest amount of care (28.4%).

These general patterns also can be observed within the different countries for most of the variables. However, there were considerable differences regarding the mean values of some variables. For example, the average age of informal caregivers was the lowest in Estonia at about 57 years and the highest in Sweden at 72 years. The best overall health status was reported in Finland, France and the Netherlands (72 from 100) and the worst in Spain (61). In Germany, the average proportion of health care utilization which can be attributed to caregiving was 24.2 percent, whereas the corresponding value for Finland only amounted to 5.5 percent. Also with respect to PwD's disease severity some differences occurred between

countries: e.g. the lowest mean S-MMSE score was measured in Estonia (10.6) and the highest was measured in Finland (16.5).

### *3.2 Regression Results*

Table 2 presents the regression results for both health outcome measures (GHQ-12 and EQ-VAS) for the pooled data. Regarding psychological health, spending more time on providing informal care was significantly associated with less psychological wellbeing in all models.

#### **Table 2**

In model 1 (left column), controlling for demographic factors only, one additional hour of caregiving was associated with an increase of about 0.24 GHQ-12 index points. Including ADL-independency and cognitive impairment in model 2 and 3 did not change much of the magnitude of the caregiving coefficient, whereas the relevance of caregiving intensity decreased clearly when behavioral problems were taken into account: in the full specified model (model 5), increasing caregiving time by one hour translated in an increase of about 0.16 GHQ-12 index points. The strongest predictor for decreased psychological wellbeing was the existence of behavioral problems with beta equal to 0.28, whereas the other disease severity measures did not show any significant impact.

The relationship between caregiving intensity and psychological wellbeing within the different countries is illustrated in the left columns of Table 3 where only the coefficients of caregiving hours and three disease severity measures are reported. Generally, we estimated two models for each country-specific analysis: model 1 solely included age, gender and caregiving hours, whereas model 2 was the fully specified model controlling for all independent variables simultaneously.

From model 1 (column 1) it can be seen that there was a positive relationship between caregiving hours and decreased psychological wellbeing in all countries. This association was significant in five countries (Estonia, Finland, France, Sweden and the United Kingdom) and most pronounced in France and Estonia. In these countries, increasing informal care by one hour was associated with an increase of around 0.34 index points of the GHQ-12 whereas a significant relationship was not observed between informal caregiving and psychological

wellbeing in Germany, Spain and the Netherlands. When turning to the full specified model (column 2), the caregiving estimate remained significant and its magnitude only reduced slightly in France and Estonia, whereas in all other countries the relevance of caregiving intensity reduced considerably or disappeared completely once CRs' disease severity measures were controlled for. In all countries, PwD's behavioral problems were found to be a significant predictor for caregivers' limited psychological wellbeing.

### **Table 3**

When looking at the relationship between caregiving intensity and self-rated overall health on average (i.e. in the pooled sample), the effect of informal caregiving was relatively similar to the pattern between caregiving and psychological wellbeing. As described before, providing more informal care was significantly associated with lower overall health in all models (right columns of Table 2), whereas the magnitude of the estimate decreased when disease severity measures were included in the models. Again, among the disease severity measures the strongest impact was found for behavioral problems. Holding everything else constant, an increase of caregiving time and NPI-severity by one unit corresponded with a decrease of overall health by 0.42 and 0.47 index points, respectively.

In the right-hand columns of Table 3 the country-specific regression results for self-rated overall health are presented. The negative signs of the caregiving estimates in model 1 (column 1) imply a negative association between caregiving intensity and the self-rated health status in all countries apart from the Netherlands.

This observed relationship was significant and strongest in Finland, Sweden and Estonia. When controlling for disease severity measures in the full specified model, the caregiving estimate lost its significance in Sweden but remained significant in Finland and Estonia. Furthermore, in all countries except Germany, Spain and the UK, being confronted with greater behavioral problems was a significant predictor for reduced overall health. In Sweden e.g., increasing NPI-severity by one index point, resulted in reduced health by approximately one index point. PwD's cognitive and physical impairments however were not related to overall health in any of the countries.

The regression results regarding health care utilization are illustrated in Table 4. Results for the subjective rating about the proportion of health care use which is influenced by care

giving are displayed in the left columns and the results for at least one GP visit within the last month are shown on the right-hand side of each model. In all models, providing more care was associated with a significantly higher reported proportion of health care utilization. In model 5 (the full specified model), one extra hour of caregiving resulted in 0.56 additional percentage points of health care utilization attributed to caregiving. A similar effect size was observed for behavioural problems (beta = 0.6).

#### **Table 4**

With respect to the country-specific results, more total hours of informal care were significantly associated with increased self-stated health care utilization in Estonia, Finland, Germany and Sweden in model 1 (left columns of Table 5). However in France, Spain, Sweden, the Netherlands and the UK, it was apparent that the amount of informal care did not influence caregivers' health care utilization. When additionally controlling for disease severity, the effect of caregiving intensity remained significant in Estonia and Germany. The association was highest in Germany. In Germany, providing one extra hour of care led to a raise of caregiving related health care utilization of almost three percentage points. As already indicated by the pooled model, behavioral problems were significantly related to health care utilization. In five countries (France, Germany, Netherlands, Spain, Sweden), increasing NPI-severity by one index point, translated into increased health care use between 0.52 and 1.09 percentage points.

The positive relationship between caregiving intensity and GP visits was less pronounced. Even though, on average (i.e. in the pooled model, cp. Table 4), increased caregiving was consistent with a higher probability of at least one GP visit within the last month providing behavioral problems were not controlled for (model 1 – 3), and in spite of the expected positive signs of the caregiving estimate for all countries but the Netherlands in model 1 (right columns of Table 5), the significant effect only held for France and the UK when looking at the full specified model whereas in all other countries informal caregiving had no impact on the frequency of contacts.

For all models, we tested for multicollinearity between the explanatory variables and found that even in the full specified models, where all disease characteristics were controlled for simultaneously, multicollinearity was not an issue. Moreover, we performed several

robustness checks (i.e. we used alternative estimation strategies and applied a different coding for several variables of interest). These modifications only had a minor impact on the results and the key message remained the same. Further information about the robustness checks is available upon request.

## **Table 5**

### **4. Discussion**

In the present study, we analyzed the association between caregiving intensity and caregivers' health on the one hand and health care utilization on the other hand. On average, a higher amount of informal care was significantly related to negative health outcomes. This finding held for both psychological as well as self-rated overall health. When looking at the country specific results, a negative association between caregiving hours and psychological wellbeing (respectively overall health) was observed in Estonia, Finland, France, Sweden and the UK (Estonia, Finland and Sweden). After controlling for living condition and disease severity, the impact of caregiving intensity reduced and the existence of behavioral problems emerged as a strong predictor for adverse health effects in almost all countries. Care recipients' physical and cognitive impairments played a minor role in predicting reduced wellbeing, which indicates that informal caregivers cope better with these types of deficits than they do with neuropsychiatric symptoms such as agitated or aggressive behavior. This result is in line with several other studies which identified behavioral problems to be the strongest predictor for poor psychological health (assessed by caregiver burden and depression) among caregivers [e.g. 13, 17].

