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Original Paper

# eHealth Services for Family Caregivers of Dependent Elderly People: An Exploratory Spanish Case Study

Trinidad Carrión<sup>1</sup>, MSc; Manuel Armayones<sup>2</sup>, PhD.

<sup>1</sup>Department of Nursing, University of Málaga, Spain

<sup>2</sup>Department of Psychology and Sciences of the Education, Open University of Catalonia, Barcelona, Spain

**Corresponding Author:**

Trinidad Carrión, MSc  
Department of Nursing  
University of Málaga  
Paseo de Martiricos s/n  
29071 Málaga  
Spain  
Phone: +34 952137009  
Fax: +34 952137064  
Email: [trinicar@uma.es](mailto:trinicar@uma.es)

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**Abstract**

**Background:** In Spain, the person mainly responsible for the care of elderly dependents at home is still the woman of the house. Although her social and cultural profile hardly favor her integration within the society of information and knowledge, the services afforded by eHealth may be a valuable tool for two reasons; to attain a level of information necessary for them and to enable them to care for themselves and the other members of the family more effectively. **Background:** In Spain, the person mainly responsible for the care of elderly dependents at home is still the woman of the house. Although her social and cultural profile hardly favor her integration within the society of information and knowledge, the services afforded by eHealth may be a valuable tool for two reasons; to attain a level of information necessary for them and to enable them to care for themselves and the other members of the family more effectively.

**Objectives:** To examine the possibilities for help that Internet can provide to those looking after elderly dependants and evaluate the suitability of the eHealth services aimed at the requirements of family caregivers, in order to propose improvements for the better use of these services.

**Methods:** We undertook a qualitative research project in two phases: A. Ethnographic needs study of the requirements of family caregivers by means of in-depth interviews and observation (10) and discussion groups (3). B. Study of the eHealth services for family caregivers of elderly dependents using Google searches and reviews of the web sites selected (10). **Methods:** We undertook a qualitative research project in two phases: A. Ethnographic needs study of the requirements of family caregivers by means of in-depth interviews and observation (10) and discussion groups (3). B. Study of the eHealth services for family caregivers of elderly dependents using Google searches and reviews of the web sites selected (10).

**Results:** The family caregivers studied had important requirements concerning information, education and support related with the care they give to other members of their families, with their own care and with the use of information technology and internet. The few web sites for family caregivers of elderly dependents mostly provided health information poorly related with their needs.

**Conclusions:** At the present time, eHealth services fail to provide much help to Spanish family caregivers of elderly dependents. A series of strategies needs to be developed to enable persons involved in social and health care to benefit from the advances in information technology and communication and abandon their digital isolation. **Conclusions:** At the present time, eHealth services fail to provide much help to Spanish family caregivers of elderly dependents. A series of strategies needs to be developed to enable persons involved in social and health care to benefit from the advances in information technology and communication and abandon their digital isolation.

**KEYWORDS**

eHealth services; family caregivers; digital marginalization; information development

## Introduction

The invisibility of women's role in the health care of their families has resulted in the official health care system not taking into account this informal system within the family. This situation is not exclusive to Spain but is, in fact, common all around the world. It depends on the current situation of each social group regarding the transformation process of the roles traditionally assigned to men and women.

In Spain, with the development of Primary Care established by the General Health Law of 1986, Health Services, including community nurses, started to examine the needs of families with dependent persons due to age or illness. Currently, Family Care forms part of the services offered by the Spanish National Health System.

The aging of the Spanish population and its forecast for the next few years, as well as the social and cultural context within which it is developing, require that health services offer Spanish families a more efficient social and health care service, addressed at both the dependent elderly and their family caregivers. To this end, the Spanish Government has recently passed a Bill for the Promotion of Personal Autonomy and Care of Dependent Persons, commonly referred to as the Law of Dependency. Once Parliament passes the Bill, the new and much needed National System of Dependency will be established.

According to the latest available data [1], life expectancy within the Spanish population is 80.5 years, 83.8 years for women and 77.2 years for men. The number of persons of 65 years of age or older has doubled in the last 30 years, representing 16.62% of the total Spanish population, with 7332267 people. Moreover, the old now live longer. The population aged 80 years or over has doubled in the last 20 years, and now accounts for 4.31% of the overall population, with 1903219 people, and the projection for 2016 is 2723716 persons in Spain and 25967790 persons in the 25 countries of Europe [2].

The aging of the population increases the need for social and health care, both for elderly persons with a disability, who represent more than 30% of all persons aged over 65 years [3], and for all those who, due to their age, require some assistance to carry out their activities of daily living.

