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*Published in:*
Journal of Advanced Nursing

*DOI:*
10.1111/jan.12561

2015

Link to publication

*Citation for published version (APA):*
Michel, B., Minna, S., Astrid, S., Adelaida, Z., Kai, S., Caroline, S., Lethin, C., Maria, S., & Sandra, Z. (2015). Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *Journal of Advanced Nursing*, *71*(6), 1378-1391. https://doi.org/10.1111/jan.12561

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9

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ORIGINAL RESEARCH: EMPIRICAL RESEARCH – QUANTITATIVE

# Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study

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Accepted for publication 9 September 2014

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BLEIJLEVENS M.H.C., STOLT M., STEPHAN A., ZABALEGUI A., SAKS K., SUTCLIFFE C., LETHIN C., SOTO M.E., ZWAKHALEN S.M.G. ON BEHALF OF THE RIGHTTIMEPLACECARE CONSORTIUM (2014) Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *Journal of Advanced Nursing* **00**(0), 000–000. **doi: 10.1111/jan.12561**

## Abstract

**Aims.** To describe differences in caregiver burden and health-related quality of life of informal caregivers of people with dementia in eight European countries and assess changes after transition from home to institutional long-term care.

**Background.** Country differences in the experience of burden and health-related quality of life are rarely described.

**Design.** Prospective cohort study.

**Methods.** Data on burden and health-related quality of life were collected at baseline (conducted between November 2010–April 2012) and follow-up (after 3 months) using face-to-face interviews. Two groups of informal caregivers included those: (1) of people with dementia recently admitted to institutional long-term care facilities; and those (2) of people with dementia receiving home care. Statistical analyses focused on descriptive comparisons between groups and countries.

**Results.** Informal caregivers of about 2014 were interviewed. Informal caregivers of people with dementia at home experienced more burden compared with informal caregivers of recently institutionalised people with dementia. Almost no differences in health-related quality of life were found between groups. Large differences between countries on outcomes were found. Informal caregivers of people with dementia who made the transition to an institutional long-term care facility experienced a statistically significant decrease in burden and psychological distress at follow-up.

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**Conclusion.** Cross-country differences may be related to differences in health and social care systems. Taking this into account, informal caregiver interventions need to be tailored to (country specific) contexts and (individual) needs. Findings highlight the positive impact of admission to institutional long-term care on informal caregiver well-being.

**Keywords:** burden, dementia, health-related quality of life, home care-nursing, informal caregivers, institutional care, older people

**Why is this research needed?**

- There is a lack of data regarding variations in caregiver burden and health-related quality of life across different countries and settings.
- In developing best practices to improve outcomes for informal caregivers and their relatives, insight into levels of experienced burden and health-related quality of life is needed.

**What are the key findings?**

- Levels of informal caregiver burden were higher for those caring for people with dementia at home compared with institutional long-term care in all participating European countries.
- Substantial differences between countries were evident for both informal caregiver burden and health-related quality of life.
- Informal caregiver burden decreased and psychological well-being increased following admission of the people with dementia to institutional long-term care.

**How should the findings be used to influence policy, practice, policy, research or education?**

- Interventions that aim to reduce caregiver's burden should take contextual aspects into account. Different countries and settings require different approaches.
- Admission to institutional long-term care can play an important role in the improvement of informal caregiver's well-being. The statistically significant reduction in caregiver burden and psychological distress after transition may underline this importance.
- Decision makers should take into account variation in informal caregiver's burden and health-related quality of life according to setting and country to manage and improve dementia care policies and related services for informal caregivers.

## Introduction

During the trajectory of dementia, the needs of people with dementia (PwD) rapidly change over time and PwD become more dependent on the care provided by (informal) caregivers (Bullock 2004). Often, at a certain time point, admission to an institutional long-term care (ILTC) facility is inevitable (Sury *et al.* 2013).

One of the most difficult decisions for many caregivers, together with their relative, is when and whether admission to an ILTC facility is needed (Caron *et al.* 2006). Besides personal preferences, the decision for transition to an ILTC facility is influenced by long-term care policies, social and cultural aspects and informal caregiver's personal characteristics.

In dementia care, there has been a shift towards community care provision in place of ILTC (European Commission 2005, The Organisation for Economic Co-operation & Development 2005). As a result of this deinstitutionalisation, community care has expanded with major implications for informal caregivers of PwD. Since PwD remain at home for as long as possible, they will require a range of services to maintain them at home to postpone admission to ILTC.


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Social and cultural aspects for example healthcare resources, support systems and available care services vary widely between countries (Torti *et al.* 2004). In Europe, there are large differences apparent in welfare and healthcare systems, formal care services, expenditure on ILTC and on informal care use that have an impact on caregivers. In general, it can be stated that provision of care services are lower and informal care is higher in the more southern and eastern European countries (European Commission 2005, Gustavsson *et al.* 2010, Vellas *et al.* 2012). In Spain, family caregiving plays a more crucial role (Gustavsson *et al.* 2010, Vellas *et al.* 2012) compared with other countries. The majority of PwD in Spain (about 80%) are exclusively cared for by family (IMSERSO 2005). Financial constraints are another illustration of cultural variety. Countries like Sweden and the Netherlands offer an extensive (long-term) health and social care system. Long-term care is primarily considered to be the responsibility of country councils and municipalities (Ministry of Health & Social Affairs 2007). Since all citizens are compulsorily insured for ILTC, financial constraints for informal caregivers do not exist in case of admission to ILTC. In contrast, in Estonia family members are financially responsible for providing care to their relatives/family (Paat & Merilain 2010).

As a consequence of cultural differences, informal caregivers' demographical composition also differ (Hallberg *et al.* 2013). For example, the mean age of PwD and their partners in Sweden is older compared with other European countries such as Estonia. A relatively high proportion of care in Sweden is provided by the partner (Riedel & Kraus 2011).

