



**“RING”**  
**TransferRING Supports for Caregivers**  
**LLP-LDV-TOI-09-IT-0446**

## **RING -TransferRING Supports for Caregivers**

### **WP 1 NEEDS FEASIBILITY ANALYSIS**

### **FINAL REPORT**

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**Abstract:**

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### Introduction

The improvement of living conditions, although not equally distributed, is the main reason underlying the current ageing phenomenon worldwide. Europe is particularly affected by this global trend as it is the most aged continent of all the regions of the world: on average 17% of the 501 million Europeans is aged 65 or older. In the case of the countries taking part in the RING project, there is great variability: Italy, 20.1%, Spain, 17.0%, Rumania, 14.9% and Turkey, 7.0% (Eurostat, 2010).

Ageing implies both an individual and a social dimension, thus the changes in the individual and those in the social structures are currently in the policy and research spotlight.

Moreover, ageing does not imply disability or dependency, but it does bring along frailty and the probability of suffering from what is called age-related diseases. One of these diseases is dementia.

Dementia is an acquired syndrome of decline in memory and other cognitive and brain functions sufficient to affect daily life. Alzheimer's disease (AD) is the most common form of dementia. AD is a neurodegenerative disease that causes impaired cognitive functioning. Up to date, there is no known cure for AD. The disease develops through stages that may vary in length, and symptoms may overlap. Patients can suffer for up to 20 years from first symptoms until death. This makes AD a very socially complex disease as it affects the patients' families and surrounding people for such a long period of time.

The prevalence of dementia increases with age. It is estimated that prevalence doubles every five years after the age of 65 and that nearly 50% of those aged 85+ have AD.

Currently, Alzheimer's Disease International estimates 30 million people have dementia in the world, most of them living in developing countries (66%). Moreover, 4.6 million new cases are expected to happen annually to reach 100 million people with dementia in the year 2050.

According to the European Community Concerted Action on the Epidemiology and Prevention of Dementia Group (EURODEM study), people with dementia in Europe are estimated to be 5.5 million.

Another trend linked to ageing and increasing of the prevalence of dementia is migration. Europe has transformed from a land of emigration to a destination of immigration. In fact, around 31 million people in Europe live in countries where they were not born in (Eurostat, 2010). This situation varies from country to country.

The more aged people there are, the more the prevalence of dementia increases and thus the need of more extra care for very old people and people with dementia. Care giving has become a market niche for many immigrant workers in Europe.

Many of these workers face a situation they were not trained to deal with. Care giving is both a rewarding and exhausting process. The RING project aims at identifying the training needs of care givers and developing training tools to fill the gaps they have.



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This report reviews the situation of care givers in four countries: Turkey, Romania, Italy and Spain. It highlights the main statistics, the legal framework and the available resources.

Secondly, a requirement analysis of care givers’ needs on training is carried based on the results of a survey conducted in the four countries aforementioned. Both informal and formal care givers answered a specifically designed questionnaire. Professional trainers and health practitioners were surveyed, too.



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# 1. SITUATION OF CAREGIVERS IN TURKEY

## *1.1 GENERAL FEATURES AND DEMOGRAPHIC DATA OF TURKEY*

Turkey is located at the meeting point of ancient three continents. This specific location enables Turkey to be a part of different contexts such as Europe, Caucasus, Middle East, the Balkans, and Mediterranean. All the interactions between these different contexts strongly effect Turkey’s political, economic and social structure. Republic of Turkey’s economy stands upon industrial operations since 1960s. Although this transition from agricultural based economy to industrial economy has effected Gross National Product (GNP) in a positive way (R.T. Prime Ministry - State Planning Organization, 2007), Turkey still has a place behind the European Union countries (Turkey’s General Features). Turkey is divided into 81 individual provinces which are ruled by central government.

The latest census has been done in 2008 and the results show that consistent to the world trends Turkey’s population is growing older. According to the results of 2009 census Turkey has a total number of 71.517.100 citizens. The ratio between males and females is similar (R.T. Prime Ministry- Turkey Statistics Institution, 2008).

After the transition from agricultural economy to industrial economy there were a large number of internal immigrations in Turkey. According to the governments data approximately 2 million people has immigrated to the industrially well developed western cities in 2000. Consistent to these data 2008 census shows us that 75% of Turkish citizens are located in city centers, and 25% is located in rural areas. These results also show that approximately 18% of Turkey’s population (12.697.164 people) lives in Istanbul (R.T. Prime Ministry- Turkey Statistics Institution, 2008).

By the year of 2008 6.8% of Turkish population is above 65 years old (approximately 5 million people). The ratio of other age groups is as 26.3% for 0-14 and 66.9% for 15-64 ages (Fig 1).



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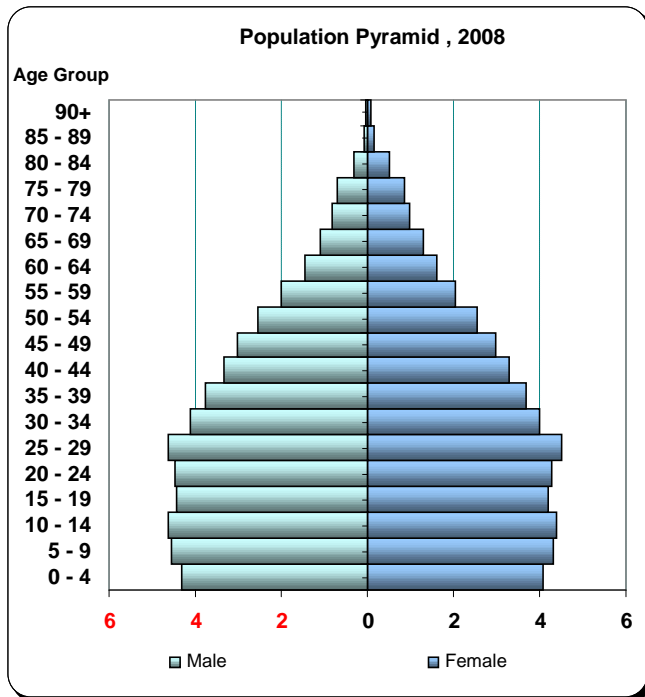


Figure 1. Population Pyramid, 2008

Data about the education level of Turkish citizens in 2008 shows that approximately 40 % of people aged above 65 are illiterate. Only 2% of elderly people have a university degree or above. Data about the marriage status of people aged over 65 shows that approximately 60% of elderly people are married and 36% of them have lost their spouse (R.T. Prime Ministry- Turkey Statistics Institution, 2008).

### 1.1.1 Demographic data of resting - nursing homes and day-care centers in Turkey

Turkish legal system regulates all the activities in elderly care under 4 different regulations and these regulations define 4 different types of institutions for elderly people. These institutions and their qualifications are defined as following:

- 1. Resting Home:** Legal regulation defines “Resting home” as a social service institution which is established with the aim of protecting, giving care, and meet the psychological, social needs of the elderly people aged over 60 in a peaceful environment (R.T. Prime Ministry, Social Services and Protection of Children Department, 2001).



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2. **Nursing Home:** nursing homes provide services for elderly people who need special care due to their disorders such as Alzheimer’s disease, dementia, stroke, etc. which requires special care. Elderly people demanding these services should have a report which indicates that it is proper for elderly person to live in an institution. These care services can be given in an institution or a part of the institution can be regulated appropriately to these caring requirements (R.T. Prime Ministry, Social Services and Protection of Children Department, 2008).
  
3. **Day Care Center:** This regulation notes that “**“a day care service”** will be provided to healthy elderly people who live with their family, relatives or alone and who has dementia or Alzheimer’s disease in order to improve life spheres, qualify spare times, help to meet social, psychological, and health needs, give vocational consulting, support for the daily life events which cannot be met by their own opportunities, enrich their social relationships by regulating social activity groups consistent to their interests, raise their activities, improve the life quality by providing support and share with the other family members (R.T. Prime Ministry, Social Services and Protection of Children Department, 2008).”
  
4. **Home Care Service:** In the same regulation it is noted that “**“home care services”** will be provided to elderly people who have complete mental and psychological health, do not need medical care or do not have any disabilities, under the conditions of insufficiencies of family and other support elements (relatives, neighbors) caring services, in order to enhance their life spheres and support their daily life activities (R.T. Prime Ministry, Social Services and Protection of Children Department, 2001).” According to this definition dementia patients or elderly people with other disabilities can not receive any kind of home care services by governmental institutions (R.T. Prime Ministry, Social Services and Protection of Children Department, 2008).

Resting and nursing homes in Turkey are managed by either government or other institutions. State’s resting and nursing homes are under the management of Prime Ministry’s Social Services and Protection of Children Department. There are 81 resting – nursing homes with capacity of 8126 residents of this state department.

Other nursing-resting homes are belonging to different types of institutions as private, minorities, and associations- charitable institutions. Most of the resting – nursing homes belonging to minority groups are serving to the non-Muslim members of the society. Total number of these resting – nursing homes is 154 with capacity of 8485 (R.T. Prime Ministry, Social Services and Protection of Children Department, 2010). In table 1 there is a distribution of capacity depending on type of institution.



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<b>Table 1</b> <b>Distribution of capacity depending on type of institution.</b>		
<b>Institutions</b>	<b>No. of Resting-nursing homes</b>	<b>Capacity</b>
State institutions	81	8.126
Associations-charity institutions	33	2.659
Minorities	7	991
Private institutions	114	4.826
<b>Total</b>	<b>235</b>	<b>16.602</b>

The centers under the name of “Elderly Service Centers” work in four different cities which are at the western part of the Turkey. Numerical data about these centers are shown in Table 2.

<b>Table 2</b> <b>Numerical data about elderly service centers</b>			
<b>ELDERLY SERVICE CENTERS</b>	<b>MALE</b>	<b>FEMALE</b>	<b>NO. OF MEMBERS</b>
ANKARA EMEK YHM	29	159	188
ANKARA MAMAK YHM	56	44	100
ÇANAKKALE YHM	23	169	192
İZMİR NEBAHAT DOLMAN YHM	64	324	388
ESKİŞEHİR YHM	12	-	12
<b>TOTAL</b>	<b>184</b>	<b>696</b>	<b>880</b>

## ***1.2. GENERAL CONDITIONS OF ELDERLY IN TURKEY***

During the history of Turkish nation elderly people has a respective position in society. In the first centuries Turkish people believed in shamanism in which elderly people are



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the leaders of the society due to their wisdom and experience through life. After acceptance of Islam by Turks same attitude towards elderly people remained (Turkey’s General Features). However in the recent years industrialization and urbanization processes have affected Turkish society deeply and changed general trends in family life. Elderly people are affected by this change excessively; they started to lose their position in family. As a result of this industrialization process extended families are replaced with immediate families. By the year 2006 80,7 % of Turkish families are immediate families while the ratio for extended families is 13 % (R.T. Prime Ministry, Turkey Statistics Institution, 2006).

