Health Policy 119 (2015) 1459–1471

Contents lists available at ScienceDirect

Health Policy

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

Informal dementia care: Consequences for caregivers' health and health care use in 8 European countries

Patrick Bremer[a,*], Esther Cabrera[b], Helena Leino-Kilpi[c], Connie Lethin[d], Kai Saks[e], Caroline Sutcliffe[f], Maria Soto[g], Sandra M.G. Zwakhalen[h], Ansgar Wübker[i], on behalf of the RightTimePlaceCare Consortium

[a] *University of Witten/Herdecke, Alfred-Herrhausen-Straße 50, 58448 Witten, Germany*
[b] *Hospital Clínic de Barcelona, Spain*
[c] *University of Turku, Finland*
[d] *Lund University, Sweden*
[e] *University of Tartu, Estonia*
[f] *The University of Manchester, United Kingdom*
[g] *University Hospital de Toulouse, France*
[h] *Maastricht University, The Netherlands*
[i] *Rheinisch-Westfälisches Institut für Wirtschaftsforschung, University of Witten/Herdecke, Germany*

ARTICLE INFO

Article history:
Received 18 July 2014
Received in revised form
23 September 2015
Accepted 30 September 2015

Keywords:
Dementia
Informal care
Caregivers' health
Health care utilization
Europe

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.

---

[*] Corresponding author. Tel.: +49 2302 926 579.
E-mail address: patrick.bremer@uni-wh.de (P. Bremer).

http://dx.doi.org/10.1016/j.healthpol.2015.09.014
0168-8510/© 2015 Elsevier Ireland Ltd. All rights reserved.

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 did not 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 a 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.