According to research undertaken by Gfk Emer Ah HOC Research for the Institute for the Elderly and Social Services (IMSERSO) on the care received by elderly persons living at home, 633685 Spanish homes have at least one family member who provides care to an elderly person. The average number of caregivers per home is 1.5, and it is estimated that there are 950528 family caregivers in Spain. This represents 6% of the population over 18 years of age who care for 1226181 elderly people, of whom 95% have some disorder [3]. Women account for 83.6% of all family caregivers of elderly dependents [4].

The social profile of the family caregiver making up the basic support of Spanish Welfare is the following: Woman – average age between 50-60 years, though often older – With no job or else had to stop working – Dedicating over 40 hours per week to the care of the dependent person – With economic difficulties

– Almost exclusive responsibility for the care, and difficulty maintaining social relations – Has worked as the caregiver for many years and expects to keep doing so – With multiple disorders, especially weariness, deficiencies, sleeping disorders, back pain and, frequently, depression – With no time or opportunity to take care of herself – And feels afraid for her own future [5].

The extra work caring for dependent persons, defined as the degree to which the caregivers perceive that their own health, social life and economic situation has changed just because of their role caring for a member of the family [6], has negative consequences on the health and the quality of life of these family caregivers.

The care provided by the family caregivers is hard and varied. It ranges from household tasks, such as cooking, cleaning and ironing, and daily activities, such as shopping, and managing the economy and the health care, to carrying out the special care required by the older family member, according to the level of dependency. The combination of sustained stress, the physical demands of caring and the greater biological vulnerability in older caregivers, may increase their risk for health problems and, therefore, death [7].

Looking after the family caregivers who care for aging dependents is a social responsibility that should be approached from the strategic framework of Health Promotion and with a gender perspective. In fact, within the Spanish National Health Care System, Primary Care professionals, mostly community nurses, attend and support the family caregivers, although this care is still not sufficient or systematic.

Scientific evidence from the emerging Information and Knowledge Society has shown the effect of the Internet-based interactive health communication programs (IHCP) on persons with chronic disorders. The Cochrane review of research in these programs suggests that IHCP have a considerable positive effect on the knowledge, perceived social support, health behavior and clinical results. The results indicate that IHCP probably have a positive effect on self-efficiency, though it was not possible to determine the effects of IHCP on emotional or economic results. In the section on implications for research, and regarding the family caregivers, the authors concluded with the following questions: Can IHCP benefit them?, if so, in what way?, what results may be affected?, if IHCP can benefit the caregivers, how do they do so?, what are the most important characteristics of IHCP regarding the benefits? [8].

With the dual purpose of contributing to the increase in the level of health and the quality of life of the family caregivers and to their development in information technology, we attempted to determine whether the eHealth services offered to the Spanish population meet the needs of the caregivers of elderly dependents; and if not, what actions and strategies should be implemented to meet those needs. Accordingly, we undertook a qualitative study of the possibilities of care that are or could be provided by the Internet to caregivers of elderly dependents, with the following objectives:

1. Identify the needs of those family caregivers studied.

2. Select the web sites offering services to family caregivers of elderly dependents.
3. Assess the suitability of the eHealth services selected in relation to the needs of the family caregivers studied.
4. Propose improvements in the optimization and systematization of these services.

## Methods

To achieve these objectives, we used a two-phase qualitative research project:

**A. Ethnographic needs study of the family caregivers**, using the following techniques:

1. In depth interview with special attention to the level or meaning of the comments: semi-structured interview, from one to one and a half hours duration, of 10 female caregivers aged 39-58 years old, recruited by the snowball technique. The script of the interview was designed to identify: biographical characteristics, the profile of the dependent person, care given, information needs, training and support, as well as ways to meet these needs, internet accessibility and uses of eHealth.
2. Participant observation to assess the family environment to reinforce the data obtained at the interview.
3. Discussion groups, in order to identify and prioritize the problems expressed by the caregivers and the assistance they require. Three sessions of five participants each were carried out, moderated by expert personnel. The 15 participants were women aged 34-60 years, chosen through institutional support programs for family caregivers.

**B. Study of eHealth services for family caregivers of elderly dependents**, using the following strategies:

1. A search in Google using the key words “cuidador familiar y anciano” (family caregiver and elderly) of at least 10 web sites that fulfilled the following criteria. Inclusion Criteria: Web-site in Spanish, containing a section for the caregiver which was indicated on the main page. Exclusion Criteria: web sites with no authorship, advertising of courses, congresses and other products, scientific publications, job advertisements, press releases, personal pages and blogs.
2. A review of the selected web sites with extraction of the following data: Web site name, Internet address, audience, type of content (information, training and support for caregivers), topics covered and their sources.

## Results

### Family Caregivers

The ready availability of all the caregivers involved to express their experiences resulted in the collection of excellent extensive information, gathered between February 2005 and January 2006.