In recent years general attitude towards institutional care is slowly changing yet the society still discourages taking a parent to an institution in their senility. Excluding metropolitans (such as Istanbul, Ankara, Izmir etc), in other city centers and rural area society plays a crucial role in obstructing people to apply to a resting home for their parents. Most of the people think that this behavior is unacceptable. The researches made in 2006 shows that only 9.3% of Turkish citizens think that they would spend their senility in a resting home. 55 % of Turkish citizens think they will be taken care of by their children when they become old, and 17,8 % consider having care at their homes (R.T. Prime Ministry, Turkey Statistics Institution, 2006). Researches made between elderly population of Turkey shows that important part of elderly people thinks that their children are responsible for their care. 56 % of elderly women and 27% of elderly men consider their children as responsible for their care.

Society’s attitude towards senility care determines life spheres of elderly people in Turkey. Most of the elderly people are living with their children in the same house or they live in a close district. Researches have shown that 70 % of elderly people live either in the same house or in the same building, street or neighborhood with their children (Turkey’s General Features). This kind of life style of an elderly is much more beneficial for a senior than living in a resting home. Having a close relationship with the other family members help elderly to protect old social status, provide social stimulation, and have independency.

### 1.2.1. Turkey’s political perspective on elderly (legal rights of elderly)

Turkish legal system gives the responsibility of the issues about elderly people to **Social Services and Protection of Children Department (Sosyal Hizmetler ve Çocuk Esirgeme Kurumu – SHÇEK)** which is subordinate to Republic of Turkey Prime Ministry. General frame of the SHÇEK’s obligations towards elderly people is defined in the law as:

- To overcome social, moral, and physical deprivations
- To support prevention and analysis of social issues



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- To provide social services for enhancing and promoting life standards in a systematic and programmed way

The duties of this institution can be summarized under two titles: 1- to provide determination, protection, care, nurture, and rehabilitation of children, disabled people and elderly people who are deprived. 2- guidance to associations and charity organizations in their support programs, determine the standards for all Social Service Institutions, investigate these institutions and stop activities of the institutions if they are insufficient in providing these standards. The first title covers the activities which are going to be held for elderly people by the state, and the second part covers the management and investigation activities for non-governmental services.

First part of SHÇEK’s legal obligations for elderly people is defined as following activities in the law:

- Arrangement, pursuing, coordination and investigation of the services about determination, care and protection of the elderly people who are socially and economically deprived.
- Establishment of resting homes and similarly qualified institutions with regard to the needs and areas.
- Planning, applying and performing of the activities about dissemination of these institutions.
- Provide arrangement and performing of the activities about protection of elderly people in society (R.T. Prime Ministry, Social Services and Protection of Children Department, 2001).

The second part of SHÇEK’s duty focuses on the relationship with non-governmental services for elderly people. The law gives SHÇEK the duties of

- Shaping activities of associations and charity organizations in social services
- Leading these institutions for providing appropriate and effective use of their financial resources of social services
- Determining standards of establishment, financial rules and performing activities for social service institutions.
- Investigating these social service institutions (R.T. Prime Ministry, Social Services and Protection of Children Department, 2008).

### ***1.3. CAREGIVING IN TURKEY***

#### **1.3.1 General Features of care givers**



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Different definitions made for “care giving” makes it hard to compromise on a common, shared concept of this profession in Turkey. As a matter of fact there is not a word which is correspondent for the “care giver”, different people choose different words for the people who are working in this are. All this terminology confuses everybody’s mind and makes it impossible to find a precise, appropriate work definition. This ambiguity about the concept of care giving is the most important obstruct which is preventing formulation of a profession in this field.

General tendency of the society is to see this profession directly related to hospital care regardless of age. In recent years, the need for elderly care either in institutions or at homes enforced people to reconsider this definition of care giving. Yet, people still have neither a common definition nor common terminology in this area.

Care giving job was not accepted as a profession which requires certain skills, capabilities and education till recent years. However increasing need and growing career opportunities in this area have changed society’s perspective on care giving profession in recent years, especially in the western part of Turkey. Unfortunately Turkey does not have sufficient formal and vocational training in this field; also most people do not aware of the training opportunities.

Thus the need is tried to be met with care givers that comes from other countries, especially countries from former Soviet Union countries such as Moldavia, Ukraine, etc. and Middle Asian Turkish countries such as Azerbaijan, Uzbekistan, etc. It is impossible to find a scientific data about the number and qualification of these care givers because most of them are working unregistered. These Asian or Balkan care givers are chosen by the families because they cost less than Turkish ones due to their unregistered working process.

Another problem mentioned by the professions in this field is the paucity of people who are eager to work in this field. Compared to institutional care service, it is much harder to find caregivers for home care. Turkish society’s prejudgments about working “inside of the home of somebody” obstruct to find professions in this field.

### 1.3.2 Training programs for care givers

Training programs for care givers are given either by universities under the department of Vocational School of Higher Education or by some training courses ruling by Ministry of National Education or municipalities.

Akdeniz University and Sakarya University have a department named “**Elderly Services Care**” under the universities’ **Vocational School of Higher Education** parts. these universities are located in Antalya (southern part) and Sakarya (near Istanbul). This department started vocational education in the year 2005. Total 80 students



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graduate from these 2 universities per year. Total duration of the education is 2 years and there is compulsory internship in each program ((Akdeniz University, 2010;Sakarya University, 2010).

General definition of their program is to train professionals who are capable of handling the elderly person with health and social aspects of care, integrating all the skills, knowledge and values of care services, and being qualified of applying and developing elderly care service.

Many different disciplines are effective on defining the content of the lectures in this department. There are medical lectures such as Basics of Gerontology, infectious diseases, physical rehabilitation etc. Also there are social lectures such as Behavioral sciences, sociology social services etc.

Training courses conducted by The Ministry of National Education is given in each region of Turkey. These training courses are not organized on a calendar; organization of them is based on demands of the citizens. If 12 people apply for this course, the ministry finds out a qualified trainer and organizes a course in the city. Training program is consisted of 11 chapters and involves 130 hours of training. This training program's general aims are

- Identifying general features of elderly people
- Skills for daily care of elderly
- Having skills for physiotherapy and occupational therapy
- Being capable of supporting the elderly in bed or out of bed
- Being informed about monitoring medication and nurturing of the elderly
- Being informed about first aid (R.T. National Education Ministry, 2010).

One of the departments of Istanbul Metropolitan Municipality ISMEK (Istanbul Occupational Training Courses) also organizes a training course for elderly care. The training course aims to gain people knowledge and skills about the social, physical and psychological needs of elderly people, communicating with elderly people. The course consists of 150 hours of theoretical and 1250 hours of practical training.

Also there are some other training courses that are given by different municipalities all over Turkey. The total number of people who have attended to this education and the effectiveness of these courses are still unknown. Because these educational activities have started just a few years ago and data about these professional care givers have not been collected and processed yet.



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### 1.3.2. Legal arrangements for caregivers

There are 4 different regulations in the elderly care system and each of them has different contexts. The work definitions and standards of care giving are defined as following:

#### **1. Regulation for resting homes of Social Services and Protection of Children Department (Sosyal Hizmetler ve Çocuk Esirgeme Kurumu – SHÇEK)**

This regulation encompasses resting homes of SHÇEK. This regulation explains staff working in a resting home as doctor, manager, assistant manager, social service worker, psychologist, nurse, physiotherapist, technical staff and assistant staff. This regulation does not mention any special staff for care giving; the responsibility of the care of the elderly belongs to nurses. Regulation just mentions that nurse assistants are obligated to help nurse in their work (R.T. Prime Ministry, Social Services and Protection of Children Department, 2001).

#### **2. Regulation for Private Resting and Nursing Homes**

This regulation encompasses private resting and nursing homes. Private resting – nursing homes are obligated to have a care giver and the duties of care give are defined as:

- Doing all physical care activities, support their nurturing in case of need
- Supporting elderly in the organization of room
- Supporting in meeting social and physical needs
- Informing super ordinates about the changes happened in elderly person’s activities

Regulation states that 1 caregiver should be employed for 10 healthy and 6 special care needed elderly people. Regulation also states that care giver should have either a degree of a vocational training from universities or a certificate from a training course (R.T. Prime Ministry, Social Services and Protection of Children Department, 2008).

#### **3. Regulation for Establishment and Management of Resting Homes of Governmental Institutions**

This regulation encompasses resting – nursing homes of municipalities, and other governmental institutions excluding SHÇEK. According to this regulation care givers are responsible for care and cleaning activities of the nursing home. 1 caregiver is needed per 15 elderly people. Care givers are obligated to have a degree of primary school education (R.T. Prime Ministry, Social Services and Protection of Children Department, 1987).

#### **4. The regulation for the day care at elderly service centers and home care services**

This regulation encompasses all day care centers and home care services of governmental and non-governmental institutions. The definition of care giver is same as the one in the Regulation for Private Resting and Nursing Homes. Regulation states that



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1 care giver for an elderly at home care, and 1 caregiver for 20 elderly people in day care center is required (R.T. Prime Ministry, Social Services and Protection of Children Department, 2008).

**Summary**

7% of Turkish population is aged over 65 and the ratio of them gets higher every year. Care giving profession for elderly will be needed more in following years. Yet legal arrangements and training opportunities are not sufficient for meeting these demands. Thus special studies should be handled about informing, training and making legal arrangements for care giving.

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## **2. CAREGIVERS NEEDS IN ROMANIA**

At the worldwide at the end of last year were 30 million people affected by Alzheimer’s and that number is expected to grow. Everyone is exposed to the risk of developing Alzheimer’s in old age, but there is a risk if there were similar cases in the family.

In Romania there are 300,000 Alzheimer’s disease patients and their number is growing. Most of the times the family takes responsibility for them, because special homes are not enough and extremely expensive.