Informal caregivers' personal circumstances (for example, carer quality of life and burden) have been shown to be extremely important determinants of ILTC admission (Yeh *et al.* 2002, Torti *et al.* 2004, Argimon *et al.* 2005). Study findings by Davies and Nolan showed that more than half of the decisions about transition are made by the caregiver (Davies & Nolan 2003), thus maintaining informal caregivers' health is of paramount importance.

### Background

The impact of caring for PwD on informal caregiver's health outcomes has been extensively studied. The effects of caregiving on PwD are typically measured in terms of caregivers' health outcomes for example, distress, depression and burden (Schulz *et al.* 2004, Brodaty & Donkin 2009) and impact on the informal caregivers health-related quality of life (HRQoL) (Markowitz *et al.* 2003). Numerous studies report that being an informal caregiver of a person with dementia is associated with negative impact on these outcomes (Serrano-Aguilar *et al.* 2006, Brodaty & Donkin 2009) which are also prominent factors in models of caregivers stress (Pearlin *et al.* 1990). However, research that focuses on the transition process from home to ILTC and the influence on informal caregivers is limited. Focusing on this breakpoint of care from home to ILTC is of special interest since it is well known that informal caregiving does not end at admission to an ILTC facility. Following admission, daily care obligations of informal caregivers often reduce but are replaced with other demands such as administrative tasks and staff interaction (Schulz *et al.* 2004, Strang *et al.* 2006, Nikzad-Terhune *et al.* 2010). Some research has reported that the majority of informal caregivers make frequent visits (Tornatore & Grant 2004) to the PwD after ILTC placement.

Evidence of existing studies on whether ILTC placement is associated with an improvement in informal caregivers' health, following ILTC admission, is mixed. Some evidence showed a reduction in burden and improvement of health status (Grasel 2002, Bond *et al.* 2003, Mausbach *et al.* 2007, Gaugler *et al.* 2008, 2010) after ILTC placement, while others have shown no improvement at all or even a decrease in informal caregivers' health outcomes (Matsuda *et al.* 1997, Elmstahl *et al.* 1998, Almberg *et al.* 2000, Lieberman & Fisher 2001, Tornatore & Grant 2002, Schulz *et al.* 2004). Reasons for these conflicting findings may relate to methodological differences between studies (for example, heterogeneity of the people and variation in people population, relatively small sample sizes, variation in follow-up measurement) (Gaugler *et al.* 2010) but could also exist because of country/cultural differences. Although a substantial amount of research has been reported on informal caregiver's health outcomes after transition of the person with dementia, country differences are rarely described. The current RightTimePlaceCare study extends previous research by focusing on these cross-national country differences. To manage any methodological drawbacks as previously discussed, this study focuses on informal caregivers of PwD who are at the margins of care (i.e. at the point when home care may become insufficient and/or inadequate and admission to an ILTC facility might be triggered) and either living at home or recently admitted to ILTC.

## The study

### Aims

The aim of this study is to describe differences in caregiver burden and HRQoL of informal caregivers of PwD in eight European countries and to assess changes in caregiver

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burden and HRQoL after transition from home care (HC) to an ILTC facility.

The specific research questions for this study are:

- How does caregiver burden and HRQoL differ for informal caregivers of PwD between HC and ILTC?
- How does caregiver burden and HRQoL differ for informal caregivers of PwD across eight European countries?
- Does caregiver burden and HRQoL of informal caregivers change following admission of PwD to an ILTC facility?

## Design

As part of the RightTimePlaceCare (RTPC) project, data were collected in a prospective cohort study in eight European countries. The eight countries included in RTPC represent Estonia in the east, England in the west, Sweden and Finland in the north, Spain and France in the south and Germany and the Netherlands in central Europe. Countries selected operate differently in terms of long-term care and welfare systems (Verbeek *et al.* 2012, Hallberg *et al.* 2013). A baseline assessment (between November 2010–April 2012) and follow-up measurement after 3 months were conducted. The study design is described in further detail elsewhere (Verbeek *et al.* 2012).

## Participants and sampling

The RTPC project focused on a specific target group: informal caregivers of PwD who were on the margins of care. 'Margins of care' refer to those PwD who are at the point when home care may become insufficient or inadequate and admission to ILTC might be triggered. Professional caregivers were asked to refer eligible PwD in their care who they deemed at risk of admission to an ILTC facility within 3–6 months. As reasons for admission may vary between countries no predefined additional criteria were used (Verbeek *et al.* 2012).

Two groups were included in this study:

- Group one consisted of informal caregivers of PwD who were recently admitted (i.e. residing in the facility between 1–3 months) to an ILTC setting.
- Group two included informal caregivers of PwD receiving formal care at home but deemed at risk of admission as judged by a professional caregiver.

Informal care was defined as care provided by spouses/partners, other members of the household, relatives, friends, neighbours or others; usually with an already existing social relationship with the person they provide care (The Organisation for Economic Co-operation & Development 2005). In this study informal caregivers were included if they visited the PwD at least twice a month. Caregivers who provided care on a voluntary basis through an organization (such as a church group), or those who provided care as a career were not defined as an informal caregiver (Verbeek *et al.* 2012).

## Data collection

*Measures*

Informal caregivers' background variables included age, gender, marital status, relationship with the PwD, paid job, working hours per week, number of visits during the last 2 weeks, duration of visits and caregiving hours (both ADL and IADL) per month (data only available in the formal home care setting). Background information and assessment on informal caregiving hours were derived from the Resource Utilization in Dementia (RUD) instrument (Wimo *et al.* 1998). This instrument has been shown to be accurate in estimating the amount of informal care provision. Previous research supports the use of the RUD as a valid measure of caregiver time. Fair to good intra-class correlations have been reported ranging from 0·74–0·93 (Wimo *et al.* 2010).

