

Do caregiver characteristics affect caregiver burden differently in different countries?

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Disclosure: The authors have reported no conflicts of interest

## Abstract

The relationships between caregiver burden as measured with the BSFC-s and six characteristics of caregivers caring for dementia patients were investigated for caregivers from England (n=36), Finland (n=42), and Greece (n=46) using survey data. In all three countries, caregiver burden increases with physical problems of the caregiver, emotional problems of the care giver, and weekly hours of care. Hence, in all three countries, special support for informal care is required when these characteristics are at high levels. When the caregiver is a spouse or long term partner of the person with dementia, lives in the same house as this person, or spends fewer than 20 hours per week for other duties than care, this is associated with less caregiver burden in England, but with more caregiver burden in Greece. Accordingly special support is required for Greek caregivers with these characteristics but the opposite is true for English caregivers.

Keywords: Dementia, informal care, informal caregivers, caregiver burden, cross-cultural, cross-national

# 1 Introduction

An essential component of care for people with dementia is performed by informal caregivers, such as close relatives or friends who did not choose caregiving as their profession but who took on this role because their close relative or friend had been diagnosed with dementia. Such informal caregivers can experience heavy caregiver burden (CB). To develop measures for alleviating CB and for identifying those caregivers who need most support, research identifying the conditions affecting CB is required. This includes research into cultural differences regarding CB because this might help in tailoring interventions to culture-specific needs. At present, hardly anything is known about such cultural differences. One of the few relevant studies stems from Konerding et al. [1]. These authors found that English, Finnish and Greek caregivers with the same level of CB endorse different items. English caregivers mainly endorse items regarding impairments in individual wellbeing, while Finnish caregivers endorse items regarding the conflict between the demands resulting from care and demands resulting from the remaining social life. Greek caregivers endorse items regarding impairments in their physical health [1]. These results indicate that CB is experienced differently in these three countries. Furthermore, cultural differences might show in the way the individual characteristics of caregivers affect CB. This is investigated here by further analysing the data used in the study of Konerding et al. [1].

## 2 Methods

The data for the original study stem from surveys performed in England, Finland, Germany, Greece, the Netherlands and Spain as part of the research project MANAGED OUTCOMES [2]. These surveys addressed informal caregivers of dementia patients who had been referred to hospitals for reasons other than their dementia and who were not yet living permanently in a nursing home. The caregivers were approached via the hospital administrations which identified eligible patients on the basis of the patient records. As the sample sizes in Germany, the Netherlands and Spain were too small, only data from England, Finland and Greece were analysed [1]. In England the survey was performed in March 2012, in Finland in November 2011, and in Greece in September 2011.

### 2.1 Questionnaire

The survey included questions addressing characteristics of the person with dementia (PWD) and the caregiver. The characteristics of the PWDs encompassed age and sex. The characteristics of the caregivers were age, sex, education (with having left school directly after the minimum school leaving age of the country classified as 'low' and longer attendance at school as 'high'), relationship between caregiver and PWD ("caregiver being spouse or long-term living partner" versus otherwise), living situation ("caregivers and PWD living in the same house" versus otherwise), weekly hours spent in providing care, and weekly hours spent for other duties. These other duties comprised 1) having paid work in addition to the care, 2) being in education, i.e. being in vocational training, being at school, or studying, 3) having children younger than 16, and 4) additionally caring for someone else than the PWD addressed in the questionnaire.

The questionnaire also contained the EQ-5D-3L (EuroQuol, 5 dimensions, 3 levels) self-completion form and the EQ-5D-3L proxy (referring to the PWD). The EQ-5D-3L is an instrument for assessing health-related quality of life. It contains five questions addressing mobility, self-care, usual activities, pain/discomfort and anxiety/depression with each dimension partitioned into the 3 levels "no problems", "some problems", and "extreme problems" [3]. There are official versions for the EQ-5D-

3L self-complete and the EQ-5D-3L proxy in English, Finnish and Greek [3]. Moreover, there is evidence that the items of these three versions are understood in the same way in these three countries [4].

