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Review

The care of the informal caregiver's burden by the Spanish public system of social welfare: A review

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ABSTRACT

This work analyzes the public social services system developed in Spain to attend dependent persons and their informal caregivers, examining in a more detailed way the current capacity of the Spanish public In-Home Help Service (HHS) to meet the demands of dependent elderly persons and its impact on their informal caregiver's burden. We begin with a brief introduction of the services by the Spanish public social services system developed to attend dependency; next, the evolution of the Spanish public HHS is described in a thorough way to identify the pros and cons of this service regarding the informal caregivers' burden of dependent elders. Finally, recommendations are proposed to redesign and restructure this public in-home service to lessen the informal caregiver's burden.

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1. Introduction

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We begin with a brief introduction of the services by the Spanish public social services system developed to attend dependency; next, the evolution of the Spanish public HHS is described in a thorough way to identify the pros and cons of this service regarding the informal caregivers' burden of dependent elders. Finally, recommendations are proposed to redesign and restructure this public in-home service to lessen the informal caregiver's burden.

1.1. The Spanish public social services system to attend dependency

Dependent people are persons who, due to the lack or loss of physical or psychological autonomy, require significant assistance or help from others to perform daily activities (Council of Europe, 1998). In Spain, the public social services system has developed different services to deliver care to dependent elderly people and support to their caregivers; namely, assisted-living residences, day centers, HHS, and telecare.

The following are definitions for these four types of care (MTAS, 2005; Garcés et al., 2006): (a) assisted-living residences are "centers designed as a stable, community home for elderly persons who have dependency and social problems which prevent them from continuing to live in their own homes. They offer support for

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activities of daily life, health supervision, rehabilitation programs and holistic geriatric care"; (b) day centers are "centers for the outpatient treatment of elderly, dependent persons who have social or family support allowing them to remain in their own homes at night and/or during part of the day. They offer catering services, help with personal hygiene, functional and cognitive rehabilitation, medical care, adapted transport and leisure activities"; (c) the HHS, which provides "personal help and/or specific housekeeping services to individuals (elderly people, disabled persons, etc.) whose personal independence is restricted or who are undergoing a personal or family crisis"; and (d) telecare, which is "an emergency service for elderly persons with health risks who live alone, consisting in a device that connects the user by telephone with a help center".

Therefore, the HHS is the only publicly provided and funded in-home service available in the Spanish public network of general social services to provide respite for informal caregivers of dependent elderly people.

In the majority of European countries, the first HHS began to appear in the post-war period of World War II, mainly in the North countries, Great Britain and the Netherlands, due to the triumph of the ideas about the Welfare State advocated by Beveridge and Keynes and in a broad context of social security (Godfrey et al., 2000); in Spain, HHS began later than in the other developed countries. Spain's delay to join the European Welfare model was mainly due to political issues and the family organization of Spanish society which involved assuming the informal support of the problems related to dependency. In general, the outset of HHS can be found in the formation of the first democratic City Halls, which took place with the local elections in 1979, although its extension in the entire Spanish territory would not be effective until well into the 80s (IMSERSO, 1990). Since then, it has undergone important growth (DGASMF and FEMP, 2000; IMSERSO, 2003).

1.2. The development of the Spanish HHS

The public HHS was specifically created to provide personal home-based care as well as psychosocial support to family members and relatives in the environment of the dependent patient's home (Rodríguez, 1997; Garcés, 2000; Garcés et al., 2006). Specifically, the services of the public HHS are quite varied and can be grouped into the following categories: (a) personal care services (basic care associated with activities of daily living and other activities such as companionship and night surveillance, conversation and active listening, and walks); (b) domestic services (activities associated with housekeeping such as shopping, preparing meals, cleaning, laundry, and ironing, etc.); (c) psychosocial support services (stimulating the dependent person's activity, their engagement in social relations and social contact using behavioral change and social skills techniques); (d) family support services (strengthening family cohesion and scheduling, briefing, training, stress management, and other sessions for informal caregivers); (e) local environment services (day-to-day activities inside and outside the home in connection with the user's lack of mobility such as errands, accompanies person on visits, support to keep a medical appointment); and (f) complementary help (home repairs or adjustments, installation of technical apparatus or aids, home meals or laundry service, inter alia) (Rodríguez and Sancho, 1999; Defensor del Pueblo et al., 2000).