Subjective burden of informal caregivers of PwD was assessed by means of the Zarit Burden Interview ((ZBI) (Zarit *et al.* 1980)) and the Caregiver Reaction Assessment ((CRA) (Given *et al.* 1992)). The total score of the 22 items ZBI ranges between 0–88. A higher score indicates greater perceived caregiver burden. (Zarit *et al.* 1980). Schreiner and colleagues used a cut-off score of 26 (Schreiner *et al.* 2006) to indicate presence of burden. The ZBI interview is a widely used and validated instrument for measuring the burden of caregivers. High levels of reliability and validity were reported by several studies. Cronbach's alpha's of 0·93 and intra-class correlation coefficients of 0·89 are reported for the ZBI (Seng *et al.* 2010). Although the CRA is not a burden measure per se, it is often used to assess burden. The CRA is a multidimensional tool that measures positive and negative components and consists of 24 items representing five domains: Caregiver's esteem (range 7–35) that reflects caregivers feelings of enjoyment and reward; Lack of family support (range 5–25) that measures to what extent caregivers feel supported by other family members; Impact on finances (range 3–15) that measures the impact on the caregivers financial situation; Impact on schedule (range 5–25) that measures to what extent caregiving inter-


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feres with the caregiver's activities; and Impact on health (range 4–20) which reflects the caregiver's capacity to provide care and health in relation to caregiving (Given *et al.* 1992). Burden scores can be calculated for the five different dimensions with a score of 1 representing no burden and a score of 5 high burden, except for the dimension of esteem where a higher score indicates lower subjective burden (Brouwer *et al.* 2004). The CRA was originally developed and validated for use in the USA (Given *et al.* 1992). Validated versions of the CRA are available in various languages including for example German (Stephan *et al.* 2013) and Dutch (Nijboer *et al.* 1999). Studies about the validity and/or reliability of the CRA in other countries show inconsistencies with regard to relevance of items and psychometrics (Malhotra *et al.* 2012). Moderate to adequate levels of internal consistency (Cronbach's alpha's varying between 0·62–0·83) have been reported for the CRA subscales (Nijboer *et al.* 1999).

HRQoL was measured with the EQ-5D. In addition, the 12-item General Health Questionnaire (GHQ-12) was used to measure psychological aspects of quality of life. The EuroQoL (EQ-5D) consists of two components namely a description of the respondent's own health within five dimensions (EQ-5D-3L that ranges between −0·594 to −1) and a rating on a visual analogue thermometer (EQ-VAS that ranges between 0–100). A higher score on the EQ-5D-3L indicates better health-related quality of life, whereas a higher score in the EQ-VAS indicates higher self-rated health. The EuroQol has been translated into more than 100 languages and often applied in dementia care studies (e.g. Jönsson *et al.* 2006, Wolfs *et al.* 2008). The EuroQol has been extensively tested (Hounsome *et al.* 2011) on aspects of reliability and validity, with additional support coming from studies of the sensitivity and specificity of the measurement.

The GHQ-12 is widely used in many studies of well-being to assess psychological aspects of quality of life (psychological distress). Each of the 12 items of the GHQ is rated on a four-point scale. The GHQ can be scored in a variety of ways. For this study, the GHQ scoring method of 0-1-2-3 (Likert) was chosen (range total score 0–36). The scores were summed by adding all the items. A higher score indicates an increased likelihood of psychological distress (Brazier *et al.* 1993). Various thresholds of the GHQ-12, 0–36 scoring method have been reported previously (Piccinelli *et al.* 1993, Goldberg *et al.* 1997, Makowska *et al.* 2002). Goldberg and colleagues suggested a cut-off score of 11/12 as indicative of psychological distress in general (Goldberg *et al.* 1997). The GHQ-12 has been translated into many different languages (including e.g. German, French and Spanish). Validity and reliability of the tool has been investigated (e.g. Goldberg *et al.* 1997, Werneke *et al.* 2000) supporting the psychometric appropriateness of the GHQ-12.

*Procedures*

Eligible dyads of PwD and their informal caregivers were identified by the care organizations either through their administrators or the professional caregivers/care managers responsible for the care of the PwD. In each of the participating countries the contact person was assigned in these care organizations to contact informal caregivers to provide them with more information about the study.

Trained interviewers collected data during standardized interviews at baseline and 3 months later. All interviewers were professionals in health or social care or medical/nursing/social care students with practical experience and qualified to at least Bachelor degree level.

## Ethical considerations

The Good Epidemiological Practice guidelines were followed. Each country obtained ethical approval from a country specific legal authority for research on human beings (e.g. an ethical committee specialized in medical or nursing science) to conduct the study in accordance with the national regulations and standards in participating countries (Verbeek *et al.* 2012). Before the start of the interview, informal caregivers who participated (mostly legal representatives) on a voluntary basis, provided informed consent. The PwD were asked to assent (providing their willingness to participate possibly without full understanding of the complexity and the whole aims of the study) (Slaughter *et al.* 2007).

## Validity and reliability

To standardize data collection a manual was used including standardized operating procedures (SOP). This manual included: (1) preparation for the interviews, with information on selection of institutions and participants, instructions for interviewers and the study pilot; (2) the interview content, explaining the measurement assessments used during the interviews; and (3) data handling, describing procedures regarding handling and storage of data, data audit and data entry (Verbeek *et al.* 2012). All questionnaires were provided in English, however, validated official versions of most measures (e.g. EQ-5D) were available in almost all languages. When this was not the case, forward

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and backward translation procedures (Mapi Research Institute 2002) were used to translate into national languages. Translations had to be obtained for the GHQ-12 (Spanish and Estonian version, the ZBI (Estonian version) and the CRA (French, Dutch, German, Swedish, Finnish, Spanish and Estonian version). To enhance variability and external validity, a minimum of three different institutional long-term care facilities and three professional home care organizations were recruited per country.

