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THE IMPACT OF INFORMAL CAREGIVERS DURING CANCER PATIENTS' TRAJECTORY IN ECONOMIC HEALTH OUTCOMES

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ABSTRACT

In the trajectory of the person with cancer, the presence of uncontrolled symptoms are the main and frequent cause of demand for health services, which increases with the advanced stage of the disease. The modernization of health systems advocates the domiciliation of health care, with proximity assistance, where informal caregivers assume a role of relevance. Persons with cancer prefer this typology of service, as well have positive impact in economic health outcomes. However, it is essential to reflect in the shapes of the professional support, health policies and incentives, which are needed with the finality to prevent burnout of the caregiver. As ensure the resources to certify the self-care and quality of life of the person with cancer and informal caregivers.

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INTRODUCTION

Globally, in 2012, there were 14.1 million new cases of cancer, 8.2 million life losses were caused by it and 32.6 million people lived with cancer (Ferlay *et al.*, 2013). At the same time, more than 14 million new cases will emerge every year in the world, where the number of people with cancer is expected to triple by 2030, as a result of survival (WHO, 2014). Survivors continue to experience significant physical limitations compared to those without a history of cancer, namely with increased fatigue (56%), pain (35%) and insomnia (30%) (Zucca *et al.*, 2012). The presence of symptoms persists permanently, due to the direct adverse effects of cancer, treatment, exacerbation and / or the emergence of new ones associated with relapse or second

cancer (Brant *et al.*, 2011). The cancer survivor experiences different magnitudes of symptoms, at different stages of the disease, with negative effects on quality of life, functional status and self-care. The end of life is reported as a period of increased incidence, intensity of symptoms and emotional distress (Dyar *et al.*, 2012). In the trajectory of the person with cancer, the presence of uncontrolled symptoms is the main and frequent cause of demand for health services (Xiao, 2010). Shi *et al.* (2011) reported that 1 in 4 cancer survivors experienced severe symptoms one year after diagnosis, even when the adjuvant treatments were finished. If the symptoms are not sufficiently controlled, it is not possible to perform the usual daily activities of daily living, since the capacity for self-care

is compromised (Boveldt *et al.*, 2014). The literature identifies the inadequate symptomatic control with negative impact on the different dimensions of human living: 1) quality of life; 2) functional status; 3) perception about health status; 4) cognitive function; 5) sexuality; 6) effective coping mechanisms; 7) comfort; 8) use of health services (Xiao, 2010; Shi *et al.*, 2011; Ripamonti *et al.*, 2012). So, it determinate the need for professional nursing care to respond to cancer-induced imbalance, as the support and participation of the informal family caregiver in controlling suffering and promoting well-being becomes essential. The economic value of informal care represents about 50-90% of the total costs of long-term care in the Member States of the European Union (Ferrer, 2015). The total number of people providing some form of care could reach 125 million across Europe. The estimated annual value of services rendered by the care of relatives, only to the elderly, is estimated to amount to \$ 375 billion, and 78% of adults in the community that continue to need long term care, depend of primary source of help (their friends and family) (National Alliance for Caregiving and Evercare, 2007).

Most care provided to people with dependency is not remunerated, however this economic value is considered as a spine column of long-term care. According to the report of the Social Protection Committee and the European Commission (2014), Member States should reshape health policies for greater support and monitoring of informal family caregivers, as well as recognition of their importance. However, the analysis of the impact of informal family caregivers on the reduction of health costs cannot be dissociated from its long-term effects (Krol, Papenburg and Exel, 2015). There is a correlation between the level of dependence of the person with cancer and the burden of caregivers, with repercussions on the quality of life, which may lead to the early institutionalization of family members. The process of care delivery is considered complex, arduous and dynamic, as it is characterized by constant variations over time, being influenced by the needs of the person and by the feelings of the one who provides and who receives care (Sarmiento, Pinto and Monteiro, 2010). Informal caregivers experience more overload, depression, anxiety, and physical health problems compared to non-caregivers of the same age (Davis *et al.*, 2011). For Life After Care (2010), caregivers present not only a greater deterioration of their health status, but also face loss of income, time to leisure and breakdown of relationships.

The future of care systems will require new models and / or reform of existing systems, requiring structured support for informal caregivers. Given that there is a remnant part of the health care that is ensured by the respective network of family and friends. According to Doty (2010) two out of three (66%) elderly people with dependency receive long-term care at home. These care is exclusively provided by their family caregiver, mostly women and daughters. Thus, when analyzing the economic repercussion of caregivers, it is essential to pursue protection and incentive policies at different levels, such as the caregiver's allowance, the co-payment to the person with care needs, tax and other additional benefits, paid leave, unpaid leave, flexible work arrangements, free training and education, respite care and counseling.

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