By 2025, it is estimated that the number of persons with dementia will increase to around 600.000 in Romania (WHO). With the increasing prevalence of dementia, issues of competency have become very important. Issues of competence are fundamental to informed consent in research and the care of demented people. Society is equally interested in maintaining the autonomy and well-being of its aging citizens as well as protecting them from risks and dangers caused by their declining capacities.

### ***2.2. The organisation of social support for people with dementia and carers***

The Ministry of Labour, Social and Family Solidarity is responsible for social support to people with dementia/dependent elderly people. Since entering the European Union, several projects have been started which involve collaboration between the State and Non Governmental Organizations(NGO) which apply to be partners for structural funds with the intention of developing day care centres and **memory** clinics.

A new law (Law 448) has been passed which regulates the rights and obligations of handicapped people in order to promote their social inclusion and integration. The methodological norms for Law 448 are not yet available.

At the national level it was found Romanian Alzheimer Society (1992), member of the organization Alzheimer disease International and of Help Age International Network for Eastern Europe and Central.

Under the auspice of Romanian Alzheimer’s Society was develop a lot of activities for sharing the information about Alzheimer in every part of our country the country information that the disease is called dementia, with the entire suite of problems that it brings can be seen in Romania.

The Romanian Alzheimer Society has six branches in the country and there is a continuing concern as their numbers grow. Company subsidiaries develop programs with the same parent company. Day care centres are in Timișoara and Piatra Neamț. Those interested are given the information for this condition, it plugs up the case, is granted telephone consultations.

Main branches are in:



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- Bucharest
- Piatra Neamț
- Timișoara
- Brașov
- Cluj
- Constanța

The main activities develop are:

- Establishing a relation with local authorities
- Day center
- Developing the program for educate the people who take care the patient with dementia
- Community Information Center

Alzheimer Associations receive support from the State for set periods of time, usually several years. This support, which tends to be provided by the local authorities, consists of designated places for day care centres where the cost of utilities (e.g. water and electricity consumption) is borne by the local authorities. Therefore, the Alzheimer Society has not had to pay for utilities or rent.

### ***2.3. Romanian legislation***

Romania’s legislation is in keeping with principles set out by the WHO and international legislation concerning the protection of people with mental illnesses.

The most important principles derived from these documents are: respecting the human dignity, recognizing equal civil rights with the others persons, warranting the medical care and treatment and the social, professional and familial rehabilitation. The legal rights, financial and other personal interests of patients with mental disorders must be protected. According to the Madrid Declaration art.4, the psychiatrist should discuss with the family and, when appropriate, seek legal counsel in order to safeguard the human dignity and the legal rights of the patient when he/she is unable to exercise proper judgement due to mental disorder. All psychiatrists face situations where compulsive interventions are required to safeguard the patients and/or those surrounding him/her.

#### **Laws**

- Law **487** - 8/8/2002 Law on Mental Health and Protection of People with Mental Disorders
- Law **448** - 6/12/2006 - this law regulates the rights and obligations of handicapped people in order to promote their social inclusion and integration.

#### **Decrees and regulations**

- *Order MSF 726* -24/10/2002 Criteria for establishing the degree of handicap for adults and application of the measures of special protection
- *H.G. 1764* -28/12/2005 Updating of the social allocation for blind adults and of the



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- monthly fee granted to adults with a severe handicap other than blind people
- *Order of Ministry of Public Works 649* 25/4/2001 Approval of the norms concerning the adaptation of civilian buildings and urban space for the special requirements of handicapped people
- *Order SSPH 79* - 29/7/2002 - Approval of average monthly cost for maintenance of handicapped people in institutions of special protection
- *H.G. 329* -4/4/2003 - Approval of rules, organisational framework, and functioning of institutions for the special protection of handicapped people
- *Order MSF and MMSS - 491/180* - 3/6/2003 - Approval of the grid for the medical and social evaluation of people admitted into assistance institutions for medical and social services
- *H.G. 729* 21/7/2005 - Establishes the amount of money allocated for daily food provided by public institutions of public assistance
- *Order ANPH 205* - 16/8/2005 - Approval of minimal standards of quality for residential centres for adult handicapped people (day care centres and sheltered housing)
- *O.G. 30* - 31/1/2004 - Modification of OUG 170/1999 regarding the gratuity of medical assistance, drugs and prostheses for some categories of people with special needs
- *Order MTCT, MS and MMSSF 216/189/3469* - 1/7/2005 - Approval of methodology and norms regarding the gratuity of transportation by metro and quantum for this gratuity for severely handicapped people and for their personal assistants
- *H.G. 1175* - 14/10/2005 - Approval of the national strategy concerning the protection, integration and social inclusion of severely handicapped people in Romania from 2006 – 2013
- *Order ANPH 367* - 30/11/2005 - Approval of criteria for the selection of projects in the field of protection, integration and social inclusion of the handicapped
- *Order ANPH 363* - 7/12/2005 - Approval of the National Plan regarding the training of personnel from the system of protection of handicapped people in 2006-2008 and the framework for training and specific training of the personnel involved in the protection and care of handicapped adults
- *H.G. 427* - 7/5/2001 - Approval of the methodological norms regarding the conditions for hiring personal assistants, and the rights and obligations of personal assistants of handicapped people
- *H.G. 197* - 1/3/2006 - Approval of the programmes of national interest in the field of protection of the rights of handicapped people and in the field of social assistance of the elderly, the homeless and victims of family violence, as well as the financing for these programmes
- *Order ANPH 175* - 12/12/2006 - Approval of minimal standards of quality for homecare social services for handicapped adults

Some of our patients, particularly older people with dementia, may not be able effectively to represent their interests, manage their affairs or agree what they are suggested. This is particularly problematic for patients who are alone and where there is a conflict between individual and family or carers' interests



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## ***2.4. Particularities in Romania***

In terms of treatment, in Romania, the medication is completely free, but these costs represent only 20% of the total care of a patient with Alzheimer's.

The family is the main supporter of a patient, and the main problems encountered are the lack of community care, the small number of day care centres, counselling centres, the hospital houses, however only 10% of cases resolve

Prevalence in the population is small, about 1%, but it increases the elderly population, or 20% in people over 70 years, reaching 50% in those over 80 years.

Beyond the statistics, although the number of patients is relatively small in our country, when her mother or father is suffering from this disease, maintenance and patient care is a major issue in family life.

In Romania there are currently some private clinics are treating people with Alzheimer's, one of them in Pitești, in Argeș County, with a capacity of 23 seats.

Assistance with housework, shopping and laundry services exist but must be totally funded by the service users. There are no transportation services. Help with the delivery of meals is available and is usually provided by NGOs and the Church. The NGOs are not directly involved in the preparation of meals but they transport food from restaurants and canteens, as well as food packages or food products, to people with dementia from poor families. This service does not function on a regular basis as it is dependent on the availability of funds. The Church also transports food to old people, some of whom have dementia.

The priority objectives for the foreseeable future remain the detection of as many cases of dementia in early evolutionary stages and as early initiation of specific treatment, and increase the level of information among the general population

Prevalence of early diagnosis, the same as all over Europe, is a 3-5 per cent in persons 65 years and it doubles every other five years added to age. The problem is that only 10 percent of patients with Alzheimer's are diagnosed and treated another 10 percent.

### *People living in rural areas*

There are many rural areas where a family doctor is not available, so for minor investigations or a simple medical consultation, the person has to go to the nearest hospital or polyclinic which in some cases is about a hundred kilometres away.

### *People with different types of dementia*

People with different types of dementia have different rights. At this moment in time, only Alzheimer's disease is recognised as a handicap by the commissions assessing handicap for adults. This means that people with other types of dementia cannot be granted the severe disability degree which would entitle them to support and services.

### *People from ethnic minorities*

There is no specific support for people with dementia and their carers from ethnic minorities, they have the same right like the majority.



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*Younger people with dementia*

Access to services and support from the State is dependent on eligibility for the severe handicap category and not on age. Consequently, younger people with dementia can access services (provided that they have Alzheimer’s disease and not another form of dementia) but these services are not necessarily adapted to the specific needs of younger people with dementia.

## ***2.5. The availability of treatments for Alzheimer Disease***

A positive list of medicines to be reimbursed is compiled annually by the Ministry of Health and the National Health Insurance. This list determines which prescription drugs are covered by health insurance funds. The list is based on recommendations from the College of Physicians and the College of Pharmacists.

The reimbursement list applies to inpatients and outpatients. In fact, there are two lists: one containing substances that are 100% reimbursable for people suffering from one or more of a list of diseases (cancer, tuberculosis, diabetes, etc.); the other containing other substances on which the reference price system is applied and of which 70% of the reference price is reimbursed.

With the exception of galantamine, all other anti-dementia drugs are available and reimbursable in Romania.

Treatment initiation and treatment continuation are restricted to specialists only (neurologists, psychiatrists or old age psychiatrists). The National Health Insurance approved guidelines that are in existence in Romania which prescribe a series of examinations that need to be carried out when making a diagnosis (neuropsychological tests, CT or MRI scans and laboratory tests). For Alzheimer medicines to be reimbursed, these tests need to be carried out and included in a medical report.

Until recently, the system did not prescribe any upper or lower treatment limits, but in some areas of the country, the Romanian Alzheimer Society reports that health insurance offices have restricted reimbursement to people with Alzheimer’s disease with an MMSE score over 12.

Although there are no restrictions for people living alone or for people living in nursing homes, the Romanian Alzheimer Society reports difficulties for these people in accessing medication due to a lack of social support.

The survey shows that the impact on the sick person’s family and carers is very important. All segments involved in Alzheimer’s disease management recognize that a person Alzheimer care is difficult, requiring physical effort, morally and financially and that family members feel overworked. Access to treatment is difficult particularly enough funds for free medicines in pharmacies and the limited budget available to doctors for free prescriptions.

### **Certified carers**

There are two types of certified carers (as they appear in the Romanian



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Occupational Code): home carers for people who are ill and home carers for elderly people. They are certified on the basis of Government Ordinance. 129/200 and they are legally certified by the Ministry of Employment. Their training should be organised by providers who have been accredited by the National Council for the Professional Training of Adults.

In the Romanian Job Monitor, issued by the Ministry of Employment, it is specified that a person can become a certified carer after attending a six-month training program. In order to be certified, home carers for people who are ill should attend 720 hours of training, and home carers for elderly people should attend 620 hours of training. This is the longest training in the field. Most people who are interested in it cannot afford to pay for it and the authorities are unable to organise it.