### Data analyses

The statistical analyses focused primarily on a descriptive comparison between the two groups (ILTC and HC). Descriptive analyses were conducted at the level of setting and country at baseline. Overall differences between settings were analysed using independent samples *t*-tests or chi-square tests. Differences across countries in settings were tested using ANOVA for normally distributed continuous variables, Kruskal–Wallis for non-normally distributed continuous variables and chi-square tests for nominal and ordinal variables.

Changes in caregiver burden and health-related quality of life were analysed in a subgroup of informal caregivers of whom the PwD made the transition from home to an ILTC facility in the 3-month study period. Only informal caregivers who participated in both baseline and follow-up interviews were included. Differences between baseline and follow-up were analysed using paired samples *t*-tests or chi-square tests. To enhance cross-country comparison, the UK index of the EQ5D was used. All data were analysed using the Statistical Package for the Social Science for Windows (Version 20.0; IBM Corp., Armonk, NY, USA).

## Results

### Sample characteristics

The overall sample consisted of 2014 informal caregivers; 791 informal caregivers of PwD living in an ILTC facility and 1223 informal caregivers of PwD living at home. Overall, the informal caregivers ($n = 2014$) had a mean age of 63-year old; the majority was female (67%) and was married (76%). Approximately, 33% were spouses of the people with dementia and 40% had paid work (on average 35 hours per week).

Table 1 presents characteristics per setting and country. Background information of caregivers across countries in Table 1 shows that all sample characteristics differed across countries. Informal caregivers of PwD in ILTC facilities were younger ($P < 0{\cdot}001$, mean difference −3·6 (independent samples *t*-test)) and this group contained fewer women caregivers (65·4% vs. 68·8%; $P = 0{\cdot}115$ (chi-square test)), fewer married caregivers (74·4% vs. 77·4%; $P = 0{\cdot}209$ (chi-square test)) and fewer spouse caregivers (18·4% vs. 41·7%; $P < 0{\cdot}001$ (chi-square test)) compared with the home care group. In addition, informal caregivers of PwD in ILTC facilities visited the PwD less often ($P = 0{\cdot}001$, mean difference −3·8 (independent samples *t*-test)) and stayed for less time ($P = 0{\cdot}001$, mean difference −54·7 (independent samples *t*-test)).

### Differences in caregiver burden and health-related quality of life between home care and institutional long-term care

In general, informal caregivers of PwD living at home reported higher levels of burden and less HRQoL compared with informal caregivers of PwD living in ILTC facilities (Table 2). Independent samples *t*-tests revealed that informal caregivers in home care experienced more burden (ZBI; ($P < 0{\cdot}001$, mean difference 7·6)); experienced less positive effects of caregiving (CRA caregiver esteem; ($P < 0{\cdot}001$, mean difference −0·9)); experienced less family support (CRA support; ($P = 0{\cdot}002$, mean difference 0·7)); experienced more negative impact on the caregivers' activities (CRA schedule; ($P < 0{\cdot}001$, mean difference 2·7)); and experienced more negative impact on health (CRA health; ($P = 0{\cdot}234$, mean difference 0·2)). However, regarding impact on finances, informal caregivers of PwD in ILTC experienced a more negative impact on finances ($P = 0{\cdot}002$, mean difference −0·45)). Informal caregivers in home care experienced worse HRQoL (EQ-5D-3L; ($P = 0{\cdot}035$, mean difference −0·02)); experienced worse self-rated health ($P < 0{\cdot}001$, mean difference −3·5)) and more psychological distress ($P = 0{\cdot}064$, mean difference 0·49)).

### Differences in caregiver burden and health-related quality of life between countries

Overall, informal caregivers in the home care sample scored 32·4 points on the ZBI indicating relatively high levels of burden (Table 2). The Netherlands had the lowest burden score (mean 26·5), while Estonia reported the highest burden score (mean 39·7), followed by England (mean 36·7). Informal caregivers in Sweden had the most favourable score compared with other countries on almost all CRA subscales (esteem, support, finance and health), indicating that Swedish informal caregivers felt most positive about caring for their relatives. In contrast, Estonian informal


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**Table 1** Informal caregivers background information baseline ILTC/HC.

