Preventive Medicine 70 (2015) 64–68

Contents lists available at ScienceDirect

Preventive Medicine

journal homepage: www.elsevier.com/locate/ypmed

Providing personal informal care to older European adults: Should we care about the caregivers' health?

Laura Hiel [a,b], Mariëlle A. Beenackers [a,*], Carry M. Renders [b,c], Suzan J.W. Robroek [a], Alex Burdorf [a], Simone Croezen [a]

[a] Department of Public Health, Erasmus MC, University Medical Center Rotterdam, The Netherlands
[b] Department of Health Sciences, Faculty of Earth and Life Sciences, VU University, Amsterdam, The Netherlands
[c] EMGO+ Institute for Health and Care Research, VU University, Amsterdam, The Netherlands

ARTICLE INFO

Available online 24 November 2014

Keywords:
Informal care
Health
Caregivers
Elderly
Europe
MeSH terms: Elderly
Health status
Longitudinal studies
Patient care

ABSTRACT

Objective. In Europe, the demand for informal care is high and will increase because of the ageing population. Although caregiving is intended to contribute to the care recipient's health, its effects on the health of older European caregivers are not yet clear. This study explores the association between providing informal personal care and the caregivers' health.

Method. Data were used from the longitudinal cohort (2004/2005–2010/2011) of the Survey of Health, Ageing and Retirement in Europe (SHARE) (n = 7858). Generalized estimating equations were used to explore the longitudinal association of informal care and the caregiver's health using poor self-rated health (less than good), poor mental health (EURO-D score for depression ≥4), and poor physical health (≥2 health complaints).

Results. Providing informal personal care was significantly associated with poor mental health (OR = 1.23, 95% CI = 1.04–1.47) and poor physical health (OR = 1.18, 95% CI = 1.01–1.38), after adjusting for various socio-demographic and health-related factors. No statistical significant association was found for self-rated health in the adjusted models.

Conclusion. Providing informal personal care may negatively influence the caregiver's mental and physical health. More awareness of the beneficial and detrimental effects of caregiving among policy makers is needed to make well-informed decisions concerning the growth of care demands in the ageing population.

Introduction

The population in Europe is ageing. In the European Union, the proportion of people aged 65 years and older has grown from approximately 14.1% in 1992 to 16.0% in 2002 and 17.8% in 2012. This proportion is likely to further increase during the coming decades (Eurostat, 2013). When the proportion of elderly people in the population increases, the demand for health care is expected to do so as well. To meet the growing health care demands, governments rely increasingly on the provision of informal care by family, neighbours and friends. In 2008, around 35% of the adult population of the Netherlands provided informal care of which 23% provided care for more than three months (CBS, 2013; Oudijk et al., 2010). In 2009, about 4 million of the 65 million people in France provided informal care compared to 4.3 million people providing formal care, and in Italy around two-thirds of the care needed by older people is provided by their relatives (Triantafillou et al., 2010).

Informal care is defined as "care given to dependent persons, such as the sick and elderly, outside the framework of organized, paid, professional work"(Oxford Dictionary of Sociology, 2009), and can involve several types of help, such as personal care, practical or instrumental care, or supervision. Providing personal care is often more physically and mentally demanding for the caregiver than other types of informal care, and might even have a negative influence on the caregivers' health (Broe et al., 1999). So far, most studies investigating the provision of informal personal care in relation to the carer's health have been conducted in specific care situations, such as caring for partners with dementia (Beaudreau et al., 2008; McCurry et al., 2007) or for patients with schizophrenia (Ukpong, 2012). These studies indicate that providing informal personal care may lead to sleep inefficiency (Beaudreau et al., 2008; McCurry et al., 2007), emotional distress (Beaudreau et al., 2008; McCurry et al., 2007; Ukpong, 2012) and depression (Beaudreau et al., 2008; McCurry et al., 2007). Additionally, stress derived from caregiving could be a risk factor for mortality through the development of coronary heart disease (Vitaliano et al., 2002). Providing personal care to one's spouse for over 14h per week has been indicated as a significant

* Corresponding author at: Department of Public Health, Erasmus MC, University Medical Center Rotterdam, PO Box 2040, 3000 CA Rotterdam, The Netherlands.
E-mail address: m.beenackers@erasmusmc.nl (M.A. Beenackers).

http://dx.doi.org/10.1016/j.ypmed.2014.10.028
0091-7435/

predictor of hypertension (Capistrant et al., 2012b) and may increase the risk of cardiovascular diseases with 35% (Capistrant et al., 2012a). Furthermore, when spending a considerable amount of time to caring, caregivers have less time to exercise and will therefore benefit not as much from the favourable influences of physical exercise on both physical and mental health (Bauman, 2004; Burton et al., 1997; U.S. Department of Health and Human Services, 1996; Schulz et al., 1997; Warburton et al., 2006).

Because of the potential negative influence of providing informal care on the caregiver's health and the potential increase in informal health care demand, it is important to have more insight in the relationship between caregiving and health from the caregiver's perspective. Therefore, this study investigated the longitudinal association between the provision of informal personal care and the caregiver's self-rated, mental and physical health in an older adult population. In addition, potential moderators of this association were studied in order to gain insight into potential mechanisms and vulnerable groups.

Methods

Study design

A prospective study was conducted with data of the longitudinal cohort of the Survey of Health, Ageing and Retirement in Europe (SHARE) (Börsch-Supan et al., 2005, 2013). In SHARE, information of non-institutionalised adults aged 50 years and older and their spouses were collected using computer-assisted personal interviews. The first wave included 31,115 participants across twelve countries, with a total household response of 61.6% (SHARE-Project, 2012). In this study, only subjects participating in all three prospective waves were included: waves 1 (2004/2005), 2 (2006/2007) and 4 (2010/2011). Wave 3 (2008/2009) was not included because it was a retrospective study focusing on the life history of participants and did not include relevant measures for the current analysis. The prospective sample covered ten European countries: Austria, Belgium, Denmark, France, Germany, Italy, Spain, Sweden, Switzerland and The Netherlands ($n = 7858$).