Once they are trained however, they can be hired by different organisations (state social departments, NGOs, private sector) or they can become authorised personnel in the field (i.e. they can be self-employed and pay their taxes). Such training courses are only organised by NGOs within different specific projects and the carers have a chance of being hired afterwards.

Private companies avoid having certified carers because the training period is too long and expensive. Most of the private companies work with untrained personnel; they only recommend “carers” and require a fee from the carer and from the beneficiary. Then the patient or the family illegally pays the carer. Taxes on wages are so high that only rich people can afford to hire a carer legally.

#### **Kinds of home care services available**

Family members complain that there are no specific home care services for people with dementia.

Available services include:

- State services – described above
- Services offered by NGOs – most of them are specialised in elderly care; some of them even refuse to offer services to people with dementia
- Private services – they offer home care for people with dementia but they do not have trained staff even if there are specific accreditation regulations

#### **Types of care**

Home care

There are several laws which relate to home care services (but only medical services). There are also laws regarding people with handicaps which also cover people with dementia.

There are two laws regulating the activity of personal assistants i.e. Law 519/12.07.2002 and Romanian Government Decision no. 427/2001 regarding the approval of Methodological Norms for working, rights and responsibilities of personal assistants for people with handicaps.

Medical home care services are provided on the basis of contracts signed between the National Health Assurance Company and people or organisations



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accredited to provide such services, by GPs or specialists who recommend medical home care, taking into account the state of health of the person in need (who must have a health assurance) and the person's dependency grade. There are 3 dependency grades: totally dependent, partially dependent and independent.

All Romanian citizens who have a health assurance can access medical home care but only for 56 days per year (art. 2, annex no.27, order.1220/24.12.2003). In the past, people were entitled to medical home care for as long as it was needed. This was limited to 14 days maximum in 2003 and then extended to 56 in 2005.

A person can apply for medical home care (not for a personal assistant, but for medical personnel – nurses) on the following conditions:

- they have been previously hospitalised for their disease
- the specialist/GP recommends medical home care
- the doctor who made the recommendation has a contract with the National Health Assurance Company
- The medical home care providers (most of them NGOs) should also have a contract with the National Health Assurance Company

Patients are offered a basic medical services package containing 23 types of medical interventions.

#### **Day care**

There are very few day care centres for people with dementia in Romania. A few were opened by the Romanian Alzheimer Society under the PHARE LIEN programme in Nehoiu, Galati, Bucharest and Timisoara but since the local authorities stopped supporting these projects, only the one in Timisoara is still functional. In the past, the State provided the premises and covered expenses for utilities.

There have been several project proposals from local authorities (town halls) to open day care centres but sometimes premises that are initially proposed for day care centres end up being used for other purposes, especially if alternative usage is likely to generate a profit. There is a growing number of project proposals and it remains to be seen in the coming months or years if any of these will be for people with dementia.

There are reports of two further day care centres, partly funded by Dutch organisations and partly by the local council in Bistrita Nasaud County.

There are several day care centres in the country which benefit from the support of the Church but they are for elderly people with social problems and not specifically for people with dementia. Some NGOs have developed day care centre projects but without the support of local authorities (i.e. for premises and utilities), they are unlikely to last for more than a couple of years.

#### **Respite care**

There are no organised services covering respite care at home. However, in rural areas, there have been isolated cases of carers asking their relatives to come and look after the person with dementia for a couple of weeks so that they can have a break or go on holiday.

Sometimes, when carers are no longer able to cope, they try to arrange for the



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person with dementia to be admitted into a psychiatric ward for several days. This is possible if they know a doctor who is understanding and willing to admit the person with dementia for a short time. Private homes exist which accept people with dementia for short periods of time. This usually costs between EUR 600 and EUR 1,400 per month.

#### **Long-term residential care**

Long-term residential care services funded by the State are not specifically designed for people with dementia. Means testing is applied and there may be out-of-pocket payments but property is not included in the calculation of available means.

There are long waiting lists for available places (sometimes over a year) and no social assistants to carry out accurate assessments. To make matters worse, there is a tremendous amount of bureaucracy surrounding applications for places in these institutions. As it is not possible to obtain assistance with the paperwork, this makes the whole process very difficult for carers and virtually impossible for people with dementia.

Private long-term residential homes also exist but they are not specifically designed for people with dementia either.

#### **Palliative care**

Several discrete attempts have been made by NGOs to provide palliative care at home. The Casa Sperantei from Brasov is a good example although it does not just provide this service for people with dementia. Apart from these limited attempts to provide palliative care, there are no palliative care services either at home or in centres.

#### **Monitoring in the home via alarm systems**

There are no tele-alarm systems whereby a person can signal for assistance in case of emergency.

#### **Personal assistance and home help**

##### **Personal assistants**

In order to be provided with a personal assistant, a person has to obtain a grade one handicap certificate. For a person with dementia, the following procedure applies:

1. Diagnosis of dementia from a specialist (psychiatrist, neurologist) and a form describing the evolution and symptoms. The specialist should demonstrate that the patient needs permanent supervision and recommend either the necessity of a personal assistant or institutionalisation in a long-term institution
2. An Expertise Commission for Persons with Handicap will examine the patient and his/her medical documents and will decide on the grade of handicap.
3. The patient or the family should find a person willing to become the personal assistant. The personal assistant will be paid by the local authorities. Personal assistants must complete training programmes offered by local authorities.



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4. The patient’s condition is periodically revised by the Commission.

Personal assistants are considered and treated like staff hired by the local authority. They are paid for 8 hours’ work per day. They have to have a daily schedule and present an activity report every week. Their activity should be monitored by representatives of the Social Protection Departments, but the Romanian Alzheimer Society stresses that this is not always the case.

People who qualify for the severe handicap degree issued by the territorial commissions responsible for assessing adult handicap are entitled to the following services, for which they must nevertheless contribute towards the costs:

1. Assistance with personal hygiene
2. Supervision/assistance taking medication
3. Assistance with eating and drinking
4. Assistance with mobility (e.g. lifting, moving and walking)
5. Assistance with incontinence
6. Assistance with skin care

Services exist linked to companionship and assistance maintaining social activities but the costs must be covered totally by the service users. There are no services for occupational therapy/ergotherapy, assistive devices and home adaptation/transformation.

#### **Psychosocial support and training for people with dementia and carers**

There is no general information service designed to inform people about available services in Romania.

Limited psychosocial support exists for people with dementia and their carers. For example, individual counselling for people with dementia may be offered by psychiatrists but only if they are specifically involved in the field of dementia. Psychiatrists are paid for a maximum of 14 consultations per day and cannot make a separate charge for counselling. Consequently, counselling is only offered by those who are willing to do it freely.

For carers, there are support groups organised by the Alzheimer Society in Bucharest. A token fee is requested from carers attending these groups. The rest of the costs are covered by the Romanian Alzheimer Association.

Training is available for carers. This is partly funded by the State and partly by the carers themselves.

There are no holiday services for people with dementia e.g. either alone, with carers or with personal assistants. Similarly, there are no provisions to enable carers to take a holiday e.g. payment or a substitute carer.



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### **3. CAREGIVERS SITUATION IN ITALY**

#### ***3.1 Epidemiology of dementia in Italy***

Available data on the incidence and prevalence of dementia in Italy remains limited. The most important study is the “ILSA Study” (Italian Longitudinal Study on Aging, Di Carlo et al., 2002)<sup>ii</sup>, started in 1993 with 3,208 individuals ranging from 65 to 74 years, screened with a standardized test for dementia, and re-examined every 5 years to control development of the different types of dementia. This study underlined that the incidence of dementia in Italy is similar to figures in industrialized countries: the average incidence rates were 12.47 per 1,000 persons/year for dementia, 6.6 for Alzheimer’s disease, and 3.30 for vascular disease. Around 150,000 new cases a year are expected. The annual incidence rate for males over 65 was 1.0% and 1.3% for females.

The Italian Superior Institute for Health estimates that in Italy there are currently around 1 million people with dementia and around 3 million of family caregivers involved in caring for their relatives (Ruggeri & Vanacore, 2008). Given the constant aging of the population, we expect that by 2020 we will be seeing 213,000 new cases a year, 113,000 of which will correspond to Alzheimer’s disease.

An extensive and qualitative analysis conducted in Italy in 2007 by the Censis Research Foundation (AIMA Censis) underlined that:

- people with dementia have an average age of 77.8;
- there is a high prevalence of women among persons with dementia, largely due to their longer expectancy of life;
- the majority of persons with dementia live in their own homes: 48.1% live with their spouses and 34.7% with a child or formal caregiver. 7% live in the homes of another family member, particularly their children.

In 2000, the Italian public health system founded the “Chronos” Project (Ruggeri & Vanacore, 2008), aiming to create a unique reference point for the care and cure of persons with dementia. This project involved the creation of a multi-professional unit (UVA: Unità di Valutazione Alzheimer) in all local public health systems for the diagnosis, evaluation and prescription of specific drugs, all approved by the Italian Health System for Alzheimer’s disease: AchE inhibitors and, for the last few months, Memantine. This meant increased UVA activity in all Italian local health systems: as things currently stand, these units are making the greatest number of dementia diagnoses (42%). 37.8% of these diagnoses are made by a multidisciplinary hospital



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team or by a family doctor and 18.2% by a specialist physician (neurologist or geriatrician).

During the evolution of dementia, the needs of affected persons and their caregivers change, hence we could say that UVA is extremely useful in the first stages of the disease. People with dementia subsequently use other types of health and socio-sanitary services: home-based care services, day care centres, hospitals and gerontological centres.

Around 20% of Italian persons with dementia have access to ‘Integrated at-home assistance’: a public service, managed by family doctors and social workers, offering home care and to a certain extent preventing premature institutionalization.

Around 30% of people diagnosed with some form of dementia have access to a day care centre: depending upon the specific socio-economic and cultural context. Health care in Italy varies greatly between the north and the south of the country. Taking this situation into account, we can estimate that around 35% of people living in the North of Italy have access to a day care centre, while the option is only available to 10% in the South.

44.3% of the caregivers caring for people with dementia interviewed by the Censis Foundations stated that, for the time being, public services are sufficient for their needs; while 28.3% were not satisfied with health and social services, due to considering them insufficient for their specific needs. The most important critical situation underlined by caregivers was the lack of information and communication at the moment of diagnosis. Around 64.8% of the caregivers judged insufficient the information received from doctors about the disease, while 76.8% judged insufficient the information received from doctors and other operators about public health and social services.