| | Overall | England | Estonia | Finland | France | Germany | The Netherlands | Spain | Sweden | *P* value |
|---|---|---|---|---|---|---|---|---|---|---|
| Number of participants (*n*) | | | | | | | | | | |
| Total | 2014 | 157 | 287 | 304 | 224 | 235 | 290 | 287 | 230 | |
| ILTC | 791 | 76 | 115 | 122 | 49 | 119 | 113 | 113 | 84 | |
| HC | 1223 | 81 | 172 | 182 | 175 | 116 | 177 | 174 | 146 | |
| Age, mean (SD) | | | | | | | | | | |
| ILTC | 61·1 (11·1) | 61·5 (9·7) | 56·9 (12·3) | 60·9 (10·0) | 62·5 (9·7) | 59·6 (11·4) | 62·3 (10·7) | 62·5 (10·8) | 64·6 (11·8) | ***† |
| HC | 64·7 (13·4) | 65·4 (12·2) | 56·8 (13·4) | 65·4 (12·5) | 63·2 (12·8) | 62·7 (12·0) | 66·3 (12·9) | 66·6 (13·5) | 72·0 (12·3) | ***† |
| Women (%) | | | | | | | | | | |
| ILTC | 65·4 | 63·2 | 72·2 | 71·3 | 50·0 | 63·6 | 60·2 | 73·5 | 57·1 | *‡ |
| HC | 68·8 | 66·7 | 76·2 | 60·3 | 68·0 | 76·7 | 66·1 | 70·7 | 67·1 | *‡ |
| Married (%) | | | | | | | | | | |
| ILTC | 74·4 | 77·6 | 67·0 | 81·1 | 68·8 | 72·9 | 79·6 | 66·4 | 81·0 | *‡ |
| HC | 77·4 | 88·9 | 57·6 | 79·1 | 75·4 | 73·3 | 91·5 | 71·8 | 87·0 | ***‡ |
| Spouse (%) | | | | | | | | | | |
| ILTC | 18·4 | 14·5 | 12·2 | 13·9 | 18·8 | 17·8 | 21·2 | 23·0 | 27·4 | **‡ |
| Home care | 41·7 | 50·6 | 15·1 | 36·8 | 33·7 | 35·4 | 51·4 | 48·9 | 68·2 | ***‡ |
| Paid job (%) | | | | | | | | | | |
| ILTC | 46·2 | 43·4 | 67·0 | 48·4 | 29·2 | 42·4 | 46·4 | 31·0 | 52·4 | ***‡ |
| HC | 35·2 | 28·4 | 55·8 | 31·9 | 33·1 | 40·5 | 31·1 | 32·6 | 25·5 | ***‡ |
| Working hours/week, mean (SD) | | | | | | | | | | |
| ILTC [*n*] | 35·0 (12·5) [*n* = 363] | 30·3 (14·9) [*n* = 33] | 39·4 (6·9) [*n* = 76] | 34·9 (10·0) [*n* = 59] | 36·1 (4·5) [*n* = 14] | 34·4 (14·4) [*n* = 50] | 32·4 (13·6) [*n* = 51] | 32·7 (16·0) [*n* = 35] | 35·9 (14·1) [*n* = 44] | *† **† |
| HC [*n*] | 35·9 (1) [*n* = 440] | 31·0 (11·9) [*n* = 23] | 35·7 (9·1) [*n* = 96] | 38·2 (8·5) [*n* = 58] | 36·4 (15·2) [*n* = 58] | 33·9 (12·3) [*n* = 47] | 29·3 (13·7) [*n* = 53] | 38·2 (20·7) [*n* = 56] | 43·2 (31·6) [*n* = 47] | |
| Number of visits last 2 weeks, mean (SD) | | | | | | | | | | |
| ILTC | 6·6 (5·0) | 6·5 (3·7) | 3·3 (3·0) | 4·6 (3·6) | 7·7 (5·4) | 6·9 (4·9) | 7·2 (5·0) | 11·4 (5·5) | 5·5 (4·2) | ***† |
| HC (PwD lives not with IC) [*n*]§ | 10·4 (12·5) [*n* = 456] | 9·5 (6·8) [*n* = 26] | 8·5 (5·5) [*n* = 48] | 6·1 (4·2) [*n* = 100] | 13·7 (18·0) [*n* = 88] | 17·6 (21·0) [*n* = 50] | 9·8 (11·3) [*n* = 76] | 12·3 (8·0) [*n* = 23] | 7·7 (6·4) [*n* = 45] | ***† |
| Duration of visits in minutes, mean (SD) | | | | | | | | | | |
| ILTC | 109·6 (93·8) | 89·2 (72·2) | 62·0 (45·0) | 84·8 (49·9) | 112·8 (64·2) | 102·7 (52·1) | 109·4 (56·0) | 196·1 (166·9) | 119·7 (96·0) | *† |
| HC (PwD lives not with IC) [*n*]§ | 164,3 (233·2) [*n* = 456] | 235·7 (301·7) [*n* = 26] | 170·8 (224·5) [*n* = 48] | 96·2 (68·7) [*n* = 100] | 177·0 (174·3) [*n* = 88] | 188·5 (229·9) [*n* = 50] | 210·7 (388·9) [*n* = 76] | 230·0 (282·5) [*n* = 23] | 105·9 (73·6) [*n* = 45] | *† |
| Caregiving hours per month (HC), mean (SD)§ | | | | | | | | | | |
| ADL (PwD lives not with IC) | 20·6 (51·2) | 23·5 (35·0) | 54·0 (108·8) | 6·7 (17·3) | 11·5 (30·8) | 47·2 (55·0) | 7·0 (15·4) | 58·4 (79·5) | 5·1 (12·9) | ***† |
| IADL (PwD lives not with IC) | 35·9 (53·8) [*n* = 456] | 36·7 (40·4) [*n* = 26] | 60·1 (71·2) [*n* = 48] | 25·2 (59·2) [*n* = 100] | 34·4 (45·7) [*n* = 88] | 52·3 (50·4) [*n* = 50] | 24·4 (28·0) [*n* = 76] | 74·5 (86·3) [*n* = 23] | 17·4 (32·9) [*n* = 45] | ***† |

*Significant at the 0·05 probability level; **Significant at the 0·01 probability level; ***Significant at the 0·001 probability level.

†For testing significant differences between countries a one-way ANOVA was used.

‡For testing significant differences between countries a Chi-square test was used.

§Data presented for informal caregiver not living together with PwD.

ILTC, institutional long term care; HC, home care; SD, standard deviation; PwD, person with dementia, IC, informal caregiver.

