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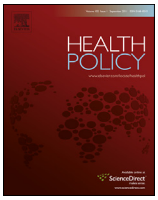

Informal and formal care: Substitutes or complements in care for people with dementia? Empirical evidence for 8 European countries

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ABSTRACT

Background: In order to contain public health care spending, European countries attempt to promote informal caregiving. However, such a cost reducing strategy will only be successful if informal caregiving is a substitute for formal health care services. We therefore analyze the effect of informal caregiving for people with dementia on the use of several formal health care services.
Study Design: The empirical analysis is based on primary data generated by the EU-project ‘RightTimePlaceCare’ which is conducted in 8 European countries. 1223 people with dementia receiving informal care at home were included in the study.
Methods: Using a regression framework we analyze the relationship between informal care and three different formal health care services: the receipt of professional home care, the number of nurse visits and the number of outpatient visits.
Results: The relationship between formal and informal care depends on the specific type of formal care analyzed. For example, a higher amount of informal caregiving goes along with a lower demand for home care services and nurse visits but a higher number of outpatient visits.
Conclusion: Increased informal caregiving effectively reduces public health care spending by reducing the amount of formal home care services. However, these effects differ between countries.

1. Introduction

The simultaneous decline in mortality and birth rates which cause Europeís population to grow older also leads to

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an increase in the proportion of elderly with extensive care needs. Estimates indicate that the number of these dependent individuals will nearly triple from around 101 million in 2010 to 277 million in 2050 [1]. At the same time, around 50 percent of those people in need of care are estimated to suffer from dementia [1]. Dementia is a complex neurodegenerative disorder that affects cognitive, mental and functional capabilities and results in a high dependency on care and assistance of those affected by the disease. Given the fact that the prevalence of dementia increases almost exponentially with older age, European health care systems will face a considerable higher demand for long-term care during the next decades [1].

Although, rising health care costs are an issue that policy makers have debated for more than two decades, the tendency described above goes along with a growing concern of expanding public expenditures on long-term care services in the future [2]. Therefore, in some European countries policy has encouraged informal caregiving in order to reduce public health care spending [3–5]. However, it needs to be taken into account that the strategy of enhanced incentives for informal caregiving in order to ease the financial pressure upon the public purse is feasible only if the assumption holds that informal caregiving is an effective substitute for formal care. This indicates that to formulate adequate long-term care policies a clear understanding is required as to how the provision of informal care affects the use of formal care services.

Comprehensive literature documents that two different relationships between formal and informal care can be distinguished. Both types of care can either substitute or complement each other. The empirical analysis of the relationship between formal and informal care is not straightforward to assess as the provision of care by family members might be endogenous to the care recipientsí (CR) formal health care use. Because of the complex nature of both types of care, previous studies do not definitively establish whether formal and informal care substitute or complement each other. E.g. Van Houtven and Norton [6], Bonsang [7] and Bolin et al. [8] found that informal care is a substitute for formal home care and paid domestic help respectively, whereas Liu et al. [9] and Langa et al. [10] ascertained that the increased paid home care in the US primarily went to people who were already receiving a greater amount of informal care from their adult children. Mixed evidence also was found regarding doctor and hospital visits in general: Some studies indicate that informal care is a complement for both [e.g. [8]] and others found a negative relationship between informal caregiving and both doctor and hospital visits. On the other hand, for outpatient surgery and nursing home entry, the relationship is unambiguous: previous findings clearly suggest that informal care complements outpatient surgery [6,11] and substitutes for (or at least delays) nursing home entry [12,13].

However, considerably less is known about the relationship of both types of care in the specific case of dementia caregiving. In general, previous studies indicate that both formal and informal care increases with dementia severity and that once a certain degree of severity is reached, informal care is replaced more and more by formal care services [14]. Furthermore, analyzing data from patients with dementia in Spain and Sweden respectively, Peña-Longobardo/Oliva-Moreno and Wimo et al. found that informal care substitutes for paid domestic help and complements the utilization of day care facilities [15,16].

Although the studies mentioned above delivered consistent results for two different European countries, there is substantial evidence of cultural and hence institutional differences between Northern and Southern European countries, which cause the outcomes of healthcare provision for people with dementia (PwD) to differ tremendously across Europe [17–20]. Particularly with regard to informal dementia caregiving, previous studies suggest a significant north-south gradient within Europe. Bremer et al. for example, found a negative association between the amount of informal caregiving and caregiversí health status in northern and central parts of Europe, whereas no such relationship was observed in Southern Europe [21]. Moreover, a higher preference for receiving informal care was reported in southern regions of Europe and variations were found in the relationship between informal care provision and labor market participation in different European countries [22]. Generally, countries in the south of Europe are commonly described as countries with stronger family ties, suggesting that norms regarding family responsibilities and inter-generational support are more pronounced compared to more northern or central European countries – which the contrary often are referred to as having less distinct family ties [23].

In the specific case of informal dementia caregiving, such a comparison between several European countries is to our best known not available. Therefore, in this paper we analyze the effect of informal dementia caregiving on the use of several formal health care services (the receipt of professional home care, the number of nurse visits and the number of outpatient visits), with special emphasis on differences between European countries.

The remainder of the paper is structured as follows: section two gives a brief overview of the data source, discusses some econometric issues regarding the relationship between formal and informal care, and describes the empirical strategy. Section three presents the empirical results, section four discusses these findings and section five offers some conclusions.

2. Data and methods

2.1. Data source

The empirical analysis is based on primary data obtained from a large European research project called ‘RightTimePlaceCareí (RTPC). RTPC is a prospective cohort study conducted in eight European countries which can be assigned to more northerly (Estonia, Finland and Sweden), the southern (Spain), and more central areas of Europe (France, Germany, the Netherlands and England). Data were collected by face-to-face interviews between November 2010 and April 2012. The dataset contains comprehensive information about PwD and their informal caregivers. A detailed description of the study’s rationale and its methodology can be found in Verbeek et al. [24].