The questionnaire also contained the BSFC-s (Burden Scale for Family Caregivers – short form). The BSFC-s consists of 10 items with the answer categories “Agree”, “Partly agree”, “Mainly disagree”, and “Disagree”. These categories are coded with numbers from zero for “Disagree” to three for “Agree”. The corresponding sum scores range from zero to 30 with higher scores indicating a greater caregiver burden [5].

## 2.2 The investigated caregiver characteristics

Six characteristics of the caregiver were investigated: 1) physical condition, 2) emotional condition, 3) living situation (i.e. whether or not living in the same house as the PWD), 4) personal relationship to the PWD (i.e. whether being a spouse or long term living partner or not), 5) extent of care given, and 6) extent of other duties in addition to providing care for the PWD. In the following text these variables will be referred to as the ‘investigated caregiver characteristics’.

Caregivers were classified as having physical problems when they had reported a problem for at least one of the first four EQ-5D-3L items. Accordingly, caregivers were classified as having emotional problems when they had reported problems for the last EQ-5D-3L item. The variable “extent of care provided” was constructed by dichotomising weekly hours spent for care into “less than 20 hours” and “at least 20 hours”. The variable “extent of other duties” was constructed by dichotomising the total number of weekly hours spent for other duties into “less than 20 hours” and “at least 20 hours”. The limit of 20 hours was chosen because this is the equivalent of a ‘half-time’ working position.

## 2.3 Statistical analyses

Descriptive statistics were computed for age and gender of PWD and caregiver, education of caregiver, and the six investigated caregiver characteristics. All computations were performed for the three countries separately as well as for the total sample. Country differences for age were tested using multiple linear regression models with dummy coded countries as independent variables. For the other variables a chi-square test was applied when the corresponding conditions were fulfilled. Otherwise Fisher’s exact tests were computed.

To examine whether the investigated caregiver characteristics relate differently to CB as reflected by the BSFC-s sum score, two multivariate linear regression models with the sum score as dependent variable were computed for each characteristic. The first model contained dummy-coded countries and test variable as independent variables, the second model also contained terms for the interaction between countries and the characteristic in question. Both models were compared using an F-test. Statistically significant better fit of the model with interaction terms was interpreted as evidence for country specific differences in the relationships between the sum score and the characteristic. Additionally, the BSFC-s sum score means were computed for the two levels of each characteristic, as well separately for each country as for all countries together, and the differences between the two levels were statistically tested.

### 3 Results

In total, 36 English, 42 Finnish and 46 Greek participants were finally included in the analyses. The caregivers were predominantly in their early sixties and female; the PWDs were predominantly in their early eighties and also female. The countries differed significantly with regard to two of the six investigated caregiver characteristics and three of the five additionally assessed characteristics of the caregivers or, respectively, the PWDs (see Table 1). The Finnish PWDs were distinctly younger than PWDs in England or Greece. Moreover, the Finnish caregivers were distinctly better educated, had fewer emotional problems and spent less time in providing care than the caregivers from the other two countries. The remaining two country differences are mainly caused by the Greek sample. In comparison with the caregivers from the other countries the Greek caregivers were younger and less frequently spouses or long-term-living partners of the PWDs.

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Insert Table 1 about here

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For two of the six investigated caregiver characteristics there is no statistically significant interaction between country and test variable (see Table 2), i.e. these two variables relate in the same way to CB in all three countries. There is, however, a statistically significant main effect in both cases. CB is stronger when caregivers suffer from physical problems or spend at least 20 hours on providing care (see Table 2). For one of the investigated caregiver characteristics with significant interaction, i.e. for emotional problems, there are statistically significant effects in the same direction in all three countries, i.e. CB increases with emotional problems. There are, however, large differences in the size of these effects. The effect is largest for Greece and smallest for England (see Table 2). For three of the four investigated caregiver characteristics with significant interaction there are country specific tendencies - if not effects -in the opposite direction. Being a spouse or long term partner of the PWD, living in the same house as the PWD, and spending fewer than 20 hours per week for other duties are associated with less CB in England but with more CB in Greece (see Table 2).