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**Table 2** Informal care-givers outcome measures baseline ILTC/HC.

| | Overall | England | Estonia | Finland | France | Germany | The Netherlands | Spain | Sweden | *P* value |
|---|---|---|---|---|---|---|---|---|---|---|
| Number of participants (*n*) | | | | | | | | | | |
| Total | 2014 | 157 | 287 | 304 | 224 | 235 | 290 | 287 | 230 | |
| ILTC | 791 | 76 | 115 | 122 | 49 | 119 | 113 | 113 | 84 | |
| HC | 1223 | 81 | 172 | 182 | 175 | 116 | 177 | 174 | 146 | |
| Caregiver Burden (ZBI), mean (SD); range (0–88)‡ | | | | | | | | | | |
| ILTC | 24·9 (15·2) | 25·6 (14·2) | 30·4 (16·5) | 21·2 (12·5) | 28·8 (17·4) | 23·0 (13·2) | 18·0 (12·2) | 34·2 (16·5) | 19·3 (12·2) | ***† |
| HC | 32·4 (15·8) | 36·7 (18·5) | 39·7 (16·8) | 28·5 (14·1) | 32·1 (16·2) | 31·7 (13·2) | 26·5 (12·9) | 35·1 (15·3) | 31·6 (16·2) | ***† |
| Positive and negative reactions to caregiving (CRA) | | | | | | | | | | |
| Esteem (mean (SD); range (7–35))‡ | | | | | | | | | | |
| ILTC | 26·5 (4·6) | 27·2 (4·4) | 22·7 (4·7) | 25·6 (3·5) | 27·3 (4·7) | 26·5 (4·3) | 27·6 (3·3) | 27·5 (4·8) | 29·1 (4·9) | ***† |
| HC | 25·6 (5·1) | 24·7 (6·0) | 22·2 (4·7) | 24·7 (4·4) | 26·2 (5·5) | 25·7 (4·4) | 26·5 (4·0) | 26·0 (4·6) | 28·5 (5·2) | ***† |
| Support (mean (SD); range (5–25))‡ | | | | | | | | | | |
| ILTC | 11·6 (4·7) | 11·6 (4·5) | 12·3 (4·4) | 12·3 (3·5) | 12·6 (6·6) | 11·0 (4·4) | 11·4 (4·5) | 12·6 (4·9) | 8·7 (4·4) | ***† |
| HC | 12·3 (5·0) | 13·0 (5·3) | 13·0 (4·6) | 12·4 (3·9) | 13·0 (6·6) | 11·2 (4·3) | 11·5 (4·1) | 14·0 (5·0) | 9·8 (4·5) | ***† |
| Finance (mean (SD); range (3–15))‡ | | | | | | | | | | |
| ILTC | 7·4 (3·2) | 7·8 (2·9) | 9·3 (3·1) | 6·2 (1·9) | 7·6 (3·6) | 7·6 (3·1) | 5·8 (1·8) | 9·7 (3·6) | 4·9 (2·6) | ***† |
| HC | 6·9 (3·3) | 6·6 (3·1) | 10·3 (3·0) | 5·9 (2·1) | 6·7 (3·5) | 6·5 (2·5) | 5·8 (2·0) | 8·5 (3·3) | 4·7 (2·6) | ***† |
| Schedule (mean (SD); range (5–25))‡ | | | | | | | | | | |
| ILTC | 13·0 (4·8) | 14·6 (4·7) | 13·3 (4·9) | 11·7 (3·4) | 12·2 (5·3) | 12·0 (3·9) | 13·2 (3·8) | 16·2 (5·0) | 10·4 (5·5) | ***† |
| HC | 15·7 (5·3) | 18·3 (4·2) | 17·0 (4·9) | 13·7 (4·9) | 15·0 (6·5) | 16·0 (4·6) | 14·3 (4·6) | 17·4 (4·3) | 15·7 (6·1) | ***† |
| Health (mean (SD); range (4–20))‡ | | | | | | | | | | |
| ILTC | 9·8 (3·9) | 10·5 (3·8) | 11·7 (4·3) | 9·1 (2·8) | 8·8 (4·7) | 9·6 (3·6) | 9·2 (3·0) | 11·2 (3·9) | 7·4 (4·1) | ***† |
| HC | 10·0 (3·9) | 11·1 (3·7) | 12·5 (3·7) | 9·2 (3·2) | 8·8 (4·6) | 10·0 (3·2) | 9·5 (3·0) | 10·8 (3·9) | 8·7 (4·1) | ***† |
| Health-related quality of life of informal caregiver (EQ-5D-3L), mean (SD); range (−0·594 to −1)‡ | | | | | | | | | | |
| ILTC | 0·78 (0·25) | 0·80 (0·23) | 0·82 (0·22) | 0·80 (0·24) | 0·76 (0·26) | 0·77 (0·26) | 0·81 (0·24) | 0·73 (0·26) | 0·77 (0·27) | NS† |
| HC | 0·76 (0·26) | 0·79 (0·27) | 0·75 (0·25) | 0·83 (0·22) | 0·73 (0·32) | 0·74 (0·24) | 0·80 (0·22) | 0·70 (0·31) | 0·75 (0·25) | ***† |
| Health-related quality of life of informal caregiver (EQ-VAS), mean (SD); range (0–100)‡ | | | | | | | | | | |
| ILTC | 72·0 (18·4) | 72·2 (18·7) | 71·3 (17·6) | 77·8 (15·9) | 69·2 (15·6) | 71·9 (21·1) | 75·3 (17·0) | 63·2 (17·8) | 73·5 (19·1) | ***† |
| HC | 68·5 (18·7) | 70·2 (18·9) | 65·7 (18·6) | 72·6 (15·1) | 72·3 (18·9) | 67·7 (17·4) | 72·1 (15·9) | 60·1 (21·8) | 68·0 (19·0) | ***† |
| Psychological distress (GHQ-12), mean (SD); range (0–36)‡ | | | | | | | | | | |
| ILTC | 12·5 (5·7) | 11·2 (5·4) | 13·1 (5·3) | 10·9 (5·3) | 13·0 (6·1) | 13·5 (6·4) | 11·2 (5·3) | 15·0 (5·6) | 11·7 (5·1) | ***† |
| HC | 13·0 (5·8) | 13·3 (6·2) | 14·9 (6·8) | 11·3 (4·8) | 12·2 (5·9) | 13·0 (4·7) | 11·9 (4·9) | 14·8 (5·7) | 12·5 (5·9) | ***† |

***Significant at the 0·001 probability level.

†For testing significant differences between countries a one-way ANOVA was used.