The second important shortfall lies in home-based services: the majority of caregivers and persons with dementia interviewed considered a home health and social service to be the best option for managing this type of disease. Formal or informal caregivers must receive support from the public system in order to prevent physical and emotional stress often leading to premature institutionalization of the person with dementia.

As far as the cost of dementia in Italy is concerned, the Censis research considers ‘Direct costs’ to be all costs of purchasing goods and services required to manage a person with dementia; and ‘Indirect costs’, rather than a specific expense, to be the time ‘lost’ by informal caregivers when caring for a person with dementia, i.e. time when they could be doing a paid job.

The average annual cost of an Italian person with dementia is approximately €61,000: €14,886.89 in ‘Direct costs’ (UVA, day care centre, home-based health care, hospitalization, pharmacological expenses, informal home care), and €46,019.02 in ‘Indirect costs’: the time occupied by informal caregiving and the lack of remuneration by the ill person. Most direct costs (71.4%) are paid by the family or by the person with dementia; only 28.6% is paid by the public health system.

95% of indirect costs are supported by the caregiver, due to job loss and spending a great deal of time caring for the person with dementia.

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### 3.2 Italian caregivers in ‘numbers’

In Italy, particularly in the last twenty years, in the context of a general ageing of the population, there has been an increase in the demand for assistance within families. These needs are twofold: on the one hand for attending to housework and, on the other, for taking care of a sick elderly relation, especially those with dementia.

The last ISTAT (National Institute of Statistics) research study<sup>2</sup> shows that 5% of the Italian population is over 80, and that those who have turned 100 number over 10,000.

One specific aspect of the Italian culture is the ‘family culture’. Respect for the elderly and for those suffering from illness therefore means that 75-80% of people affected by dementia are cared for at home by a family member. In the majority of cases by a spouse, who is also likely to be elderly, or by a child, particularly a daughter.

Today our country has no specific policy for supporting caregivers. Given that, in Italy, the responsibility for social services lies with the municipalities and the responsibility for health services with the regional government, different initiatives exist at local level. Certain public subsidies do exist, such as the ‘Assegno di invalidità’, which is paid out according to an evaluation of the degree of disability, or the ‘Indennità di accompagnamento’, introduced as a measure to help families with the cost involved in managing the disease. Every region could therefore establish other services or economic subsidies for supporting caregivers.

Changes in family social conditions and working schedules making it more and more difficult to organize life, often make it impossible for family members to perform the necessary duties. The high demand for ‘outside’ help (formal caregivers), which doesn’t seem to reflect a temporary phenomenon but looks likely to rise in the future, is mostly covered by immigrants who work as family assistants. A recent Italian report (Rapporto Caritas e Fondazione Migrantes, 2009), states that the number of people doing this kind of job in Italy stands at around 700,000, of which only 350,000 are in a regular situation under the 2002 Bossi-Fini Law, with 150,000 assistants living with the person for whom they are providing care. Although the majority is women, men are a growing reference point. 13% of these family assistants are aged over 50 years, 29% are between 41 and 50 years and 40% are between 41 and 50 years. The average monthly cost of a formal caregiver is around €819. Thousands of families are now discovering what it’s like to live with a foreigner: 35.6% of these family assistants live in the homes of people with dementia, taking most of the household tasks into their responsibility besides looking after the elderly person: they clean the house, cook meals, take care of basic expenses and general everyday chores. This new form of cohabitation with formal caregivers is causing major changes in our culture. This assistant, often coming from a very different culture, becomes a constant part of our everyday lives, sharing the physical spaces of the house, a great deal of our time and many family habits. The elderly person will have to accept that she/he will not be assisted by a daughter or by a member of the family but by an outsider and particularly by someone who gets paid to do the job. Daughters and

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sons have to become the employers and must act as intermediaries between the elderly parent and the assistant. Overcoming the many difficulties involved in this situation often leads to extraordinary results: often we see how the foreigner provides highly affectionate care, and it's not rare to observe a true feeling developing whereby the alien worker becomes 'one of the family'.

### *3.3 A look at the situation of caregivers in Italy and the Lazio Region*

According to the recent estimates in Italy, Alzheimer's Disease (AD) patients stand at around 520,000. New cases are estimated at approximately 80,000 a year (Rapporto CENSIS). These figures will rise in the future. Considering current demographic trends and the consequent aging of the population, we can predict that by 2020 new cases of dementia will rise to 213,000 per year, including 113,000 attributable to Alzheimer's disease.<sup>3</sup>

Compared to the previous CENSIS (Italian Centre of Statistical Analysis on the Population) survey of 1999, the average age of AD patients has risen: 77.8 instead of the 73.6 registered in 1999.

This figure has therefore changed in comparison to the findings of the previous survey. Particularly, caregivers are mainly aged between 46 and 60 (51.6%), reflecting a higher prevalence of caregivers among patients' sons and daughters, who represent 64.1% of the respondents, (while the spouses/partners amounted to the usual 25.2%). These results confirm previous data that AD patients' carers are mostly relatives of the *female* gender (76.6% women versus 23.4% men). Furthermore, wives take care of their spouses, while female AD patients are mostly cared for by their daughters. We must point out that most of these people have received no training. This percentage is significantly lower than it was in the last survey (from 62.3% in 1999 to 52.6% in 2006), pointing towards a scenario in which reconciling working hours, caregiving and, in many cases, also taking care of the family has become a critical matter in caregivers' lives (30% of cases are women who do not live with the patient).

In Italy, caregivers are usually patients' relatives: this type of assistance is labelled 'informal' in order to distinguish it from the 'formal' care provided by the institutions. The majority of caregivers choose to live at home with AD patients (65%); of these, 78% are women (wives or daughters) between 45 to 60 years old, and most of them either don't work (31.95%) or are housewives (27.9%) (2-7).

Another survey conducted by CENSIS (8) shows that the percentage of female caregivers exceeds 80% at the severe stage of the disease, confirming the eternal female role of caring.

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<sup>3</sup> Di Carlo A, Baldereschi M, Amaducci L, Lepore V, Bracco L, Maggi S, Bonaiuto S, Perissinotto E, Scarlato G, Farchi G, Inzitari D, for the ILSA Working Group. "Incidence of Dementia, Alzheimer's disease and Vascular Dementia in Italy. The ILSA Study," Journal of The American Geriatrics Society 2002; 50:41-48



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On average, ‘caregiving’ time is 7 hours of direct assistance and 11 hours of surveillance, which will respectively develop into 10 and 15 hours as the disease progresses. This runs parallel to the average free time of 15 hours a week in the early stages and 4 hours a week during the more advanced stages. The forms of aid received by the caregiver from their relatives or professional staff are, in 36.5% of cases, surveillance, and 45.9%, personal care.

The family cost of the disease, whether direct or indirect (often the caregiver either chooses to resign from work or get a part-time job), is important. It has a significant impact on their health, psychological conditions and social relationships, often pushing them to use anxiolytics and antidepressants.

Hence, we can see that the pre-existing balance, both personal and relational, is put strongly to the test by the onset and course of the disease, putting a strain on the ability to share and the closeness of family ties.

Beyond this general framework, there are many different types of ‘caregivers’. Some choose to be a caregiver, while others are pushed into doing the task for reasons of necessity or ‘family designation’. The patient’s condition, the caregiver’s personal and health situation and socio-environmental factors necessarily influence the style and quality of caregiving.

CENSIS studies also point towards several types of caregivers. Most at risk of burn-out are those defined as ‘worn out’ and ‘dedicated’, a total of over 50% of respondents, mostly women over 60 years of age, who provide full-time attention to spouses already in the advanced stage of the disease. They receive no help whatsoever, have poor social relationships, a certain amount of conflictual relationships within the family, health problems and suffer from extreme psychological exhaustion.

Another category is that of multi-task daughters (19.1%), working on several fronts besides providing assistance, and who generally do not live with the patient. They feel tired, overloaded with responsibilities, and their continued commitment has a negative impact mainly at the level of psychological and social relations.

The neo-caregiver type and caregiver supports are predominantly family members who deal with monitoring patients who are still relatively autonomous; they therefore experience no major changes in lifestyle; they are usually a son or a grandson of the patient whose age ranges from 21 to 35 and have a modest involvement in monitoring patients still in the early stages of the disease.

A recent retrospective survey was carried out in Lazio Region on 200 caregivers recruited by random selection (Ferrara, Langiano, Di Brango, De Vito, Di Cioccio, & Bauco), focussing on stress, anxiety and depression.

Data on caregivers and their patients were collected using a specific form to assess cognitive, behavioural, functional patient (MMSE, and ADL-IAD) and caregiver stress (CBI). The relationship between stress, depression and disease was assessed by means of a linear regression, logistic analysis revealing the relationship between anxiety, stress and depression and cognitive problems, age and the patient's income.

Data emerging from this study indicate that the quality of life of informal caregivers is closely correlated to the severity of the behavioural disorders and to the duration of the disease. Most of the subjects interviewed had to change many of their own habits to meet



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the needs of patients living with the family. This situation of forced adaptation causes problems not only of an economic nature, due to the expensive care needed by the patient, but also in family life since the entire nucleus has to adapt to the single patient. Hostility towards relatives represents another variable that negatively affects the health of the person who *in primis* takes care of the patient, and this is also a source of stress. The most serious problem concerning the large number of caregivers consistently suffering from anxiety and depression is that this situation stems from the overwhelming responsibilities involved in the role that they have to bear. The burden of responsibility significantly increases in relationship to the complexity of the disease and our study, in accordance with the national and international scientific literature, clearly confirms that the depressive state of the caregiver depends on the severity of the AD, thus demonstrating that the psychological condition, and, therefore, anxiety and depression of the caregiver, are closely related to MMSE, ADL, IADL values, and to the several phases of cognitive and physical deterioration suffered by the patient; as in the case of the depression, the caregiver's condition is also linked to social situations, such as income. However, it has been emphasized that some of the tension between the patient and caregiver stems from the type of relationship that had existed before the onset of AD.