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Insert Table 2 about here

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### 4 Discussion

The findings that the Finnish PWDs were younger and that the Finnish caregivers spent less time in providing care are in line with PWDs being referred to a nursing home at an earlier stage of their dementia in Finland than in other countries [1,6-7]. Accordingly, those PWDs who have not yet been referred to a nursing home need less care and are younger than non-hospitalized PWDs from other countries. The finding that the Greek caregivers were younger and less frequently spouses or long-term-living partners of the PWDs is in line with PWDs in Southern Europe having a distinctly lower risk of being institutionalised within a given time period than PWDs from Northern Europe [1, 8]. Accordingly, informal care must more often be provided by the PWDs' children or children in law who are usually younger than the PWDs' spouses or long term living partners.

Further results must be discussed with the caveat that the three country samples have not been drawn at random from the populations of caregivers in these countries. Hence, the relationships

between the investigated caregiver characteristics and caregiver burden might be different for those caregivers not included in the samples. However, there are hardly any studies regarding caregiver burden based on randomly drawn samples; hence, research in this area depends upon interpreting results from samples which might not be representative.

With the caveats just mentioned the analyses regarding the impact of the investigated caregiver characteristics on CB suggest that CB increases in all cultures when caregivers have emotional or physical problems or when they spend much time for the care. The effects for physical and emotional problems have also been found in a sample of Irish caregivers [9], and the effects for physical problems and time spent for care in a sample of South Korean caregivers [10]. The finding that emotional problems of the caregiver have the strongest effect on CB in Greece might be explained by the fact that there is hardly any support for informal caregivers in Greece. This explanation is corroborated by the result patterns for the two investigated characteristics of care without interaction effect. For all these variables the difference between the two compared groups is largest for Greece (see Table 2).

The further findings regarding the relationships between caregiver characteristics and CB indicate essential cultural differences. Being a spouse or long-term living partner, living in the same house and spending not much time for other duties attenuates CB in England but intensifies it in Greece. The characteristics just enumerated establish a close bond between the caregiver and the PWD. The results suggest that this close bond supports English caregivers in their care whereas the Greek caregivers suffer from it. An effect similar to that in Greece has also been found in a South Korean sample [10].

## 5 Conclusions

The results suggest that some caregiver characteristics relate basically in the same way to CB in different cultures. CB seems to increase in all cultures with the amount of care provided and with impairments of caregiver's health state. On the other hand, some characteristics seem to have a different impact in different cultures. One of these characteristics is the relationship between caregiver and PWD. There might be different characteristics which affect CB in different cultures differently. Therefore, before developing public health programs for supporting caregivers in a specific culture the manner in which different caregiver characteristics affect CB in this culture should be investigated. On the basis of such an investigation specifically tailored programs could be developed or, if available, adopted from countries in which caregiver characteristics relate to CB in a similar way.