With respect to the second part of the analysis, the association between caregiving intensity and health care utilization, we observed a strong and positive relationship between the amount of informal care and the self-stated proportion of health care use which was influenced by caregiving. That is, individuals who provided more care contended to use a higher percentage of health care resources due to their caregiving tasks. Again, the strength of the observed relationship reduced considerably after including CRs' illness characteristics in the model. In particular, CRs' behavioral problems were identified as a strong predictor for increased health care utilization. A similar pattern appeared in Estonia, Finland, Germany and Sweden.

However, with regard to actual utilization, the claim of increased health care demand due to caregiving was only partly confirmed: caregiving hours did not exhibit a significant impact on the probability of at least one GP visit within the last month in the full specified model. Though, in the country-specific models we found positive associations in France and the UK.

Previous findings about the effect of informal caregiving on health care utilization have been ambiguous. For example, Van Houtven, Wilson and Clipp found that caregivers providing more intensive support had higher drug utilization than those providing less support although the magnitude of the effect was relatively small: increasing informal care by 10 % led to a 0.7 % increase in drugs consumed per day [5]. However, some previous studies which compared medication use between caregivers and non-caregivers found that neither groups differed significantly from each other [37, 38].

Furthermore, results regarding differences in GP visits between caregivers and non-caregivers have been inconsistent, with some studies reporting more frequent visits by the group of caregivers [e.g. 16] and others who did not find such differences [e.g. 39].

## **5. Conclusion**

Which conclusions can be drawn from these findings? First, when evaluating the full economic effect of informal care, besides the reduction of public formal care expenditures (through a substitution of formal care by informal care on net), the effect of providing care on caregivers' health and health care utilization has to be considered. In this analysis we found further evidence for the negative association between the intensity of caregiving and caregivers' health. The investigation also revealed that these adverse health effects go along with increased (self-stated) general health care utilization and a higher probability for GP visits on average. It can be assumed that such increased health care utilization results in higher health care costs for informal caregivers. Cost studies should consider these additional costs, especially when they compare home care to institutional care, as both settings are affected differently by these costs [e.g. 40]. For the purpose of identifying the true cost-effectiveness ratio of home care, future research should try to assess precisely how informal caregiving affects the use of several formal health care services (e.g. medication use, visits to a GP or to a specialist). In order to get a profound understanding of the additional costs, this auxiliary amount of health care use should be valued with relevant prices. As individuals often act as caregiver for many years and alleged health deteriorations might not directly

result in increased health care use, cost studies should choose a sufficiently long time frame. Otherwise, the cost-effectiveness ratio of informal caregiving might be underestimated.

Second, the findings also indicate that it is not just the provision of care by itself which causes negative health outcomes but rather the severity of CRs' behavioral problems, which emerged as a strong predictor for deteriorated psychological wellbeing and overall health. Thus, if it is intended to reduce the negative health effects of informal caregiving, interventions are required which reduce CRs' behavioral problems and/or improve caregivers coping strategies. In this context, previous research on support strategies particularly identified individual and family counseling, behavior-management strategies, case management and environmental modifications as effective means to improve caregivers' wellbeing [41]. From a societal perspective, these additional resources again have to be accounted for when evaluating the economic net effect of informal care.

Third, our analyses revealed that the association between caregiving intensity on the one hand and adverse health effects and increased health care utilization on the other hand varied significantly between different geographical regions in Europe: while a significant and negative association between caregiving and caregivers' health status was found in the northern and central parts of Europe, no such relationship was observed for Spain – the representative for the south of Europe. The same applies when looking at the association between caregiving intensity and health care utilization. Increased caregiving was significantly associated with a higher proportion of (self-stated) health care utilization and a higher probability of at least one GP visit in the last month in northern and central Europe compared to southern Europe.

One explanation for these findings might be that in southern Europe, where internal family support is higher, this intra-generational assistance helps informal caregivers to cope better with various types of challenges and difficulties which go along with informal (dementia) caregiving. This may result in a lower impact of informal caregiving on individual health and health care utilization in southern Europe compared to Nordic or central countries, where family ties are weaker [23] and traditionally more public health services are used.

However, in this context it has to be considered that subjective evaluation of health and health care utilization is influenced by culture and hence there is reporting heterogeneity between different countries in Europe [42]. For example, a previous study found that people in Sweden and Denmark largely overrate their health, whereas Germans tend to underrate their health status [43]. It should also be considered that even if self-reports of health might be not

appropriate for comparing aggregated health outcomes among different countries, it still seems to be valid for within-country comparisons (44). Therefore it seems to be unlikely that the association between caregiving on the one hand and health and health care utilization on the other hand within countries is affected by different reporting patterns.

Furthermore, it has to be considered that informal caregiving generally involves a considerable amount of opportunity costs through reduced labor force participation by caregivers. In this context it has been revealed that informal caregiving is associated with a lower probability of employment, reduced working hours, wage penalties and a higher risk of future poverty [3, 45]. However European countries are affected differently by these effects. For example in southern countries (especially in Italy, Greece and Spain) individuals generally provide a greater amount of informal care and reduce their working hours to a greater extent when increasing caregiving hours while individuals in the central and the north of Europe reduce their paid work to a smaller extent but use more formal health care services [46]. Thus, compared to southern countries, individuals in the central and the north of Europe more often face a stressful double obligation caused by employment on the one side and caring duties on the other side. These different patterns might be a further explanation why we identified negative health effects in Estonia, Finland, France, Sweden and the UK but not in Spain. These different patterns have to be taken into account by policy makers when providing incentives for informal caregiving. In practical terms, that means that policy makers in the south has to be less concerned about adverse health effects and increased health care utilization through increased informal caregiving. However they should be aware of the effect that increased informal caregiving significantly reduces labor force participation which especially in the view of an ageing society could lead to labor scarcity in some industries and occupations. This could be harmful for the whole economy in future years. On the contrary, policy makers in central and northern Europe should bear in mind that increased informal caregiving (especially in combination with labor market participation) results in negative health outcomes, increased health care utilization and therefore higher health care costs for informal caregivers. To address this, policy should establish the legal framework for more family-oriented working conditions. In practice this might mean the simplification of paid leave and more flexible working hours through telecommuting for example.

