

# Family caregivers burden of patients with chronic diseases

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- Family caregivers
- informal caregivers
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- burden identifiers
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Under the influence of the past decade's social, technological and economic developments Greece has been undergoing a period of important demographic changes. The birth deficit, immigration and the increasing life expectancy have changed the country's aging structure profile. The population pyramid is based on an aging population and the trend does not show any signs of reversal. At the same time, under the influence of medical technological developments and the changing lifestyle, a transformation of the disease model towards an increase of chronic diseases is taking place. Greece's health system is unable to cope with the increased nursing needs of chronic disease patients and as a result home caregivers have taken on more serious responsibilities on top of performing their daily duties.<sup>1,2</sup>

According to data of the Hellenic Statistical Authority one in two people, over the age of 15, has declared suffering from chronic illness.<sup>3</sup> As Biegel has suitably asserted "given that no person lives in a vacuum all the consequences of a chronic illness are being borne directly or indirectly by his immediate environment meaning the family".<sup>4</sup> As stated by the Organization for Economic Co-operation and Development (OECD), at least one in ten adults is engaged in the informal unpaid care of friends or relatives saving up and underwriting the gaps of the national health system. The existing bibliography suggests that the role of the home caregiver is most frequently assumed by other family members (mostly spouses, children, siblings and grandchildren). To a lesser extent other relatives and friends also take the role of the home caregiver although they seldom take full care responsibilities. It is the social framework, religious beliefs and the cultural context that are usually putting the family in the role of the informal health carer.<sup>5,6</sup>

The main impact of informal home care- with only a few exceptions- has been to place emotional and physical burdens to the home caregivers but also social and financial ones. Serious consequences on mental health have also been observed such as depression, anxiety disorders, drugs and other substances abuse as well as in physical health with cardiovascular diseases, infections, malignant tumors and ultimately deaths. The literature also mentions some positive effects such as development of self-esteem, companionship, pride, and satisfaction. Patient features on the one hand, such as their age, functional level, as well as traits of their caregiver, such as gender, age, nationality, educational level, working status, income, care giving time, the existence of social support or the reciprocity of relation-

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ships and their state of health, all seem to be involved in the manifestation of the burden.<sup>7-10</sup>

In an attempt to record the burden of family caregivers of chronic patients hospitalized in the pulmonary clinic of the General Hospital of Serres, we performed a cross-sectional study involving 100 family caregivers of patients with one or more chronic diseases, of whom others were admitted to the Pulmonary Clinic and others went to regular outpatient clinics of the General Hospital of Serres. The Zarit Burden Interview questionnaire was used to measure the burden, while the Katz and Lawton questionnaires were used to rank patients' functional level. At the same time, demographic data of patients and their caregivers were also recorded.<sup>11,12</sup>

Based on the sampled data, we observe that family caregivers of patients with chronic illnesses experience a moderate to severe burden. After applying a multivariate linear regression, it was found that caregivers with self-reported low personal incomes, lower self-reported overall health status, who care for a patient with reduced functional ability and older age are experiencing a greater burden degree.

The results highlighted the magnitude of the problem of the burden of family caregivers of patients with one or more chronic illnesses with or without dementia. The moderate to severe burden found in our study is confirmed by a number of studies in the literature.<sup>13-17</sup>

As the health system in Greece and other countries increasingly transfers responsibility to families of patients with chronic illnesses burdening them both financially and socially and psychologically, support actions are required. Health policies with the social network of health services need to organize strategies and interventions such as home care by professional caregivers who can at the same time teach skills and techniques to responsible relatives, handing out care allowances, and providing caregivers with periods of respite along with a transfer of accountability to official health structures or voluntary organizations at regular intervals to prevent or minimize the impact of the burden on this group of people and protect their quality of life.

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