Health measures

Information about self-rated health, mental health and physical health was available in all three prospective waves. Self-rated health was measured using a 5-point scale with response options "excellent", "very good", "good", "fair" and "poor". The first three response options were collated into the category 'good health' and the other two options into the category 'poor health'. Mental health was measured by the EURO-D scale for depression (Prince et al., 1999). The EURO-D scale consisted of twelve items, which were "depressed mood", "pessimism", "suicidality", "guilt", "sleep", "interest", "irritability", "appetite", "fatigue", "concentration", "enjoyment" and "tearfulness". Each item could be scored one if the item was present, or zero if the item was not present, with a minimum possible score of zero and a maximum possible score of twelve. A score of four or higher was defined as 'poor mental health'. Physical health was measured by the appearance of health conditions in the past six months, namely "pain in your back, knees, hips or any other joint", "heart trouble or angina, chest pain during exercise", "breathlessness, difficulty breathing", "persistent cough", "swollen legs", "sleeping problems", "falling down", "fear of falling down", "dizziness, faints or blackouts", "stomach or intestine problems, including constipation, air, diarrhoea" and "incontinence or involuntary loss of urine" or "health condition not present in the list". Scores of one or zero conditions were operationalized as 'good physical health', and two or more conditions were defined as 'poor physical health'.

Informal personal care

Informal care information was available for SHARE waves 1 and 2. Informal care was defined as "the provision of personal care, e.g. dressing, bathing or showering, eating, getting in or out of bed and using the toilet, either inside or outside the household and in the past 12 months" (=yes), or "no provision of personal care" (=no) which also included those who only provided other types of informal care outside the household such as practical care, e.g. home repairs, gardening, transportation, shopping and household chores, or help with paperwork, e.g. filling out forms and settling financial or legal matters.

Covariates

Age, gender, marital status, educational level, employment status, household size, and exercising behaviour were taken into account as covariates, and were available across all waves. Marital status was dichotomized into 1) "married and living together with spouse" and "registered partnership"; 2) "married, living separated from spouse", "never married", "divorced" and "widowed". Educational level was classified according to the categories of the international standard classification of education (ISCED) (UNESCO, 2006). The categories were pooled into three groups, which were "low educational level" (ISCED 0–2), "average educational level" (ISCED 3–4) and "high educational level" (ISCED 5–6) (Avendano et al., 2009; Galobardes et al., 2006). Employment status was categorized into "retired", "employed or self-employed", "permanently sick or disabled", and "unemployed, homemaker, or other". Household size was categorized as "alone", "with two persons", "with three persons" and "with four or more persons". Finally, exercising behaviour was measured as a dichotomous variable indicating if respondents were vigorously to moderately active or not.

Statistical analysis

The analytical sample size was determined by the number of respondents who had non-missing information on providing informal care ($n = 7858$). Descriptive statistics were used to obtain socio-demographic characteristics of the study population at baseline. To explore the longitudinal relation between the provision of personal care and the outcome measures, first-order autoregressive generalized estimating equations (GEE) were used with an exchangeable correlation structure. The first order autoregressive model takes into account that the health outcome at follow-up is not only related to caregiving, but also to the health outcome at the previous wave. This first order autoregressive GEE model estimates the influence of caregiving at T0 and T1 on health at T1 and T2, adjusted for health at T0 and T1. Hence, the model estimates the influence of caregiving at baseline on change in health during follow-up. The exchangeable correlation matrix was considered most appropriate based on the observed correlation between the different time points and the aim to use the simplest structure possible in order to optimize power and efficiency of the model (Twisk, 2003). GEE is considered relatively robust against the choice of the working correlation structure (Twisk, 2003). The crude model was an unadjusted model (model 0). Model 1 was adjusted for age (centralized around the mean), gender, marital status, educational level, status of employment, and household size. Model 2 expanded Model 1 with country of residence and Model 3 additionally adjusted for exercising behaviour. Model 4 additionally included mutual adjustment for the other health outcomes. To study potential interaction, interaction terms between providing personal care and covariates age, employment status and exercising behaviour were separately added to Model 3. Small differences in sample size occurred depending on the valid values for all the variables included in a given model. All analyses were conducted using IBM SPSS 20.

Results

At baseline, gender was almost evenly distributed (Table 1). Most participants were between 50 and 69 years of age, were married or living together in a household and were mostly low educated and retired. About 12.7% stated to give personal care, which increased to 15.3% in the second wave. Poor self-rated health was reported by 23.5%, while EURO-D scores indicating depression were reported by 21.7% and approximately one-third (33.6%) reported poor physical health (Table 2). There were moderate, but statistically significant correlations between the original scales of the three health measures (Spearman's rho ranging from 0.37 to 0.46). In waves 2 and 4, the prevalence of poor health increased to 35.0% for poor self-reported health, 24.9% for poor mental health and 45.1% for poor physical health. In all waves and for each health measure, the percentage of unhealthy participants was largest among caregivers.

Table 3 shows that provision of personal care was associated with poor self-rated health in the crude model, but in the adjusted models the association was no longer significant. The crude association between providing care and poor mental health (OR = 1.47, 95% CI = 1.27–1.72) attenuated after adjusting for socio-demographic variables, but remained significant even in the fully adjusted model that included self-rated and physical health (OR = 1.23, 95% CI = 1.04–1.47). Furthermore,