This analysis extends previous research on the effects of informal caregiving on caregivers' health and health care utilization in several ways: first, in contrast to past research which mainly focused on individuals from one country and therefore exacerbates comparisons



between countries due to methodological differences, our data was collected across eight different countries from various regions of Europe in a consistent manner which enabled us to compare country-specific results directly with each other. Second, using specific inclusion criteria, the RTPC study was the first that focused on people with dementia at risk of institutionalization. Since the need of assistance and care for those individuals is above average which implicates particular requirements and challenges for informal caregivers, the research question posed in this paper is of special interest for this subgroup of people with dementia.

Nonetheless, the results and their implications must be viewed in light of certain limitations. One limitation of the study is its cross-sectional design, which does not allow causal relationships between the variables to be tested. Regarding caregivers' wellbeing one could assume, that the negative effect of informal caregiving is attenuated through the fact that caregivers in better (worse) initial health are more (less) likely to provide extensive informal care. If this assumption holds, the negative association found in the present analysis will be underestimated.

Second, it should be kept in mind that the study sample consists of people with dementia at risk of institutionalization, which means that the country-specific samples are not representative of the average population of people with dementia.

Third, the analysis is based on retrospective self-reported data which are known to be prone to inaccuracy. In respect of the amount and duration of informal care, previous studies have found that caregivers tend to overestimate their time spent caring [47].

Fourth, in the empirical analysis, we used two subjective parameters as dependent variables: subjective health (EQ-VAS) and subjective health care utilization. As with all subjective indicators, we were not able to verify the reliability of these parameters which might restrict their validity.

Fifth, country specific coefficients for caregiving intensity on health might be driven by the impact of the financial crisis which affected countries differently. This would be the case if caregiving behavior is correlated with both the economic consequences of financial crisis and health. Unfortunately we cannot test for this potential confounding factor with our data and further research on this would be fruitful [48].

Finally, the magnitude of the caregiving coefficients is relatively small (e.g. on average, one additional hour of informal caregiving merely reduces self-rated overall health about 0.4

index points on a scale which ranges from 0 – 100) and therefore, the clinical significance is limited in some cases. However, it should be kept in mind that usually informal dementia caregivers assist their relatives for a longer period of time and thus initially small deteriorations in health could cumulate over time and may result in serious health impairments and increased health care utilization after several years.

Despite these limitations, the results point towards negative health effects and increased health care utilization due to caregiving in different European countries. Besides other effects of informal caregiving, this aspect should be considered when searching for the best strategies of dealing with the huge societal challenge of increasing dementia prevalence.

## Literature

- [1] Alzheimer's Disease International: World Alzheimer Report (2013). Journey of Caring. An analysis of long-term care for dementia, <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf> (assessed: 08/12/2013).
- [2] Gibson, M.J., Gregory, S.R., Sheel, M.P. (2003). Long-Term Care in Developed Nations: A Brief Overview, The AARP Public Policy Institute.
- [3] Colombo, F., Llana-Nozal, A., Mercier, J., Tjadens, F. (2011). Help Wanted? Providing and Paying for Long-Term Care, OECD Health Policy Studies, OECD Publishing, <http://www.oecd.org/els/health-systems/47836116.pdf>(assessed: 02/06/2014).
- [4] Van Houtven, C.H., Norton, E.C. (2006). Economic Effects of Informal Care, *Schweizerische Zeitschrift für Volkswirtschaft und Statistik*, 13-22.
- [5] van den Berg, B., Brouwer, W.B.F., Koopmanschap M.A. (2004). Economic valuation of informal care. An overview of methods and applications, *European Journal of Health Economics*, Vol. 5, 36-45.
- [6] Van Houtven, C.H., Wilson, M.R., Clipp, E.C. (2005). Informal Care Intensity and Caregiver Drug Utilization, *Review of Economics of the Household*, Vol. 3, 415-433.
- [7] Brodaty, H., Donkin, M. (2009). Family caregivers of people with dementia, *Dialogues in Clinical Neuroscience*, Vol. 11, No. 2, 217-228.
- [8] Zwaanswijk, M., Peeters, J.M., van Beek, A.P., Meerveld, J.H., Francke, A.L (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey, *The Open Nursing Journal*, Vol. 7, 6-13.
- [9] Schulz, R., Martire, L.M. (2004). Family Caregiving of Persons With Dementia – Prevalence, Health Effects and Support Strategies, *American Journal of Geriatric Psychiatry*, Vol. 12, No. 3, 240-9.
- [10] Teri, L., Logsdon, R.G., Uomoto J., McCurry, S.M. (1997). Behavioral treatment of depression in dementia patients: a controlled clinical trial. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, Vol. 52, No. 4, 159-166.
- [11] Kiecolt-Glaser, J.K., Dura, J.R., Speicher, C.E., Trask, J.O., Glaser, R. (1991). Spousal Caregivers of Dementia Victims: Longitudinal Changes in Immunity and Health, *Psychomatic Medicine*, Vol. 53, 345-362.
- [12] Kiecolt-Glaser, J.K., Glaser, R., Gravenstein, S., Malarkey, W.B., Sheridan, J. (1996). Chronic stress alters the immune response influenza virus vaccine in older adults, *Proceedings of the National Academy of Sciences of the USA*, Vol. 93, 3043-7.

- [13] Pinquart, M., Sörensen, S. (2003). Associations of Stressors and Uplifts of Caregiving With Caregiver Burden and Depressive Mood: A Meta-Analysis, *Journal of Gerontology*, Vol. 58B, No. 2, 112-128.
- [14] Givens, J.L., Mezzacappa, C., Heeren, T., Yaffe, K., Fredman, L. (2014). Depressive Symptoms among dementia Caregivers: Role of mediating Factors. *The American Journal of Geriatric Psychiatry*, Vol. 22, No. 5, 481-8.
- [15] Haley W.E., LaMonde, L.A., Han, B., Burton, A. M., Schonwetter, R. (2003). Predictors of Depression and Life Satisfaction Among Spousal Caregivers in Hopice: Application of a Stress Process Model, *Journal of Palliative Medicine*, Vol. 6, No. 2, 215-224.
- [16] Chan, A., Malhotra, C., Malhotra, R., Rush, A.J. Ostbye, T. (2013). Health Impacts of Caregiving for Older Adults With Functional Limitations: Results From the Singapore Survey on Informal Caregiving, *Journal of Ageing and Health*, Vol. 25, No. 6, 998-1012.
- [17] Schulz, R., O'Brien, T., Bookwala, J., Fleissner, K. (1995). Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates and Causes, *The Gerontologist*, Vol. 35, No. 6, 771-791.
- [18] Baumgarten, M., Battista, R.N., Infante-Rivard C., Hanley J.A., Becker R., Gauthier, S. (1992). The psychological and physical health of family members caring for an elderly person with dementia, *Journal of Clinical Epidemiology*, Vol. 45, No. 1, 61-70.
- [19] Beerens, H.C., Sutcliffe, C., Renom-Guiteras, A., Soto, M.E., Suhonen, R., Zabalegui, A., Bökberg, C., Saks, K., Hamers, J.P., RightTimePlaceCare Consortium (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*, Vol. 15, No.1, 54-61.
- [20] Afram B., Stephan, A., Verbeek, H., Bleijlevens, MH., Suhonen, R., Sutcliffe, C., Raamat, K., Cabrera, E., Soto, M.E., Hallberg, I.R., Meyer, G., RightTimePlaceCare Consortium (2014). Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries, *Journal of the American Medical Directors Association*, Vol. 15, No.2, 108-116.
- [21] Hallberg, I.R., Leino-Kilpi, H., Meyer, G., Raamat, K., Soto, M.E., Sutcliffe, C., Zabalegui, A., Zwakhalen, S., Karlsson, S. (2013). Dementia Care in Eight European Countries: Developing a Mapping System to Explore Systems, *Journal of Nursing Scholarship*, Vol. 45, No. 4, 412-424.
- [22] Bolin, K., Lindgren, B., Lundborg, P. (2008). Your next of kin or your own career? Caring and working among the 50+ of Europe, *Journal of Health Economics*, Vol. 27, 718-738.
- [23] Reher, D.S. (1998). Family ties in Western Europe: persistent contrasts. *Population and Development Review*, Vol. 24, No. 2, 203-234.