‡Underlined score is most favourable score.

ILTC, institutional long term care; HC, home care; SD, standard deviation.

caregivers had the least favourable scores on three subscales (esteem, finance and health).

The results show that the mean score on the EQ-5D-3L was 0·76 in the home care sample. Scores on the EQ-5D-3L ranged from 0·70 (Spain)–0·83 (Finland) (Table 2). Caregiver's health indicated on the EQ-VAS was on average 68·5. Spanish informal caregivers scored the lowest (mean 60·1) of all countries. Overall the respondents in the home care setting scored 13 points on the GHQ-12. Using the suggested 11/12 threshold (Goldberg *et al.* 1997), only Finland (11·3) and Netherlands (11·9) scored below. The remaining countries had scores above the threshold (range 12·2 (France) to 14·8 (Spain)) indicating higher levels of psychological distress.

The average score on the ZBI for informal caregivers in the ILTC sample was 24·9, indicating low burden (Table 2). However, scores across countries ranged from 18·0–34·2. The Spanish informal caregivers reported the highest burden score of all countries, scoring on average almost ten points higher (mean 34·2) than the overall average score (24·9). According to the cut-off point of 26, informal caregivers in Estonia (30·4), France (28·8) and Spain (34·2) reported high burden. Sweden had the most favourable scores on all subscales of the CRA (caregiver's esteem, lack of family support, impact on finance, impact on schedule and impact on own health), indicating that Swedish informal caregivers were the most positive about caregiving for their relatives. While France and Spain had less favourable scores on the subscale


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Support, the Spanish informal caregivers had also less favourable scores on the subscales Finance and Schedule. Informal caregivers in Estonia demonstrated less favourable scores on the subscales Esteem, Health and Finance.

Overall, the mean score on the EQ-5D-3L in the ILTC sample was 0·78 and ranged from 0·73 (Spain)–0·82 (Estonia) (Table 2). Caregiver's health indicated on the EQ-VAS was on average 72·0. Spanish informal caregivers of PwD living in ILTC scored the lowest (mean 63·2) of all countries. Overall, the respondents from the ILTC setting scored just under 13 points on the GHQ-12. Thus, informal caregivers from all countries had a mean score just above the 11/12 threshold suggested by Goldberg and colleagues (Goldberg *et al.* 1997). Country differences ranged from 10·9 in Finland–15·0 in Spain, with a higher score indicating more psychological distress.

### Change in caregiver burden and health-related quality of life (transition sample)

A total of 126 PwD made the transition from home to an ILTC facility 3 months after the baseline measurement. For 109 of these 126 PwD the same informal caregiver was present at both baseline and follow-up. These comprised 8 responses from informal caregivers in the UK, 19 from the Netherlands, five from Germany, 13 from Sweden, 18 from Finland, five from Estonia, 38 from France and three from Spain.

Overall, all outcome measures improved in the first 3 months after transition except for CRA's subscale finance. Table 3 shows a statistically significant change in caregiver burden of informal caregivers of PwD, who received professional home care at baseline and had moved to an ILTC facility within 3 months (mean difference 13, $P < 0{\cdot}001$), meaning that informal caregivers experienced less burden after transition of the PwD. Only small differences were found regarding consequences of caregiving (CRA; subscales caregiver's esteem, impact on schedule, impact on finance and impact on health). No significant overall changes in health-related quality of life of informal caregivers were reported after transition (EQ-5D-3L and EQ-VAS). Psychological distress as measured by the GHQ-12 decreased significantly after transition (mean difference 2·3, $P < 0{\cdot}001$).

**Table 3** Changes in informal caregiver's outcome measures after transition of PwD from HC to ILTC (Transition sample ($n = 109$)).

| | Baseline (HC) | Follow-up (ILTC) | *P* value |
|---|---|---|---|
| Caregiver burden | | | |
| ZBI; mean (SD) | 35·4 (16·4) | 22·4 (16·6) | ≤0·001* |
| CRA esteem; mean (SD) | 25·0 (5·7) | 25·8 (4·6) | 0·023* |
| CRA support; mean (SD) | 12·0 (5·0) | 11·9 (5·3) | 0·726* |
| CRA finance; mean (SD) | 6·4 (3·2) | 7·3 (3·6) | 0·001* |
| CRA schedule; mean (SD) | 15·6 (6·2) | 12·2 (5·7) | ≤0·001* |
| CRA health; mean (SD) | 10·4 (4·8) | 9·6 (4·5) | 0·013* |
| HRQoL | | | |
| EQ-5D-3L; mean (SD) | 0·77 (0·3) | 0·77 (0·3) | 0·875* |
| EQ-VAS; mean (SD) | 70·1 (17·5) | 70·5 (19·1) | 0·749* |
| GHQ-12; mean (SD) | 14·2 (6·6) | 12·0 (5·8) | ≤0·001* |

*For testing differences between baseline and follow-up paired samples *t*-test was used.
HC, home care; ILTC, institutional long-term care; SD, standard deviation; ZBI, Zarit burden interview; CRA, caregiver reaction assessment scale; HRQoL, health-related quality of life; GHQ-12, general health questionnaire 12.

## Discussion

This study showed that there were considerable differences between settings (HC vs. ILTC) and countries on burden and HRQoL in informal caregivers of PwD. Country differences showed a pattern of eastern and southern European countries expressing more burden and lower HRQoL. Lower HRQoL and higher levels of burden were expressed by informal caregivers of PwD living at home in comparison to the caregivers of recently institutionalised PwD in all participating European countries. Taking care of PwD at home seems to impose higher demands on informal caregivers. This finding was confirmed by a consistent decrease in burden and psychological distress in the subsample of informal caregivers of PwD who made the transition to an ILTC facility during the 3-month study period.