The complexity of the treatment, the constant commitment of the person taking care of the AD patient, as well as the inadequacy of the public service; the consequent effects on emotional and interpersonal relations; the direct and indirect costs of care also play a major role in influencing the social, psychological and physical wellbeing of the caregiver and of his/her family. Caring is held to be very demanding and emotionally involving. The main complaint of caregivers is the lack of support from the Public Health Service. The continuous commitment to caring also leads to health problems and depression with negative repercussions on the family. Summing up, AD should not be considered exclusively as a health problem, but, most importantly, as a social problem. This study highlights and confirms fundamental data: the severity of the disease plays the most important role in re-organization of the family structure in those families that have to take care of patients who are not hospitalized. It has become mandatory to improve public facilities capable of offering valid emotional and financial support, and helping informal caregivers to tolerate the burden of caring, by increasing the quality of the service provided. It is vital to promote interventions capable of reducing the strong impact that the AD patient has on his/her own caregiver; these initiatives should improve the quality of life of the patient. When planning these interventions, the physical, psychological and economic aspects of the patient and his/her caregiver must be taken into consideration. The planning and putting into practice of support interventions, guidance and aid to families could be a valid solution to the loneliness and consequent care burden experienced by the family and the caregiver.

### ***3.4 Integrated services network of Lazio Region and the Municipality of Rome – Italy***

Organizing an integrated network of social and health care services has now become a necessity for effectively dealing with the discomfort of families helping an AD patient.



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This network should be able to take care of the AD patient and his/her family from the moment of diagnosis and throughout the course of the disease.

For some years now, the Lazio Region has been operating a care network providing assistance to patients suffering from Alzheimer and their caregivers. The request for ‘access’ to the network services must be submitted on a form to the Home Care Centre of the Health Services District.

The backbone of the network lies in the 34 Alzheimer Evaluation Units (AEU) existing throughout the region.

46% of all AEUs are to be found in hospitals, 35% are territorial units, 13% are in university campuses and the remaining 6% are in non-hospital facilities (for example, residential care). Hospital AEUs provide normal ward and day hospital services, while territorial AEUs usually operate outpatient activities. The activity most practiced by AEUs is the prescription of atypical neurolytics, followed by counselling, and only 44% of the total (mainly found in hospitals or universities) also offers laboratory tests, neuroimaging and neuropsychological assessment. Only 22% of these AEUs do not perform diagnostic tests.

Other government-run facilities to be considered among the support services available for caregivers of AD patients are:

- Alzheimer’s Home Care (*AHC*), which is offered by all ASLs (Local Health Services) in close collaboration with Home Care Centre (HCC) CAD and general practitioners.
- Another support service is the *ADCC* (Alzheimer’s Day Care Centre). The ADCC offers a semi-residential service to patients diagnosed with Alzheimer’s Disease, with priority for those residing in the ASL RM G (Roman Local Health Centre G); however, the service is also available to specific patients of other Local Health Centres. There are 443 beds for the whole Lazio Region, 11 centres in the Municipality of Rome, one in Guidonia (a province of Rome), and 4 in other provinces of the Region. The specific goals of the ADCC are: planning, implementation and monitoring of programmes for the reactivation of cognitive and motor functions through psycho-sensory stimulation of the patient intended to slow progression of cognitive functions affected by the disease. The ADCC staff consists of both health care professionals (geriatrician/neurologist, nurse, physiotherapist, OTA staff), and social welfare personnel (psychologist/social worker/professional educator, animator, OSS-Social-Health Aid). This service also provides information and support for the families of guests, responding to questions regarding the care of patients and trying to alleviate, through practical advice and suggestions, the burden of caring for a dependent person in addition to the inevitable isolation experienced by the family. Among the services offered by the ADCC (which is open Monday to Friday) to family members (payable and on request) is a shuttle service from their homes to the Centre and back.
- Other structures in the Lazio region are the Ward Units for Dementia Patients of the Alzheimer’s type which are temporary residential facilities where beds are available for the homeless elderly. Here patients can stay for a maximum of



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twenty days per year. On days when the elderly person is a guest of respite care, the service operates as an extension of the Alzheimer’s Day Care Centre. These units are therefore aimed to give families the opportunity to have a period of relief from their daily burden of care. There is currently no accurate census of how many units are operating in the territory nor of how many patients are followed in this way.

The Lazio Region has also published a handbook for family members of patients suffering from AD, in collaboration with the Alzheimer's Association Onlus Rome, with the cooperation of Fatebenefratelli Association for Biomedical Research and Health (A.Fa.R.), the Saint Lucy Foundation in Rome, the Italian Hospital Group and the Geriatric Department Area of the Alzheimer Evaluation Unit of Geragogic Core Training.

The City of Rome, in particular, has activated a hotline serving as a *call centre* and providing information for patients’ families about facilities, specialized hospital services (Alzheimer Evaluation Unit and the like), and structures operating in municipalities and Local Health Service Units (ASL) which they can contact. It also provides support in social and health care (home care and the like), psychological help for patients and their caregivers, and legal assistance in terms of informing them about the laws regarding the rights of patients and their families. Note should also be taken of the efforts being made to develop understanding of the disease for the purposes of improving patient management (training courses, support groups for family members, etc.).

#### **Profile of a Family Caregiver**

In the last five years, in addition to the informal caregiver, emphasis and importance is increasing around the figure of the formal caregiver. The phenomenon of ‘carers’ is a spontaneous response to the inadequate trend of the public sector to provide assistance to the elderly and the aging which has heavily penetrated the national fabric.

In this regard, the Lazio Region has approved the job description and training of the *Family Caregiver*, defining the duration of the training requirements for obtaining a professional qualification and certification of specific skills. This profile includes a training course to acquire the skills needed to respond as well as possible to the needs of persons receiving care. A regional decree requires the standard duration of 300 hours of training in order to issue the certificate of competency and 120 hours of training for the acquisition of scientific competence.

The family caregiver is a figure with practical and operational characteristics, whose activity is aimed at ensuring assistance to self-sufficient and non-self-sufficient people in their basic needs by promoting well-being and autonomy in the family atmosphere in the home. Training the family caregiver is therefore aimed at providing useful assistance to the families of sick persons. Selected applicants to the course are trained in:

- ❖ interacting with the patient and his or her family;
- ❖ guidance in the social and institutional context;



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- ❖ providing care and support, while respecting the patient’s needs and psycho-physical condition;
- ❖ assisting the person in the preparation and intake of food;
- ❖ looking after the hygiene of the different parts of the house.

To help families find and identify qualified family caregivers and to support family caregivers’ professional development and insertion to the job market a National Register of Family Caregivers has been created. This register contains the names of male and female workers who have undergone a training course specifically addressing those who provide family-care and are therefore experts in taking care of the elderly. Adult Italians and foreigners can add their names to this list. In the case of Italian citizens, they should have completed compulsory education; in the case of foreigners they should have a resident’s permit for employment purposes. Two key conditions are indispensable for featuring on the register: the absence of court conviction for any offence related to professional and moral conduct, and having attended a training course with a qualifying final examination in the area of personal assistance or possession of a qualification/professional title related to the area of social and health services with reference to personal care. Names remain on the register for three years and the loss of even one of these requirements means automatic removal of the applicant from the list. This register was created as a result of the project ‘Together we can’, funded by the City of Rome. The main objectives of this project are: to improve the quality of work provided by family caregivers in the home; to provide family caregivers with an opportunity for professional growth and job placement; to facilitate families’ search for trained family caregivers, and to support the elderly through economic help and care. The range of services available to senior citizens is therefore extended and quality-improved, reducing the demand for care of the fragile elderly thanks to providing training courses for family caregivers.

These courses on caring are available to the frail or partially self-sufficient elderly (who must be at least 65 years of age) having employed (or who are about to employ) family caregivers, and wishing to obtain an agreement with the City of Rome allowing the employee to attend, for a period of one year, training courses organized by the Municipality of Rome.

The training courses sponsored by the City of Rome under the project ‘Together we can’ last for a total of 120 hours (60 hours of teaching activity in the classroom and 60 hours of practice and training), are organised for a maximum number of 25 students (who will sit a written examination and an oral test at the end of the course) per course, and are divided into modules, each dealing with different topics related to caring for the elderly.

#### **Training course for formal caregivers provided by the CEPSAG (Centre for the Promotion and Development of Geriatric Care), Catholic University of the Sacred Heart**

This course has been running at the Catholic University of Sacred Heart in Rome since 1999. Students learn the ‘art’ of professionally caring for the non-self-sufficient elderly.



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With an increasingly growing number of courses for domestic helpers, the Catholic University continues to obey its vocation of helping to develop required attitude and motivation and a wealth of theoretical and practical tools corresponding to the specific job profile of the caregiver.

The course includes 120 hours of lectures on the theoretical basics of care and practical training at a ward of the Policlinico Agostino Gemelli, focussing on the development of communication skills with the elderly. Caregivers completing the course and passing an examination are issued with a certificate by the Catholic University of the Sacred Heart, declaring them to have achieved the rank of family caregiver and therefore allowing them to add their names to the Citizen Register of the City of Rome. The training includes a wide range of personal aspects: basic relief techniques, geriatric nursing, medicine, aging concepts, how to prevent falls and bedsores, nutrition and diets for the elderly, how to manage, communicate and relate with the elderly, occupational therapy, personal hygiene and clothing, assistive devices and rehabilitation techniques, the use of drugs, issues related to incontinence, management of domestic emergencies, health, issues of public interest, the cultural and religious needs of the elderly and behaviour in the home.

Until now, 1,581 people have attended the course and passed the final exam. Most of these people are women (84%). The prevailing age group of course participants is over 40 years, in women and men alike, with a smaller percentage falling to the younger age groups. These students came from 42 different nations, mostly from Latin America (48%), followed by Europe (36%) and to a lesser extent, Africa and Asia.

This type of training, initially for people of foreign nationality, was extended to Italian citizens, so much so that, since 2002, the courses are open to all without distinction of nationality. The growing demand for training by Italian citizens is explained by the changing economic condition of the country and by the increasingly urgent need for practical and cultural baggage to ensure a more realistic chance of inclusion in the working world.

Apart from training, CEPSAG promotes another initiative in the shape of a forum on the elderly, which has, over the years, served almost as an observatory on the condition of elderly and as a place for meetings and proposals. This portal contains a database with the names of those who have taken and successfully concluded the family assistant training course, offering families practical answers and a customised search for caregivers. It has also shown itself to be useful, firstly as a way of protecting families, who can communicate the outcome of their experiences and, secondly, of protecting family carers in the peaceful going about of their activities while serving in the homes of sick AD patients or non-self sufficient patients.