- [24] Verbeek, H., Meyer, G., Leino-Kilpi, H., Zabalegui, A., Rahm Hallberg, I., Saks, K., Soto, M.E., Challis, D., Sauerland, D., Hamers, J.P. (2012). A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study, *BMC Public Health*, Vol. 12, No. 68.
- [25] Goldberg, D.P., Gater, R., Sartorius, N., Ustun, T.B., Piccinelli, M., Gureje, O., Rutter, C. (1997). The validity of two versions of the GHQ in the WHO study of mental illness in general health care, *Psychological Medicine*, Vol. 27, No. 1, 191-7.
- [26] The EuroQol Group (2014). <http://www.euroqol.org/about-eq-5d/how-to-use-eq-5d.html> (assessed: 03/06/2014). Van Houtven, C.H., Norton, E.C. (2004). Informal Care and Elderly Health Care Use, *Journal of Health Economics*, Vol. 23, No. 6, 1159-1180.
- [27] 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*, Vol. 2, 169-180.
- [28] Brettschneider, C., Hans-Helmut König, H.H., Herzog, W., Kaufmann, C., Schaefer, R., Konnopka, A. (2013). Validity and responsiveness of the EQ-5D in assessing and valuing health status in patients with somatoform disorders, *Health and Quality of Life Outcomes*, Vol. 11, No. 3.
- [29] Khanna, R., Jariwala, K., Bentley, J.P. (2013). Psychometric properties of the EuroQol Five Dimensional Questionnaire (EQ-5D-3L) in caregivers of autistic children, *Quality of Life Research*, Vol. 22, No. 10.
- [30] Wimo, A., Wetterholm, A.L., Mastey, V., Winblad, B. (1998). Evaluation of the health care resource and caregiver time in anti-dementia drug trials: a quantitative battery, in A.Wimo, B. Jönsson, G. Karlsson & B. Winblad (eds), *Health Economics of Dementia*, John Wiley & Sons Ltd, Chichester.
- [31] Wimo, A., Jonsson, L., Zbrozek, A. (2010). The resource utilization in dementia (RUD) instrument is valid for assessing informal care time in community-living patients with dementia. *Journal of Nutrition, Health & Aging*, Vol. 14, No. 8, 685-690.
- [32] Hooker, K., Bowman, S.R., Coehlo, D.P., Lim, S.R., Kaye, J., Guariglia, R., Li, F. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers, *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, Vol. 57, 344-353.
- [33] Katz, S. (1983). Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living, *Journal of the American Geriatrics Society*, Vol. 31, 721-7.
- [34] 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*, Vol. 148, No. 1, 102-5.
- [35] Kaufer, D.I., Cummings, J.L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O.L., DeKosky, S.T. (2000). Validation of the NPI-Q, a Brief Clinical Form of

- the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, Vol. 12, 233-9.
- [36] Folstein, M.F., Folstein, S.E., McHugh, P.R. (1975). „Mini-mental state“. A practical method for grading the cognitive status of patients for the clinician. *Journal of Psychiatric Research*, Vol. 12, No. 3, 189-198.
- [37] Grafstrom, M., Fratiglioni, L., Sandman, P.-O., Windblad, B. (1992). Health and social consequences for relatives of demented and non-demented elderly. A population-based study, *Journal of Clinical Epidemiology*, Vol. 45, 861-870.
- [38] Vitalino, P.P., Russo, J., Bailey, S.L., Young, H.M., McCann, B.S. (1993). Psychosocial factors associated with cardiovascular reactivity in older adults, *Psychosomatic Medicine*, Vol. 55, 164-177.
- [39] Kiecolt-Glaser, J.K., Glaser, R., Shuttleworth, E.C., Dyer, C.S., Ogrocki, P., Speicher, C.E. (1987). Chronic Stress and immunity in family caregivers of Alzheimer’s disease victims, *Psychosomatic Medicine*, Vol. 49, 523-535.
- [40] Wübker, A., Zwakhalen, S.M.G., Challis, D., Suhonen, R., Zabalegui, A., Karlsson, S., Soto, M.E., Saks, K., Sauerland, D. (2014). Costs of care for people with dementia just before and after nursing home placement: primary data from 8 European countries, *European Journal of Health Economics* (forthcoming).
- [41] Brodaty, H., Green, A., Koschera, A. (2003). A meta-analysis of psychosocial interventions for caregivers of people dementia, *Journal of the American Geriatrics Society*, Vol. 51, No. 5, 657-664.
- [42] Bago d'Uva, T., Van Doorslaer, E., Lindeboom, M., O'Donnell, O. (2008). Does reporting heterogeneity bias the measurement of health disparities?, *Health Economics*, Vol. 17, 351-375.
- [43] Jürges, H. (2007). True health vs response styles: exploring cross-country differences in self-reported health, *Health Economics*, Vol. 16, 163-78.
- [44] Jürges, H., Avendano, M., Mackenbach, J.P. (2008). Are different measures of self-rated health comparable? An assessment in five European countries, *European Journal of Epidemiology*, Vol. 23, 773-81.
- [45] Gibson, M.J., Houser, A. (2007). Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving, *Issue Brief*, AARP Public Policy Institute, Washington, DC.
- [46] Kotsadam, A. (2011). Does informal eldercare impede women’s employment? The case of European welfare states, *Feminist Economics*, Vol. 17, No. 2, 121–144.
- [47] Winblad, B., Hill, S., Beermann, B., Post, S.G., Wimo, A. (1997). Issues in the Economic Evaluation of Treatment for Dementia: Position Paper from the International Working Group on Harmonization of Dementia Drug Guidelines, *Alzheimer Disease and Associated Disorders*, Vol. 11, 39-45.