Although in this study, ILTC placement seemed to have a positive impact on informal caregivers' experienced burden and HRQoL, previous studies have debated about the course of burden and HRQoL of informal caregivers after transition (e.g. Matsuda *et al.* 1997, Grasel 2002, Schulz *et al.* 2004, Mausbach *et al.* 2007, Gaugler *et al.* 2008, 2010, Sury *et al.* 2013). The course of burden might relate to the course of transition. In the period just prior to transition, burden might be increased because of higher care demands (Gaugler *et al.* 2009). In this study, this could have contributed to the subsequent decrease in the 3 months following admission.

Mild-to-moderate levels of burden were reported by informal caregivers in almost all countries in both settings. Overall, informal caregivers in Estonia and Spain experienced more burden compared with other countries. The finding that caregiver burden was higher and HRQoL was lower in eastern and southern European countries is consistent with a previous study that investigated caregiver experiences across Europe (Vellas *et al.* 2012). Without any

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doubt, the role of informal caregivers differs between countries, which could explain this country variation. Informal caregiver demands are known to be lower in the Netherlands and Sweden in comparison to countries such as Estonia and Spain. This is also emphasized by the hours of care spent per month by the informal caregiver in our current study (ADL hours (mean 20·6; range 5·1–35·9) and IADL hours (mean 35·9; range 17·4–74·5). These hours varied widely between countries. A recent study by Wimo and colleagues comparing studies on the time informal caregivers spent assisting with ADL and IADL, showed that on average caregiver spent 2·0 hours per day (range 1·1–3·0) on ADL and IADL assistance (Wimo *et al.* 2013) which is more than in this study. Informal caregivers who reported low burden lived in countries such as Sweden, Finland and the Netherlands that also reported a limited amount of objective caregiving hours per month. Not only does the informal caregiver role differ but also available care and support systems vary enormously between countries involved in this European study. Greater availability of formal care services and more heavy reliance on the social security system in countries such as the Netherlands and Sweden (Triantafillou *et al.* 2010), may account for variation in the outcomes of caregiver burden and HRQoL.

Furthermore, it needs to be acknowledged that country variation in this study could also relate to sampling differences. Informal caregivers differed in terms of age, gender, work status and their relationship with the PwD. Such factors, the literature suggests, may influence caregiver's experiences negatively (Schulz *et al.* 2004, Varona *et al.* 2007, Mioshi *et al.* 2013). In our study, the more burdened Estonian caregivers of PwD living at home were overall younger and more often children of the PwD. A study by Andren and Elmstahl also detected higher burden in younger caregivers (Andren & Elmstahl 2007). In addition, previous studies reported higher levels of burden in child–parent relations compared with spouses (Varona *et al.* 2007), which may relate to the higher levels of burden reported in Estonian informal caregivers in this study.

Although levels of caregiver burden and HRQoL varied considerably, there was a stable pattern showing lower levels of burden and higher HRQoL in caregivers of recently institutionalised PwD. Previous studies on caregiver burden supports this finding (Zarit & Whitlatch 1992, Gaugler *et al.* 2010). Research by Zarit and Whitlack showed an improvement in caregivers' feeling of tension after admission of their relative (Zarit & Whitlatch 1992). However overall it should be mentioned that levels of caregiver burden were still relatively low to moderate in comparison to other previous published data (Meiland *et al.* 2001, Yurtsever *et al.* 2013).

### Limitations

In interpreting the findings, it should be pointed out that the sample in this study included a specific group of caregivers, namely caregivers of PwD at the 'margins of care' when home care may become insufficient and admission to an ILTC facility might be needed. Therefore, the informal caregivers in this study were caregiving for a considerable period and may not represent all informal caregivers of PwD. The strength of the study lies in the large amount of descriptive data gathered using valid measures highlighting interesting contrasts between countries and settings. However, only a limited number of PwD were admitted to ILTC in the 3 month follow-up period ($n = 109$) and numbers varied extensively between countries. Due to the small sample sizes in each country, it was impossible to perform further country-specific analyses in this subsample. Previous studies have suggested that the length of the caregiving relationship relates to the amount of caregivers burden (Brodaty & Donkin 2009). In this study, no information was collected about the duration of caregiving. The 3 month study period is also relatively short. To investigate further changes in caregivers' HRQoL and burden, measurement over a longer follow-up period would be warranted.

## Conclusion

On the basis of this study, we conclude that across countries the perceived level of burden and HRQoL is lower in caregivers of PwD who reside in ILTC. Transition to ILTC seems helpful to reduce caregiver strain and may lead to a reduction in burden. Given the current policy that encourages people to stay at home as long as possible and that many caregivers want to continue caring for as long as possible, optimal provision of home health care must be achieved to support informal caregivers and the PwD. This is only achievable with a dual aim of optimizing well-being and minimizing stress in the PwD and their informal caregivers. A balanced approach is needed. Policy makers and European governments should be committed to assure accessible home healthcare support services for PwD and their informal caregivers. Policy makers and care providers should look beyond the PwD solely and include informal caregivers as full partners in the process of care. Interventions need to be developed that are specifically designed to reduce burden in caregivers of PwD living at home. Nurses play an important role in assessing PwD and informal caregivers needs and applying available interventions to prevent or reduce caregiver burden. If the PwD is living at home, nurses are often the key contact to the outside world.


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Nurses can provide guidance to informal caregivers by providing information regarding the dementia caregiving process. Nurses can optimize care by enhancing appropriate support tailored to the informal caregivers specific needs such as support groups, case management and availability of respite care. Offering optimal support will improve outcomes for both the caregiver and the PwD.

## Funding

The *RightTimePlaceCare* study is supported by a grant from the European Commission within the 7th Framework Programme (project 242153).

## Conflict of interest

No conflict of interest has been declared by the author(s).

## Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/ethical_1author.html)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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