**Table 1: Features of the study sample**

	England	Finland	Greece	Total	Comparison <sup>a</sup>
General characteristics of PWDs and caregivers					
Age of PWD <sup>b</sup>	83.4 SD=6.4 68; 98 n=32	78.4 SD=9.3 56; 95 n=42	83.4 SD=6.6 70; 95 n=43	81.6 SD=8.0 56; 98 n=117	F(2,114)= 5.733 p<0.01
Female PWDs	20 (34) (58.8%)	20 (39) (51.3%)	30 (45) (66.7%)	70 (118) (59.3%)	$\chi^2(2)= 2.054$ n.s.
Age of caregiver <sup>b</sup>	68.4 SD=12.3 44; 86 n=29	65.3 SD=12.1 35; 90 n=33	59.3 SD=12.8 33; 85 n=41	63.8 SD=12.9 33; 90 n=103	F(2,100)= 4.963 p<0.01
Female caregivers	20 (29) (69.0%)	18 (30) (60.0%)	32 (41) (78.0%)	70 (100) (70.0%)	$\chi^2(2)= 2.708$ n.s.
Caregivers with low education level	17 (28) (60.7%)	6 (30) (20.0%)	21 (38) (73.7%)	44 (96) (45.8%)	$\chi^2(2)=11.923$ p<0.01
Investigated caregiver characteristics					
Physical problems	17 (32) (53.1%)	14 (42) (33.3%)	16 (44) (36.4%)	47 (108) (39.8%)	$\chi^2(2)= 3.320$ n.s.
Emotional problems	16 (31) (51.6%)	10 (42) (23.8%)	31 (42) (73.8%)	57 (115) (49.6%)	$\chi^2(2)=21.073$ p<0.001
Being spouses or long-term living partner of PWD	20 (36) (55.6%)	25 (42) (59.5%)	11 (46) (23.9%)	56 (124) (45.2%)	$\chi^2(2)=13.455$ p<0.01
Living in the same house as PWD	25 (35) (71.4%)	29 (41) (70.7%)	26 (42) (61.9%)	80 (118) (67.8%)	$\chi^2(2)= 1.041$ n.s.
At least 20 hours per week for care	25 (30) (83.3%)	12 (26) (46.2%)	26 (36) (72.2%)	63 (92) (68.5%)	$\chi^2(2)= 9.304$ p<0.01
At least 20 hours per week for other duties	7 (36) (19.4%)	12 (40) (30.0%)	15 (41) (36.6%)	34 (117) (29.1%)	$\chi^2(2)= 2.758$ n.s.

<sup>a</sup>Test for statistical significance of the country differences; for nominal variables chi-square-test unless a different test was stated; for variables with at least interval scale level multivariate regression with dummy coded country; n.s. means not significant.

<sup>b</sup>First number = mean, second number = standard deviation, third number = minimum, fourth number=maximum, fifth number = number of valid data.

**Table 2: Relationships of caregiver characteristics with CB measured by the BSFC-s sum score**

	England <sup>a</sup>	Finland <sup>a</sup>	Greece <sup>a</sup>	All <sup>a</sup>	Interaction <sup>b</sup>
Physical problems	22.2; 18.5 3.7 32	14.6; 11.9 2.7 42	22.6; 13.4 9.2** 44	20.1; 13.9 6.2*** 118	F(2,112)= 1.670 n.s.
Emotional problems	23.0; 17.5 5.5* 31	18.6; 11.2 7.4** 42	20.8; 5.3 15.5*** 42	21.0; 11.6 9.4*** 115	F(2,109)= 3.899 p<0.05
Being spouses or long-term living partner of PWD	18.4; 24.1 -5.7** 36	13.2; 12.2 1.0 42	22.2; 15.1 7.1 46	16.8; 16.5 0.3 124	F(2,118)= 4.736 p<0.05
Living in the same house as PWD	20.6; 22.4 -1.8 35	13.3; 10.4 2.9 41	21.0; 11.8 9.2** 42	18.1; 14.2 3.9* 118	F(2,112)= 3.732 p<0.05
At least 20 hours per week for care	22.7; 18.2 4.5 30	17.8; 12.3 5.5 26	20.9; 8.0 12.9** 36	21.0; 11.8 9.2*** 92	F(2,86)= 2.172 n.s.
At least 20 hours per week for other duties	24.3; 20.1 4.2* 36	15.5; 12.3 3.2 40	13.0; 18.8 -5.8 41	16.2; 17.1 -0.9 117	F(2,111)= 3.316 p<0.05

<sup>a</sup> Cell entries are: (1<sup>st</sup> row) mean of BSFC-s sum score for the category given in the first cell of the row; mean of BSFC-s sum score for the alternate category; (2<sup>nd</sup> row) difference between the two means listed in the first row; asterisks mark statistically significant deviation from zero; \*=p<0.05, \*\*=p<0.01; \*\*\*=p<0.001; (3<sup>rd</sup> row) sample size (variations due to missing values for the investigated characteristics of care)

<sup>b</sup> Cell entries are: (1<sup>st</sup> and 2<sup>nd</sup> row) test statistic for interaction; (3<sup>rd</sup> row) result of the statistical test; n.s. = not significant.