- [48] Masedo-Gutiérrez, A.I, Swenson N. (2015). Past, Present and Future of Caregiving. AASCIT Journal of Health, Vol. 2, No. 1, 1-6.

**Table 1: Descriptive statistics of Informal Caregivers in 8 European countries**

Country	Variables	ADL low (≤ 3 h)	ADL med (4-8 h)	ADL high (≥ 9 h)	Ø
Estonia (N=161)	<b>CG's demogr. characterist.</b>				
	Age	49.1 (11.2)	57.8 (14.7)	59.3 (12.1)	56.9 (13.7)
	Gender: female in %	75.0	78.1	76.7	77.0
	<b>CG's Health status</b>				
	GHQ-12	11.2 (5.1)	15.0 (6.2)	17.0 (7.3)	15.1 (6.7)
	EQ-VAS	78.4 (13.1)	63.8 (16.8)	62.0 (2.6)	65.6 (18.5)
	<b>PwD's characteristics</b>				
	KATZ	4.1 (1.6)	3.4 (1.8)	2.28 (2.3)	3.1 (2.1)
	S-MMSE	13.2 (5.8)	11.6 (6.4)	8.1 (6.3)	10.6 (6.5)
	NPI-Q	9.14 (7.8)	10.55 (6.8)	10.77 (7.0)	10.38 (7.1)
	Age	80.4 (6.5)	82.3 (7.5)	82.7 (8.4)	81.8 (7.4)
	Gender: female in %	89.1	69.7	64.2	73.4
	<b>CG's Health care utilization</b>				
	GP visits in %	14.3	23.3	26.7	23.0
	Health care due to ICG in %	7.1 (16.5)	24.7 (26.8)	30.0 (26.0)	23.6 (26.1)
Finland (N=157)	<b>CG's demogr. characterist.</b>				
	Age	60.1 (11.2)	70.1 (11.7)	70.7 (12.1)	64.8 (12.5)
	Gender: female in %	56.0 (0.05)	63.3 (0.07)	62.5 (0.10)	59.2
	<b>CG's Health status</b>				
	GHQ-12	10.7 (4.0)	11.8 (5.0)	13.7 (6.2)	11.5 (4.8)
	EQ-VAS	77.3 (11.2)	69.80 (17.7)	60.4 (17.1)	72.3 (15.7)
	<b>PwD's characteristics</b>				
	KATZ	4.6 (1.4)	3.7 (1.6)	2.9 (1.5)	4.1 (1.6)
	S-MMSE	18.0 (4.2)	15.9 (6.2)	12.4 (6.9)	16.5 (5.7)
	NPI-Q	7.5 (5.4)	9.12 (5.6)	9.88 (5.8)	8.37 (5.6)
	Age	83.5 (5.8)	81.5 (5.8)	79.7 (7.9)	82.5 (6.3)
	Gender: female in %	73.5	50.0	47.8	64.2
	<b>CG's Health care utilization</b>				
	GP visits in %	11.9	24.5	16.7	16.6
	Health care due to ICG in %	3.4 (11.7)	5.3 (11.6)	13.6 (26.4)	5.5 (15.0)
France (N=142)	<b>CG's demogr. characterist.</b>				
	Age	59.1 (11.8)	68.4 (12.6)	61.8 (12.4)	63.3 (12.9)
	Gender: female in %	60.9	78.0	71.4	69.0
	<b>CG's Health status</b>				
	GHQ-12	11.4 (5.2)	12.3 (5.4)	14.8 (9.5)	12.1 (5.8)
	EQ-VAS	75.2 (17.4)	68.9 (19.4)	68.6 (19.6)	72.0 (18.6)
	<b>PwD's characteristics</b>				
	KATZ	4.7 (1.6)	3.7 (1.9)	2.6 (2.2)	4.1 (1.9)
	S-MMSE	15.2 (5.3)	13.9 (6.1)	12.4 (5.7)	14.4 (5.7)
	NPI-Q	7.96 (6.4)	8.27 (6.9)	10.0 (6.5)	8.29 (6.6)
	Age	82.4 (5.1)	83.5 (5.7)	81.8 (6.0)	83.1 (5.1)
	Gender: female in %	81.8	43.8	44.4	66.6
	<b>CG's Health care utilization</b>				
	GP visits in %	31.9	47.5	57.1	40.8
	Health care due to ICG in %	10.4 (22.9)	8.8 (15.3)	11.5 (21.9)	9.8 (19.8)
Germany (N=91)	<b>CG's demogr. characterist.</b>				
	Age	57.5 (11.0)	61.3 (12.7)	69.6 (10.0)	62.1 (12.4)
	Gender: female in %	53.8	79.5	85.7	73.6
	<b>CG's Health status</b>				
	GHQ-12	12.2 (3.9)	12.3 (4.1)	14.14 (5.1)	12.7 (4.3)
	EQ-VAS	73.6 (17.5)	65.6 (18.2)	68.2 (14.9)	68.5 (17.5)
	<b>PwD's characteristics</b>				
	KATZ	3.5 (2.0)	2.4 (1.6)	1.7 (1.3)	2.5 (1.8)
	S-MMSE	14.8 (7.3)	11.8 (8.4)	7.7 (8.1)	11.7 (8.4)
	NPI-Q	9.0 (6.5)	10.64 (5.7)	12.38 (7.1)	10.57 (6.3)
	Age	84.3 (5.6)	82.6 (6.2)	80.6 (5.5)	82.7 (5.9)
	Gender: female in %	81.3	67.6	28.6	63.3