Once transcribed and analyzed, the information was classified as:

- Need for information and training relevant to the care-giving provided, their own care, social and health care resources, and the use of information communication technology (ICT). (Table 1)
- Need for support for alternative care services, Relation with self-help groups, and Communication with social and health care professionals. (Table 2)
- Problems expressed by the caregivers and the assistance they require. (Box 1)
- Access to Internet and Uses of eHealth.

**Table .** Need for Prioritized Information and Training

#### 1. Care they give:

- 1.1. Basic nursing care, according to the level of dependency of the ill person.
- 1.2. Problems presented by the ill person they treat related with signs and symptoms of the disease and the aging process.
- 1.3. Solutions to the social and health care problems.
- 1.4. Alarm symptoms of the disease and Prevention of social and health care problems.

#### 2. Self-care:

- 2.1. Knowledge and acceptance of the role of Family Caregiver.
- 2.2. Postural hygiene and physical exercise.
- 2.3. Techniques for coping with stress, relaxation and communication.
- 2.4. Management of time.

#### 1. Social and health care resources:

- Social and economic assistance from different public organisms and private entities.
- Guides from Mutual Support Associations and Volunteers.
- Mutual Support Groups on Internet.

- 3.4. Current legislation regarding Family Support and the services offered by the Formal Healthcare System.

#### 1. Use of ICT:

- Computer skills.
- Internet skills.

- 4.3. Economic aid for use of ICT.

**Table .** Support Needs**1. Alternative Care Services:**

1.
  - Partial assistance in care-giving
  - Program for Family Relief.
  - Units for daytime and nighttime stays.

1.4. Fast services for prescriptions, consultations with social and health care professionals, appointments,...

**1. Relationship with self-help groups:**

- Advertising of existing self-help groups within the Caregiver environment.
- Encourage participation in self-help groups.

2.3. Creation of new self-help groups.

**1. Communication with the social and health care professionals:**

- Training workshops for the Caregivers.
- More time with the social and health care professionals.

3.3. More frequent home visits by these professionals.

**Table .** Textual Quotes from the Discussion Groups**Main problems of the Caregivers**

“I do not know anything about the illness and care of my relative”  
 “I do not know how to care for him/her. I feel very insecure”  
 “When something happens to him/her, I think it is my fault”  
 “I cannot assume his/her illness”  
 “It is too much work for me alone”  
 “There are many things to attend to at the same time”  
 “I have no patience”  
 “I get more and more tired”  
 “I have no time for myself”

**Main help requested**

“More help from my family, without having to ask for it”  
 “Learn about my relative’s illness”  
 “Teach me how to take care of my relative”  
 “Psychological help”  
 “Daytime and nighttime centers for the elderly”  
 “More nursing workshops on “Caring for the caregiver”  
 “Facilities to carry out bureaucratic formalities”

Of the 25 women studied, only eight had a computer at home, four with an internet connection. Only two of all the women had used internet at some time to look for health-related information

**Web-Sites**

The key words “cuidador familiar y anciano” (family caregiver and elderly) produced approximately 45800 results in Google

in a search carried out in March 2006. Of all these, 990 were visited to be able to select 10 web sites with the relevant inclusion and exclusion criteria. After the review of each web site selected, the following data was obtained and classified into spanish websites (Table 3) and websites translated into Spanish (Table 4).

**Table .** Spanish Websites

Websites	Type and Content	Information Sources
Web-site for the elderly. Institute for the Elderly and Social Services. Ministry of Labor and Social Affairs <a href="http://www.imsersomayores.csic.es">http://www.imsersomayores.csic.es</a> For geriatric professionals and general consumers	Informative: <sup>1</sup> GI: Scientific Legislation and Information. <sup>2</sup> SI: Self-care. Planning care-giving.	GI: Connection to Medline and other scientific and institutional sources. SI: Own elaboration without authorship.
Eroski Foundation <a href="http://mayores.consumer.es">http://mayores.consumer.es</a> For general consumers	Informative: GI: Very varied topics of an informative and commercial character. Aging diseases. SI: Self-care. Planning care-giving.	All Information: Own elaboration without authorship.
Spanish Society of Geriatrics and Gerontology <a href="http://www.segg.es">http://www.segg.es</a> For geriatric professionals and general consumers	Informative: GI: Scientific Information in Geriatrics and Gerontology. SI: Role of the Caregiver. Self-help. Assistance. News.	GI: Connection to Cochrane plus and other scientific and institutional sources. SI: Own elaboration without authorship. Many related links
Spanish Alzheimer Foundation <a href="http://www.fundacionalzheimeresp.org">http://www.fundacionalzheimeresp.org</a> For members of the family of persons with Alzheimer's disease	Informative: Summary of the scientific information about Alzheimer. Relevant legislation. The role of the caregiver. Self-help. How to treat the patient. Existing help. Support for the Caregiver. Forum. Medical practice.	Own elaboration with references from scientific publications. Related links.
Pharus Innovaciones S.L. <a href="Http://www.todoancianos.com">Http://www.todoancianos.com</a> For the elderly and the general public	Informative: GI: Commercial news and information. SI: Role of the Caregiver. Alzheimer's disease. Support: search engine for Residences. Forum. Medical consultation. EShop.	Own elaboration without authorship. Press releases.
Portal Alzheimer Online <a href="http://alzheimer-online.org">http://alzheimer-online.org</a> For the families of patients with Alzheimer's disease	Informative: The role of the Caregiver. Alzheimer's disease. How to care for the patient. Legal information. Support: Medical consultation.	Own elaboration and related links.