#### **Voluntary associations and self-help/mutual aid groups**

Alzheimer's Associations United (AU) is a national volunteer initiative based in Rome with the mission of obtaining appropriate treatment for Alzheimer's patients and support for their families. It serves as a partner and spokesperson for citizens in public and private institutions, giving voice to the real material and spiritual needs of the sick and of those who care for them.



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This organization networks with regional, provincial and municipal bodies based on memoranda of understanding, helping to take charge of more fragile and complex patients while giving particular attention to stress of the caregiver.

To share the difficult everyday path followed by patients and their families, the association has created a telephone number acting as an element of information, providing support and organizing training courses for practitioners at all levels (doctors, psychologists, nurses, therapists, rehabilitation therapists, occupational therapists, social workers and health assistants, family members).

Since 2007, the association headquarters has operated an Alzheimers' Centre (accredited by the City of Rome on the corresponding Register) divided into a day care centre and home care service, aimed at reducing the impact on the disease of the degree of self-sufficiency and providing relief to families in their difficult undertaking. Two family support groups also meet monthly at the Centre.

In order to promote socialization of the AU, the first Alzheimer's Café has been up and running since 2000 in Rome's Garbatella district as a place of meeting and sharing for families of AD patients. The Association also offers a legal advisory service with particular stress on administrative support.

The association offers a scholarship for young researchers who turn their interest towards the study of Alzheimer's Disease. It also organises events with rewards for caregivers, stands on caring for the sick, prizes for plays, photos and other artistic expressions highlighting the problems of patients and their caregivers and publishes a quarterly newsletter, *Alzheimer's U.S. News*, in the endeavour to maintain ties with and between its members and people involved in the matter.

### ***3.5. Care for the elderly non-self-sufficient in Italy-Report 2009 Sospiro (Aa. Vv. Maggioli Editore, Ravenna 2009)***

Home services consist of a series of services providing ongoing assistance to the elderly non-self-sufficient in their homes. These services endeavour to tackle pathological forms, deal with ongoing functional decline and improve quality of life.

The main types of services are: planned home care (ADP), integrated home care (ADI), hospitalized at-home services (OD) and home care social assistance (SAD).

For ADP, ADI and OD the main responsibility corresponds to the National Health Service, while SAD is the social responsibility of Municipalities. ADI and SAD represent publicly owned home care centres based on the size and role of users in the Italian welfare state network.

In Italy, home care is provided to 49% of the elderly, with 3.2% corresponding to ADI and 1.7% to SAD. A significant pocket of unmet needs are grouped together under the heading of 'neither/nor'. These are elderly people who are neither poor enough to receive the SAD service nor wealthy enough to pay for another type of support. There is yet another group whom, although they don't have needs serious enough to receive ADI at present, do have problems requiring some kind of assistance.



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The intensity of the public effort devoted to each ADI user is measured by the number of care-hours provided during the year. The average value of 24 hours per year per user demonstrates the unsuitability of an action aimed at a wide range of people. This is approximately the same number of hours as supplied in 2000 and indicates that the rise in users appearing for this decade is a result of failure to increase the intensity. Compared to the SAD, the only available indicator of the intensity of services is the average expenditure per user, amounting to €1,728/year. This indicator is only one of the factors contributing to our conclusions that the analysis performed on the intensity of sporadic SAD in Italy reveals a large presence of problematic situations.

Expenditure figures show that the position held by home care services in the Italian welfare state is marginal in several areas. In the health system, the proportion of public expenditure on ADI came to only 1.08%. The extension of ADI occurring this decade was solely due to the growing health expenditure and not to an increase in the amount dedicated to the service; in fact, between 2001 and 2006 the increase was very small, from 1.06% to 1.08%. Public spending on social protection amounted to 26.4% of the GDP and for home care services addressed to the elderly only 0.1%. Home care services account for 0.04% of the total expenditure devoted to social protection in Italy, one of the countries with the lowest percentage of users. Italy shares bottom place in Europe with a group of countries in the Mediterranean basin (Greece, Spain, Portugal). The small percentage of users means that the focus is on elderly people who are particularly vulnerable: the beneficiaries of home services in Italy have much higher functional and cognitive impairment rates than most other European countries.

In the case of home care social assistance (SAD), the pervasiveness of the figure of family assistant has kept requests for intervention low, giving rise to the need to rethink this kind of service. Many professionals in the SAD service had to work with older people often also cared for by a family member with scarce experience and qualification. The challenge is to coordinate the various professionals in such way that the SAD service supports and accompanies family assistants through forms of tutoring

#### **Who do we carers work for?**

***(The places of care, Carla Facchini, year VI, No.4: 7-10, 2008)***

It is currently estimated that approximately 600/800,000 immigrants, the vast majority of them women, live with elderly people who are non-self-sufficient, assisting them full-time or almost full-time in their homes. Resorting to ‘family assistants’ as carers is a peculiar trait of welfare in certain (Mediterranean) countries combining modestly developed home and residential services with the persistence of a strongly family-oriented cultural model. The objective of this work is to present information resulting from a study (conducted on behalf of SPI-CGIL - Lombardy Region) of a substantial number of carers (almost 650) in the region.

In most cases, the people assisted are very elderly (more than half are 85 years and over), and more often than not women.

50% of these cases have motor problems, 18.8% cognitive problems and a small percentage suffer from both problems (13.8%), whereas in 17.5% of cases no specific

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problems are reported. The cognitive problems are closely related to various forms of dementia (primarily Alzheimer's Disease).

The overall criticality of the situation of elderly people receiving care is obvious considering the overall levels of self-sufficiency; the overall rate of dependence (ADL) is very high, standing at 30.9% of all cases, average in 28.1% and, only in 9.1% very low, where the elderly person can be regarded as essentially self-sufficient.

The situation in relation to cognitive problems is as follows: 18.3% very high, 19.7% high, 33.5% average, 28.4% low. While those who have no specific problems usually require only a few interventions programmable throughout the day, those who have problems (particularly cognitive and associated with mobility limitations) require substantial continuous assistance which goes far beyond the interventions planned or programmed. It is interesting to underline the strong heterogeneity of the situations considered, showing a large proportion of high concern marked by a considerable burden of care (about 60%), a smaller but still significant part (around 30%) marked by intermediate problems, and finally a similarly smaller yet not insignificant part (10-15%) marked by demands of attention and reassurance for the elderly and their families rather than specific needs. In little over half of the cases, the “intermediate” gravity of the persons assisted can largely be suitably answered with the work of a caregiver, but here we come across the situation that there is often only one person in charge of this work, normally with no specific training (approximately 20% of cases in which the elderly are strongly affected by the disease).

A final consideration concerns the individual experience of ‘carers’: if the carer has positive feelings towards the person cared for, the experience is normally very trying, marked by concerns for the future, sadness, effort and loneliness. If the use of ‘carers’ (in countries where it is adopted) is a model helping to meet the cost of caring for non-self-sufficient family members, in reality for most of those doing the work it translates into a worsening of relations with the family and, in many cases, the tendency towards a crisis in relations with its constituents.

### ***3.6. Experience of caregiver’s support to patients with dementia***

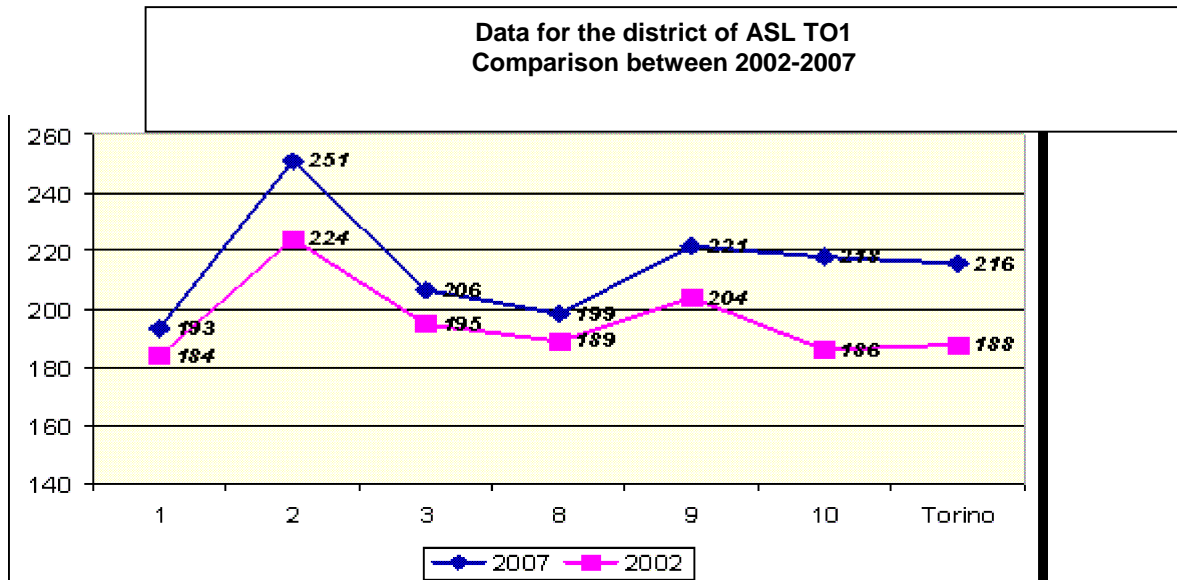
AT ASL 1 IN TURIN

The city of Turin has experienced a gradual increase in the number of senior citizens, who stand today at a quarter of the population.

There are 487,126 inhabitants in ASL TO1. Of these, 105,691 (21.6%) are between the ages of 65 and 84 and 13,570 (2.7%) over 84<sup>1</sup> (2007 data )



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**Fig. 2 Data for the district of ASL TO1**

In 2005, Turin’s ASL TO1 Department of Long-term Assistance and the Elderly opened a “**Caregivers’ School**” as part of the services network for people with dementia. Teaching and training courses on issues related to dementia were set up for primary caregivers (primary caregiver: the most responsible person in the taking of decisions and daily care of a relative), secondary caregivers (secondary caregiver: the person who develops a relationship of assistance but who is not directly responsible for providing the care), formal caregivers (carers), residential care staff (OSS) and hospital volunteers. The courses mainly targeted caregivers of patients belonging to the Alzheimer’s Network at ASL TO1: UVA (Alzheimer Evaluation Unit), the Day Centre for Alzheimer Disease and health homes providing sheltered relief.