	<b>CG's Health care utilization</b>				
	GP visits in %	38.4	43.2	47.6	42.9
	Health care due to ICG in %	8.7 (19.9)	25.0 (27.0)	41.7 (34.8)	24.2 (29.5)
<b>Netherlands (N=157)</b>	<b>CG's demogr. characterist.</b>				
	Age	64.5 (13.4)	69.3 (11.7)	63.4 (16.3)	66.2 (13.0)
	Gender: female in %	64.2	74.1	75.0	68.2
	<b>CG's Health status</b>				
	GHQ-12	11.8 (5.3)	12.2 (4.7)	11.5 (6.0)	11.9 (5.0)
	EQ-VAS	72.3 (18.7)	72.13 (10.9)	68.75 (19.3)	72.2 (16.1)
	<b>PwD's characteristics</b>				
	KATZ	3.7 (1.7)	3.0 (1.5)	3.3 (2.2)	3.4 (1.7)
	S-MMSE	15.8 (6.1)	13.8 (7.0)	11.0 (8.4)	14.9 (6.5)
	NPI-Q	8.54 (5.8)	11.5 (6.5)	12.5 (11.2)	9.73 (6.3)
	Age	82.5 (5.7)	79.6 (7.1)	81.8 (8.7)	81.4 (5.9)
	Gender: female in %	69.3	37.6	66.7	59.4
	<b>CG's Health care utilization</b>				
	GP visits in %	42.1	37.9	-	39.5
Health care due to ICG in %	12.5 (25.1)	12.3 (22.7)	-	12.1 (23.9)	
<b>Spain (N=136)</b>	<b>CG's demogr. characterist.</b>				
	Age	69.3 (12.8)	65.2 (15.1)	68.8 (11.9)	67.7 (13.5)
	Gender: female in %	53.2	75.5	77.5	68.4
	<b>CG's Health status</b>				
	GHQ-12	14.6 (5.2)	13.5 (5.7)	15.8 (6.1)	14.6 (5.7)
	EQ-VAS	61.9 (20.9)	62.8 (22.2)	58.0 (22.8)	61.1 (21.9)
	<b>PwD's characteristics</b>				
	KATZ	4.3 (1.7)	3.6 (1.7)	2.8 (1.9)	3.6 (1.8)
	S-MMSE	17.1 (4.9)	16.2 (5.7)	14.8 (5.5)	16.1 (5.4)
	NPI-Q	5.83 (5.1)	7.16 (5.5)	9.2 (5.2)	7.3 (5.4)
	Age	79.3 (6.7)	82.5 (7.0)	82.9 (7.6)	81.1 (7.1)
	Gender: female in %	77.1	57.1	56.4	64.0
	<b>CG's Health care utilization</b>				
	GP visits in %	31.9	34.7	45.0	36.7
Health care due to ICG in %	20.7 (22.3)	21.8 (22.9)	28.8 (27.8)	23.1 (24.4)	
<b>Sweden (N=127)</b>	<b>CG's demogr. characterist.</b>				
	Age	66.4 (14.2)	77.4 (7.4)	75.1 (5.8)	72.0 (12.1)
	Gender: female in %	64.4	66.0	86.7	67.7
	<b>CG's Health status</b>				
	GHQ-12	11.5 (5.9)	13.1 (6.0)	15.9 (5.8)	12.7 (6.0)
	EQ-VAS	73.8 (19.8)	64.0 (18.1)	61.3 (20.7)	68.3 (19.8)
	<b>PwD's characteristics</b>				
	KATZ	4.2 (1.6)	3.2 (1.4)	3.0 (1.7)	3.6 (1.6)
	S-MMSE	17.7 (5.1)	14.0 (6.5)	13.2 (5.9)	15.6 (6.1)
	NPI-Q	9.2 (5.4)	9.38 (5.7)	11.9 (6.2)	9.59 (5.6)
	Age	83.1 (5.0)	81.3 (6.0)	79.9 (6.3)	82.1 (5.3)
	Gender: female in %	64.9	34.0	40.0	47.6
	<b>CG's Health care utilization</b>				
	GP visits in %	22.0	22.6	26.7	22.8
Health care due to ICG in %	9.1 (21.8)	13.7 (24.8)	16.7 (29.4)	11.9 (24.0)	
<b>UK (N=58)</b>	<b>CG's demogr. characterist.</b>				
	Age	59.7 (12.5)	66.8 (11.7)	68.9 (12.4)	65.2 (12.5)
	Gender: female in %	72.2	73.9	52.9	67.2
	<b>CG's Health status</b>				
	GHQ-12	11.0 (2.6)	14.08 (8.0)	15.0 (6.8)	13.4 (6.5)
	EQ-VAS	72.9 (14.5)	67.0 (19.6)	67.8 (22.2)	69.1 (18.8)
	<b>PwD's characteristics</b>				
	KATZ	4.1 (2.0)	3.7 (1.7)	3.1 (1.8)	3.6 (1.8)
	S-MMSE	15.2 (6.8)	13.2 (6.6)	12.9 (7.7)	13.7 (6.9)
	NPI-Q	9.72 (4.2)	11.39 (6.7)	13.94 (7.5)	11.62 (6.4)
	Age	85.0 (5.9)	81.2 (6.0)	78.9 (5.3)	82.0 (6.2)
	Gender: female in %	57.1	61.9	68.8	62.1
	<b>CG's Health care utilization</b>				

	GP visits in %	38.9	26.1	52.9	37.9
	Health care due to ICG in %	11.1 (26.0)	14.8 (28.5)	16.2 (34.2)	14.0 (29.1)
<b>Average (N=1029)</b>	<b>CG's demogr. characterist.</b>				
	Age	61.9 (13.3)	66.8 (13.8)	66.1 (12.6)	64.6 (13.6)
	Gender: female in %	61.3	73.8	74.4	68.7
	<b>CG's Health status</b>				
	GHQ-12	11.7 (5.0)	13.1 (5.7)	15.5 (6.7)	12.98 (5.8)
	EQ-VAS)	73.3 (17.6)	66.7 (18.0)	62.7 (20.1)	68.7 (18.7)
	<b>PwD's characteristics</b>				
	KATZ	4.2 (1.7)	3.3 (1.7)	2.6 (1.9)	3.5 (1.8)
	S-MMSE	16.3 (5.6)	13.7 (6.7)	11.1 (7.0)	14.3 (6.6)
	NPI-Q	8.1 (5.9)	9.68 (6.4)	10.85 (6.6)	9.3 (6.3)
	Age	81.7(5.2)	81.5 (5.1)	81.7 (7.7)	82.9 (6.1)
	Gender: female in %	73.8	51.2	52.7	62.7
	<b>CG's Health care utilization</b>				
	GP visits in %	28.4	32.6	35.4	31.4
	Health care due to ICG in %	10.2 (21.5)	15.9 (23.7)	25.0 (29.2)	15.3 (24.6)