<sup>1</sup>GI: General Information<sup>2</sup>SI: Specific Information for Caregivers**Table .** Websites translated into Spanish

Website	Type and Content	Information Sources
Caregiver New Jersey <a href="http://www.state.nj.us/caregivernj/site_map_sp.shtml">www.state.nj.us/caregivernj/site_map_sp.shtml</a> For Family Caregivers	Informative: Role of Caregiver. Self-help. Resources and help available.	All the information: Own elaboration without authorship.
Yale Medical Group <a href="http://ymghealthinfo.org/content.asp?pageid=P03695">http://ymghealthinfo.org/content.asp?pageid=P03695</a>	Informative: The Role of the Caregiver. Social and health care resources via links.	Own elaboration without Authorship.
Elder Services <a href="http://www.eldercare.org/InfoSpanish/SP_Main-Page.shtml">http://www.eldercare.org/InfoSpanish/SP_Main-Page.shtml</a> For the elderly, disabled and their caregivers	Informative: Only announcement about the services for elderly people and family caregivers from Somerville-Cambridge Elder Service.	Own elaboration without authorship.
Family Caregiver Alliance <a href="http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=545">http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=545</a> For the Caregivers of dependent people	Informative: The role of the Caregiver. Social and health care resources. Recommended reading. The role of the Caregiver. Legal information.	Own elaboration and other legal documents based on scientific publications. Related Links.

## Discussion

In the ethnographic needs study, what most surprised us during the field work was the digital isolation of the family caregivers we studied. These women mostly live outside the digital world, do not understand it, and furthermore do not even plan to; they only speak of computers and Internet when asked about it, even

those caregivers who had at some time consulted Internet to obtain health-related information. Primarily, they consider the use of Internet to be very costly and, secondly, that computers are difficult to handle and that the information they need is difficult to find on Internet.

The caregivers studied value highly the workshops "Caring for the Caregiver" given first hand by community nurses. In general,

the caregivers appreciate and are very much aware of all the attendance activities at which they can interact with social and health care professionals, such as nurses, psychologists, social workers and doctors.

The results of the study also suggest that all those needs concerning information and formation about the care given by caregivers, their own self-care, social and health care resources available and the use of ICT could potentially be covered by Internet, either synchronously or asynchronously. Likewise, certain support needs could also be resolved online via eHealth services.

However, our study of eHealth services highlighted the lack of visible web sites in Spanish aimed at family caregivers and the important presence of web sites translated from English, which accounted for 40% of the sites selected. Regarding the content of these sites, the answer to our first research question is that they do not respond to the requirements identified and are not suitable to cover them. Accordingly, the caregivers have little stimulus to start their association with Internet and the use of eHealth. The content of eHealth services should respond to the needs of the expected audience. We consider this to be a specific criteria of quality for each consumer group that should be incorporated by the web site accreditation agencies, as suggested by Gagliardi and Jadad [9].

As family caregivers begin to find answers on eHealth services to their real needs, Internet may become a valuable tool for

information, education and support for their activity of caring and their self-care. Internet may then help the caregivers to reach self-efficiency, considered according to each person's abilities, and help them to organize and execute their work in a manner that best suits the situation [10]. As Castells aptly comments, citizens generally tend to make an instrumental but not very ideological use of Internet: they use it for what it can give them [11].

For eHealth services to be useful to family caregivers and for these to use it, besides fulfilling a code of behavior accredited by a recognized body, the services should be designed with the participation of the very persons they aim to reach, in this case family caregivers. This could thus be another quality criteria to consider: participation of the end-users in the design of eHealth services. Our study population has much to say on their needs, after such a long time being invisible and, consequently, neglected.

In Spain, the National Health System is making great efforts to raise the quality of life of family caregivers, providing the support required for the hard job they perform and encouraging their self-care. These efforts might increase their efficacy and penetration capacity if they were to be completed with good eHealth services brought together under one Gateway for Family Caregivers, together with Digital Literacy Programs. As Eysenbach said, bridging this digital divide and bringing consumer eHealth services to those with the greatest need for them will be particularly challenging [12].

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## Conflicts of Interest

None declared.

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