## References

- 1 Konerding U, Bowen T, Forte P, Karampli E, Malmström T, Pavi E, Torkki P, Graessel E. Investigating burden of informal caregivers in England, Finland and Greece: an analysis with the short form of the Burden Scale for Family Caregivers (BSFC-s). *Aging Ment Health*. 2018 Feb;22(2):280-287. doi: 10.1080/13607863.2016.1239064. Epub 2016 Oct 18.
- 2 Managed Outcomes Consortium. Managed Outcomes. <http://www.youtube.com/feed/UCGR1TtIICkmp-FHKH6cEAcg>. Accessed August 23, 2018.
- 3 EuroQol Group. EQ-5D-3L. <https://euroqol.org/eq-5d-instruments/eq-5d-3l-about/>. Accessed August 23, 2018.
- 4 Konerding U, Elkhuzen SG, Faubel R, Forte P, Malmström T, Pavi E, Janssen MF. The validity of the EQ-5D-3L items: an investigation with type 2 diabetes patients from six European countries. *Health Qual Life Outcomes*. 2014 Dec 5;12:181. doi: 10.1186/s12955-014-0181-5.
- 5 Graessel E, Berth H, Lichte T, Grau H. Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatr*. 2014 Feb 20;14:23. doi: 10.1186/1471-2318-14-23.
- 6 Bleijlevens MH, Stolt M, Stephan A, Zabalegui A, Saks K, Sutcliffe C, Lethin C, Soto ME, Zwakhalen SM; RightTimePlaceCare Consortium. 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. *J Adv Nurs*. 2015 Jun;71(6):1378-91. doi: 10.1111/jan.12561. Epub 2014 Nov 17.
- 7 Verbeek H, Meyer G, Challis D, Zabalegui A, Soto ME, Saks K, Leino-Kilpi H, Karlsson S, Hamers JP; RightTimePlaceCare Consortium. Inter-country exploration of factors associated with admission to long-term institutional dementia care: evidence from the RightTimePlaceCare study. *J Adv Nurs*. 2015 Jun;71(6):1338-50. doi: 10.1111/jan.12663. Epub 2015 Apr 14.
- 8 Vellas B, Hausner L, Frölich L, Cantet C, Gardette V, Reynish E, Gillette S, Agüera-Morales E, Auriacombe S, Boada M, Bullock R, Byrne J, Camus V, Cherubini A, Eriksdotter-Jönhagen M, Frisoni GB, Hasselbalch S, Jones RW, Martinez-Lage P, Rikkert MO, Tsolaki M, Ousset PJ, Pasquier F, Ribera-Casado JM, Rigaud AS, Robert P, Rodriguez G, Salmon E, Salva A, Scheltens P, Schneider A, Sinclair A, Spuru L, Touchon J, Zekry D, Winblad B, Andrieu S. Progression of Alzheimer disease in Europe: data from the European ICTUS study. *Curr Alzheimer Res*. 2012 Oct;9(8):902-12.
- 9 Gresswell I, Lally L, Adamis D, McCarthy GM. Widening the net: exploring social determinants of burden of informal carers. *Ir J Psychol Med*. 2018 Mar;35(1):43-51. doi: 10.1017/ipm.2017.36.
- 10 Park M, Sung M, Kim SK, Kim S, Lee DY. Multidimensional determinants of family caregiver burden in Alzheimer's disease. *Int Psychogeriatr*. 2015 Aug;27(8):1355-64. doi: 10.1017/S1041610215000460. Epub 2015 Apr 8.

## **Acknowledgments**

The research leading to the results presented here has received funding from the European Community's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 241741.

The surveys have been performed with the special assistance of Apostolos Efkarpidis, Gill Garden, Ourania Kalogeraki, and Antero Vanhalla. The authors would also like to express their gratitude to the participating healthcare service provider organisations for their co-operation and support in enabling the study to take place. These were United Lincolnshire Hospitals NHS Trust in England, the Keski-Suomi Central Hospital in Finland, and the General Hospital of Syros in Greece.