**Table 2: Determinants of psychological wellbeing (GHQ-12) and self-rated overall health (EQ-VAS) (Pooled Model)**

	Model 1		Model 2		Model 3		Model 4		Model 5	
	GHQ-12 <sup>2</sup>	EQ-VAS <sup>3</sup>	GHQ-12	EQ-VAS	GHQ-12	EQ-VAS	GHQ-12	EQ-VAS	GHQ-12	EQ-VAS
Age	-0.005 (0.013)	-0.263*** (0.048)	-0.010 (0.016)	-0.252*** (0.054)	-0.010 (0.016)	-0.250*** (0.054)	0.007 (0.016)	-0.281*** (0.054)	0.007 (0.016)	-0.279*** (0.054)
Female	1.673*** (0.347)	-4.788*** (1.185)	1.702*** (0.349)	-4.827*** (1.191)	1.696*** (0.351)	-4.777*** (1.197)	1.535*** (0.333)	-4.569*** (1.176)	1.523*** (0.334)	-4.485*** (1.181)
Caregiving hours	0.235*** (0.048)	-0.514*** (0.149)	0.215*** (0.053)	-0.493*** (0.166)	0.223*** (0.053)	-0.513*** (0.163)	0.159*** (0.050)	-0.382** (0.163)	0.163*** (0.052)	-0.415** (0.167)
Living together	-	-	0.256 (0.489)	-0.640 (1.528)	0.300 (0.492)	-0.768 (1.519)	0.122 (0.470)	-0.321 (1.470)	0.150 (0.479)	-0.537 (1.509)
ADL-independency	-	-	-0.082 (0.105)	0.001 (0.345)	-	-	-	-	-0.007 (0.111)	-0.048 (0.370)
S-MMSE	-	-	-	-	-0.006 (0.029)	-0.061 (0.090)	-	-	0.016 (0.031)	-0.092 (0.096)
NPI-severity	-	-	-	-	-	-	0.274*** (0.030)	-0.460*** (0.092)	0.275*** (0.309)	-0.468*** (0.093)
Estonia <sup>1</sup>	1.120 (0.762)	-4.122* (2.293)	1.164 (0.769)	-4.051* (2.309)	1.146 (0.781)	-4.261* (2.337)	1.474** (0.723)	-4.585** (2.283)	1.531** (0.736)	-4.908 (2.314)
Finland	-1.207* (0.640)	2.026 (2.056)	-1.119* (0.645)	1.903 (2.074)	-1.143* (0.642)	1.941 (2.075)	-0.738 (0.599)	1.247 (2.043)	-0.744 (0.603)	1.306 (2.038)
France	-0.662 (0.709)	1.509 (2.263)	-0.606 (0.710)	1.468 (2.261)	-0.649 (0.712)	1.388 (2.264)	-0.153 (0.649)	0.654 (2.214)	-0.127 (0.658)	0.541 (2.213)
Germany	-0.566 (0.698)	-1.198 (2.504)	-0.615 (0.707)	-1.260 (2.551)	-0.555 (0.710)	-1.478 (2.539)	-0.545 (0.651)	-1.240 (2.472)	-0.495 (0.663)	-1.610 (2.517)
Netherlands	-0.570 (0.644)	1.862 (2.087)	-0.596 (0.648)	1.853 (2.112)	-0.571 (0.646)	1.786 (2.095)	-0.603 (0.605)	1.883 (2.047)	-0.588 (-0.610)	1.767 (2.071)
Spain	1.231* (0.711)	-6.957*** (2.486)	1.226* (0.715)	-6.879*** (2.475)	1.202* (0.716)	-6.773*** (2.495)	2.097*** (0.659)	-8.396*** (2.454)	2.076*** (0.662)	-8.347*** (2.452)
UK	0.028 (0.977)	0.419 (3.039)	0.068 (0.975)	0.392 (3.046)	0.036 (0.982)	0.335 (3.037)	-0.230 (0.942)	0.849 (3.051)	-0.213 (0.947)	0.787 (3.059)

<sup>1</sup> Reference Country: Sweden

<sup>2</sup> Psychological wellbeing

<sup>3</sup> Self-rated overall health

\*\*\* p<0.01, \*\* p<0.05, \* p<0.1

**Table 3: Country-specific determinants of psychological wellbeing (GHQ-12) and self-rated overall health (EQ-VAS)**

	Model 1 <sup>1</sup>		Model 2 <sup>2</sup>							
Independent variables	Caregiving hours		Caregiving hours		ADL-independency		S-MMSE		NPI-severity	
Dependent variables	GHQ-12 <sup>3</sup>	EQ-VAS <sup>4</sup>	GHQ-12	EQ-VAS	GHQ-12	EQ-VAS	GHQ-12	EQ-VAS	GHQ-12	EQ-VAS
Estonia	0.338*** (0.109)	-0.593* (0.314)	0.325** (0.128)	-0.784** (0.369)	0.047 (0.336)	-0.378 (0.863)	0.063 (0.089)	-0.016 (0.244)	0.267*** (0.071)	-0.298* (0.179)
Finland	0.257** (0.121)	-1.073*** (0.286)	0.179 (0.145)	-0.870*** (0.316)	-0.414 (0.317)	0.189 (0.764)	-0.090 (0.087)	-0.188 (0.238)	0.185*** (0.067)	-0.514** (0.232)
France	0.343* (0.174)	-0.372 (0.432)	0.330* (0.170)	-0.249 (0.464)	-0.020 (0.278)	-0.594 (1.067)	0.129 (0.101)	-0.127 (0.331)	0.354*** (0.080)	-0.721*** (0.258)
Germany	0.142 (0.146)	-0.037 (0.455)	0.018 (0.158)	-0.117 (0.537)	0.623** (0.286)	-0.998 (1.276)	-0.143** (0.059)	0.336 (0.243)	0.243*** (0.066)	-0.474 (0.299)
Netherlands	0.025 (0.176)	0.410 (0.549)	-0.128 (0.170)	0.766 (0.561)	0.186 (0.256)	-1.227 (0.894)	-0.028 (0.069)	0.014 (0.224)	0.166** (0.065)	-0.503** (0.213)
Spain	0.039 (0.093)	-0.413 (0.388)	-0.070 (0.093)	-0.224 (0.412)	-0.091 (0.255)	0.455 (1.029)	-0.003 (0.101)	0.018 (0.384)	0.413*** (0.101)	-0.342 (0.456)
Sweden	0.293* (0.155)	-0.959* (0.508)	0.140 (0.172)	-0.862 (0.550)	-0.010 (0.271)	0.773 (1.085)	0.046 (0.087)	-0.416 (0.294)	0.488*** (0.089)	-0.994*** (0.276)
UK	0.230* (0.172)	-0.320 (0.588)	0.165 (0.228)	-0.108 (0.761)	-0.609 (0.462)	2.485 (1.870)	0.368** (0.158)	-0.422 (0.496)	0.288* (0.150)	-0.098 (0.408)

<sup>1</sup> The model includes age, gender and caregiving hours.

<sup>2</sup> The model includes age, gender, living situation, caregiving hours and all disease severity measures simultaneously.