The public HHS services are mainly run by the Local Authorities that negotiate the delivery of the service with an agency, such as a co-operative society or non-profit organization, under an arrangement whereby the Local Authorities regulate the terms of delivery and select the beneficiaries (DGASMF and FEMP, 2000). Although the design of the public HHS care seems extensive and is intended to address the multiple needs of dependent patients and their caregivers, in reality, its operation is quite different.

Under the HHS, clients basically receive household services and the intensity of the service does not usually exceed 5 h on 1 or 2 days per week (MTAS, 2005). Furthermore, a recent Spanish study which examined the Spanish public HHS basic and instrumental activities of daily life assistance to users suggests that HHS help provided by the service is not sufficient in type, number, or weekly activity needs met and that the assignment of care tasks seems to be indiscriminate and made with no prior evaluation of dependency needs. Accordingly, this study showed that the HHS almost exclusively provides grooming and housekeeping services, possibly due to the fact that their auxiliary staff's lack of training causes them to perform the chores with which they are most comfortable and what they typically do for their families (Carretero et al., 2007).

In fact, the Spanish public HHS is provided by workers (HHS helpers) with a low level of training and in-home care qualifications (DGASMF and FEMP, 2000; MTAS, 2005). Training for HHS helpers in Spain continues to be provided by vocational training courses and modules that are not registered as formal training by the Ministry of Education and Science, and is usually given by the service agency or the Local Authority running the service without any accredited training programs or standardization. In addition, helpers are usually women with low qualifications who have entered employment for the first time through this service (IMSERSO, 2005).

Furthermore, although the HHS is a service focused on groups with social and economic needs such as minors and the disabled, people aged 65 or older are usually its greatest beneficiaries (IMSERSO, 2003; OPM, 2004). The users of this service are: 85% elderly adults, 9% disabled, 5% dysfunctional families with children, and 1% other users (IMSERSO/FEMP, 1998).

The growing demand in social services for dependency care resulting from demographic and epidemiological changes has generated a rapid increase in the social resources allocated to dependency care in Spain in recent years (MTAS, 2005). In fact, between 1995 and 2003 public spending on dependency care increased from 0.23% to 0.32% of general national product (GNP), which means a 7.6% annual increase in that period. This growth is mainly due to the social services promoted by the Autonomous Communities. Although this volume of expenditure is not very significant compared with the total volume of social and healthcare expenditures, it represents substantial growth compared with the overall reduction of spending on social protection, which declined from 23.2% of GNP in 1995 to 20.2% of GNP in 2003, and the freeze of public healthcare spending at 5.4% of GNP since 1997. For example, official data reports that the number of users of the public HHS has increased almost sixfold in the period from 1990 to 2004, from 40,728 to 228,812 elderly people. Specifically, the public social service that covered 0.76% of all Spanish elderly individuals in 1990 now covers 3.14% of this population group (IMSERSO/FEMP, 1998; MTAS, 2005).

Although these figures are encouraging, they represent a setback in comparison with the projected 8% coverage foreseen in the Spanish Gerontological Plan for the year 2000 (IMSERSO, 1993). They also appear relatively low compared to those achieved by other European countries. For example, the average European HHS coverage for elderly people is equivalent to 12% (De Andrés, 2004), although it is higher in countries such as Norway (17%) and Finland (14%) and Austria and Denmark, where it surpasses 20% (Jacobzone, 1999; Casey et al., 2003).

Currently, it is unlikely that the public HHS will reach levels of coverage similar to those in other European Union countries in which there is universal coverage, because access to social services in Spain is a limited right based upon income eligibility criteria.