<sup>3</sup> Psychological wellbeing

<sup>4</sup> Self-rated overall health

\*\*\* p<0.01, \*\* p<0.05, \* p<0.1

**Table 4: Determinants of health care utilization (pooled model)**

	Model 1		Model 2		Model 3		Model 4		Model 5	
	Proportion of Utilization <sup>2</sup>	GP visit <sup>3</sup>	Proportion of Utilization	GP visit	Proportion of Utilization	GP visit	Proportion of Utilization	GP visit	Proportion of Utilization	GP visit
Age	0.036 (0.053)	0.011*** (0.002)	0.008 (0.060)	0.009** (0.004)	0.004 (0.060)	0.009** (0.004)	0.039 (0.060)	0.010** (0.004)	0.046 (0.060)	0.010** (0.004)
Female	6.103*** (1.426)	0.010 (0.092)	6.367*** (1.425)	0.022 (0.093)	6.341*** (1.415)	0.013 (0.093)	5.865*** (1.404)	0.008 (0.093)	5.999*** (0.215)	0.010 (0.093)
Caregiving hours	0.879*** (0.202)	0.021** (0.010)	0.688*** (0.215)	0.012*** (0.011)	0.757*** (0.217)	0.018* (0.011)	0.652*** (0.210)	0.014 (0.011)	0.559*** (0.215)	0.011 (0.012)
Living together	-	-	1.494 (1.918)	0.085 (0.112)	1.915 (1.909)	0.122 (0.110)	1.884 (1.863)	0.105 (0.110)	1.278 (1.918)	0.093 (0.111)
ADL-independency	-	-	-1.068** (0.431)	-0.049* (0.025)	-	-	-	-	-0.820* (0.439)	-0.058** (0.027)
S-MMSE	-	-	-	-	-0.152 (0.128)	0.004 (0.007)	-	-	-0.024 (0.129)	0.010 (0.007)
NPI-severity	-	-	-	-	-	-	0.628*** (0.126)	0.012* (0.007)	0.604*** (0.126)	0.012* (0.007)
Estonia <sup>1</sup>	8.170** (3.178)	0.087 (0.178)	7.901** (3.169)	0.080 (0.179)	7.395** (3.223)	0.088 (0.181)	8.629*** (3.125)	0.095 (0.179)	8.517*** (3.191)	0.130 (0.181)
Finland	-6.069** (2.473)	-0.164 (0.174)	-5.305** (2.502)	-0.127 (0.175)	-5.537** (2.498)	-0.144 (0.176)	-4.662* (2.457)	-0.121 (0.176)	-4.428* (2.449)	-0.110 (0.176)
France	-1.958 (2.785)	0.613*** (0.165)	-1.398 (2.786)	0.646*** (0.166)	-2.058 (2.793)	0.627*** (0.166)	-0.770 (2.718)	0.645*** (0.166)	-0.508 (2.735)	0.685*** (0.166)
Germany	10.719*** (3.656)	0.642*** (0.185)	9.889*** (3.689)	0.612*** (0.187)	10.390*** (3.684)	0.669*** (0.187)	10.897*** (3.602)	0.657*** (0.186)	10.017*** (3.635)	0.642*** (0.188)
Netherlands	1.258 (2.824)	0.572*** (0.161)	0.854 (2.842)	0.562*** (0.162)	1.116 (2.848)	0.580*** (0.162)	1.225 (2.783)	0.576*** (0.162)	0.856 (2.812)	0.570*** (0.162)
Spain	9.068*** (3.036)	0.406** (0.169)	9.251*** (3.036)	0.418** (0.169)	9.041*** (3.047)	0.388** (0.170)	10.806*** (2.976)	0.437** (0.170)	11.125*** (2.961)	0.442*** (0.171)
UK	-0.029 (4.434)	0.463** (0.213)	0.449 (4.406)	0.492** (0.215)	-0.073 (4.446)	0.473** (0.214)	-0.595 (4.397)	0.461** (0.215)	-0.284 (4.393)	0.497** (0.216)

<sup>1</sup> Reference Country: Sweden  
<sup>2</sup> Caregivers' subjective rating about the proportion of their use of health and social care resources which is influenced by caregiving.  
<sup>3</sup> Probability of at least one GP visit within the last month.

\*\*\* p<0.01, \*\* p<0.05, \* p<0.1

**Table 5: Country-specific determinants of health care utilization**

	Model 1 <sup>1</sup>		Model 2 <sup>2</sup>							
Independent variables			Caregiving hours		ADL-independency		S-MMSE		NPI-severity	
Dependent variables	Proportion of Utilization <sup>3</sup>	GP visit <sup>4</sup>	Proportion of Utilization	GP visit	Proportion of Utilization	GP visit	Proportion of Utilization	GP visit	Proportion of Utilization	GP visit
Estonia	1.265*** (0.407)	0.014 (0.021)	0.768* (0.429)	0.024 (0.025)	-0.687 (0.935)	0.002 (0.060)	0.173 (0.309)	0.031 (0.020)	0.378 (0.292)	-0.021 (0.015)
Finland	0.752* (0.403)	0.003 (0.030)	0.186 (0.414)	-0.038 (0.041)	-0.921 (0.883)	-0.200** (0.086)	-0.179 (0.283)	-0.009 (0.021)	0.266 (0.262)	0.002 (0.022)
France	0.151 (0.533)	0.074** (0.033)	0.284 (0.541)	0.069* (0.038)	1.431 (1.068)	-0.059 (0.078)	-0.204 (0.336)	0.061*** (0.022)	0.949*** (0.312)	0.076*** (0.018)
Germany	2.907*** (0.781)	0.009 (0.035)	2.714*** (0.996)	-0.003 (0.043)	0.703 (1.650)	-0.085 (0.095)	-0.498 (0.387)	-0.008 (0.019)	0.758* (0.445)	0.011 (0.023)
Netherlands	-0.445 (0.737)	-0.061 (0.045)	-1.028 (0.687)	-0.056 (0.048)	-0.553 (1.180)	-0.049 (0.070)	0.158 (0.318)	0.014 (0.019)	0.524* (0.288)	0.005 (0.017)
Spain	0.633 (0.451)	0.022 (0.023)	0.106 (0.426)	0.002 (0.025)	-2.899** (1.303)	-0.045 (0.068)	0.189 (0.427)	-0.013 (0.023)	1.088** (0.418)	0.041* (0.022)
Sweden	1.295* (0.851)	0.015 (0.037)	0.896 (0.903)	-0.031 (0.048)	-0.820 (1.274)	-0.160* (0.090)	-0.297 (0.317)	0.013 (0.025)	1.073** (0.409)	0.029 (0.023)
UK	0.256 (0.744)	0.028 (0.035)	0.026 (0.874)	0.067* (0.040)	-5.091* (2.635)	0.148 (0.127)	0.910 (0.710)	-0.013 (0.029)	0.598 (0.666)	-0.040 (0.032)

<sup>1</sup> The model includes age, gender and caregiving hours.  
<sup>2</sup> The model includes age, gender, living situation, caregiving hours and all disease severity measures simultaneously.  
<sup>3</sup> Caregivers' subjective rating about the proportion of their use of health and social care resources which is influenced by caregiving.  
<sup>4</sup> Probability of at least one GP visit within the last month.

\*\* p<0.01, \*\* p<0.05, \* p<0.1

## **Appendix**

The *RightTimePlaceCare* Consortium partners are as follows:

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