Courses at the **Caregivers’ School** are organized into a series of four sessions divided into subject areas as follows:

1. Characteristics of dementia.
2. Cognitive problems.
3. Intervention strategies and adaptive prosthetic strategies.
4. Behavioural diseases of the patient.
5. Possible intervention strategies and knowledge based on family experiences.
6. Legal and forensic-related aspects of dementia.

The objectives of our work were to:

1. Analyse the impact of information on disease in parental stress management
2. Study whether or not non-pharmacological intervention could reduce the caregiver’s perceived care burden
3. Assess the presence of behavioural diseases and cognitive impairment of the patient related to the burden experienced by the caregiver



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All of the above was measured using validated neuropsychiatric scales and neuropsychological tests as indicators of the intervention effectiveness.

In the period between 2005 and 2009, 330 caregivers attended the course, distributed as follows:

- **252 primary caregivers (including 160 spouses and 92 sons/daughters)**
- **30 secondary caregivers (including 20 daughters-in-law and 10 sons-in-law)**
- **48 formal caregivers (carers, hospital volunteers, OSS).**
- **62% female 38% male**
- **Patients' average age: 74.4; caregivers' average age: 57.5**

#### MATERIALS AND METHODS

The patient and the caregiver were both interviewed twice, separately, to ensure greater reliability of response, before (T0) and after (T1) the course.

The interview with the patient involved administration of the Mini Mental State Examination in order to assess their level of cognitive impairment. The interview with the caregiver involved administration of the following scales:

- ADL / IADL
- NPI
- CBI

**Activities of Daily Living (ADL)** is a test investigating individual autonomy in everyday activities. The score ranges from 6 (maximum independence) to 0 (lack of autonomy).

**Instrumental Activities of Daily Living (IADL)** is a test investigating autonomy in several areas of daily life requiring more complex implementation. The score ranges from 8 to 0 for women, from 6 to 0 for men.

**Mini Mental State Examination (MMSE)** is a screening test to detect cognitive impairment, to quantitatively assess its severity and changes over time.

**Neuropsychiatric Inventory (NPI)** is a scale for the evaluation of behavioural diseases encountered by the caregiver and requiring evaluation in terms of frequency and severity.

**Caregiver Burden Inventory (CBI)** is a scale for assessing the burden of care, capable of analysing the multidimensional aspect developed for caregivers of patients with Alzheimer's disease and related dementias. This is a self-reporting instrument completed by the primary caregiver, that is, the relative or operator who supports most of the patient's burden of care. The caregiver is required to answer by ticking the box that comes closest to his or her condition or personal impression. Divided into 5 sections, it allows the evaluation of different factors of stress: objective burden, psychological burden, physical burden, social burden, emotional burden.

#### RESULTS

Statistical analysis of the data obtained was conducted using the Pearson correlation coefficient (r).

Examination of the T0 data results in:



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- a significant correlation between the level of patient’s autonomy in daily activities and the level of stress experienced by the caregiver ( $r = 0.552$ ,  $P = 0.0016$ )
- a significant correlation between the severity of behavioural diseases observed in the patient and the level of the caregiver’s care burden ( $r = 0.719$ ,  $p = <0.0001$ )
- a weak correlation, though not negligent, between the degree of cognitive impairment of the patient and the caregiver’s care burden ( $r = 0.270$ )

Examination of the data at T1 showed a significant decrease in scale scores collected at the CBI ( $p < 0.05$ )

### CONCLUSIONS

Given the highlighted correlation between a patient’s degree of autonomy in the ability to carry out tasks of daily living and the caregiver’s CBI scale score, we can state that the more energy, time and attention the patient requires, the greater the level of the caregiver’s perceived stress.

Moreover, the data also confirms that the main source of stress in the caregiver lies in behavioural changes in the patient’s disease. It is reasonable to state that the lack of social support and/or conflicts with other family members are more keenly felt in relation to the worsening of the patient’s behavioural diseases, coinciding with the study by Pearson and associates (1986)<sup>2</sup>.

The difference in collected data between the assessment at T0 and at T1 showed how the non-pharmacological approach was useful for the caregiver to:

1. improve his/her understanding of clinical and behavioural manifestations closely linked to disease
2. become more aware of his/her role and his /her own emotions.
3. adopt coping strategies aimed at reducing the burden of care and achieving a kind of home-rehabilitation

The Caregivers’ School offers caregivers an effective tool enabling them to adopt compensatory strategies for better management of the relative or, in the case of formal caregivers, the person under their care. Simplifying organization of the patient’s life may bring an improvement in his or her autonomy. This is achieved with greater awareness of care responsibilities, which are accepted by learning to recognize the potential benefits for the patient. The comparison made between patient characteristics and negative stress experienced by caregivers threw out some interesting data - useful for operators to better recognize cases, which are often caused by the same problems. These included considerable differences related to the age of the patient, type of dementia, cognitive and non-cognitive symptoms, biographical characteristics of the person undertaking the task and responsibility of assisting the patient.

The establishment of courses is part of a broader project in which the ‘instrument caregiver’ is used for a kind of home rehabilitation of the patients’ cognitive dysfunctions. Training of the person living with the patient is a prerequisite for the use of rehabilitation techniques, not only aimed at maintaining the patient’s functional and

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cognitive skills, but also at achieving a reduction in the caregiver’s stress levels and psychological well-being

## 4. CAREGIVERS SITUATION IN SPAIN

As of 1st January 2009, Spain’s general population was 46.6 million people, and 7.8 million were aged 65 or older, representing 16.6% of the whole population (INE, 2009).

<b>Table 3</b>							
<b>Spain. Total population and population aged 65+.</b>							
	Total	65+		Women		Men	
		Number	% of total population	Woman aged 65+	% of population aged 65+	Men aged 65+	% of population aged 65+
Population	46.661.950	7.780.830	16,67%	4.471.023	57,46%	3.309.807	42,54%

Source: Instituto Nacional de Estadística –INE- (2009). Avance del Padrón a 1 de enero de 2009. Datos provisionales. Comunidades autónomas y provincias. At: <http://www.ine.es/jaxi/tabla.do>. Last accessed: 10 julio 2009.

Around 700.000 people in Spain suffer from Alzheimer’s Disease (F.A.E., 2009) and around 100.000 are expected to become new sufferers every year. In relation to this figures, a recent study on informal caregivers by IMSERSO (2005), estimates that in 5.1% of the Spanish households (725,870 households) there is at least one person who provides care to another person aged 60 or older in daily activities, which this person cannot carry out by themselves.

These 725.870 households can be split into two groups: one for those where the care provided is family-related to the person being cared for (633,685 households, 4.5%) and another group where the care provider is hired and paid (92,185 households, 0.6%).

Yet, in every household there can be more than one person providing care. The average is 1.5 caregivers per family unit, which results in at least 950,528 informal care givers in Spain. This figure represents more than 6% perfect of Spain’s total population aged 18 and older.

According to the same study, the estimates for people 65+ being cared for at home by informal caregivers are 1.2 million, that is, more than 16% of the total 65+ population (Table 2). Likewise, the estimates for formal (hired & paid) caregivers are more than 100.000 people (Imsero, 2005).

In general, the most common profile of an informal care giver in Spain is a 53-year-old woman, married, with primary schooling, who carries out basically house work in her own house.



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### 4.1 Informal care givers in Spain

In fact, 83.6% are estimated to be women (Table 4) Regarding caregivers’ age, they are estimated to be mainly over 40, with a minimum share of the 20-29-year-old group (3.6%). It is imperative to point out that the important share of caregivers aged 70 and over (14.9%), an age at which where one most people are in need of care. It is then vital to segregate this percentage (14.9%) by gender because we hypothesis that most of these care givers are women.

<b>Table 4</b>			
<b>Profile of informal caregivers in Spain.</b>			
	%		%
<b>Sex</b>		<b>Education</b>	
Women	16.4	No studies - Illiterate	17.1
Men	83.6	Elementary	43.0
		High School	32.6
<b>Age</b>		University	7.0
younger than 20	1.2	Unknown	0.3
20-29	3.6		
30-39	11.9	<b>Employment</b>	
40-49	23.8	Employed	26
50-59	28.7	Unemployed	73.1
60-69	15.9	<i>Retired</i>	20.2
70 and older	14.9	<i>Unemployed</i>	7.0
Mean age	52.9	<i>Unemployed*1st job</i>	0.3
		<i>Housework</i>	44.2
<b>Marital Status</b>		<i>Student</i>	1.4
Single	14.8	N.A.	0.9
Married	76.2		
Widow	5.1	<b>Source:</b> IMSERSO (2005). Cuidados a las	
Separated	2.1	personas mayores en los hogares españoles.	
Divorced	1.5	Madrid: IMSERSO.	
NA	0.3		

#### 4.1.1 Informal caregiver’s and care recipient’s relationship

Concerning the relationship between caregivers and care recipients, most recent studies estimate that around 57.2% of caregivers are either the daughter or the son of the care recipient, generally the daughter (IMSERSO, 2005). A second group is formed by the spouse (16.8%) Likewise, it is interesting to notice that



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grandchildren are not generally involved in caring for their grand parents. (Figure 3). Estimations for formal caregivers are still scarce.

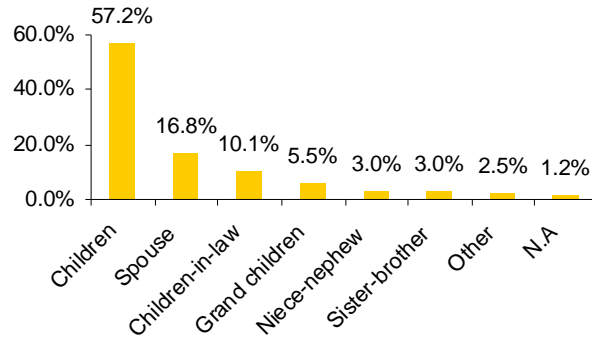


Figure 3. Informal care giver's and care recipient's relationship in Spain.

Informal caregiving is a continuous process. In fact, 77.2% of informal caregivers surveyed by the same study declare to be permanently with the care recipient. A figure not very surprising, taking into account that most of them are the care recipient's children and are mainly women. On a second instance, informal caregivers declare to play that role on specific terms such as weekends, summer, etc. (10.4%) or occasionally (9.4%) (Figure 4)

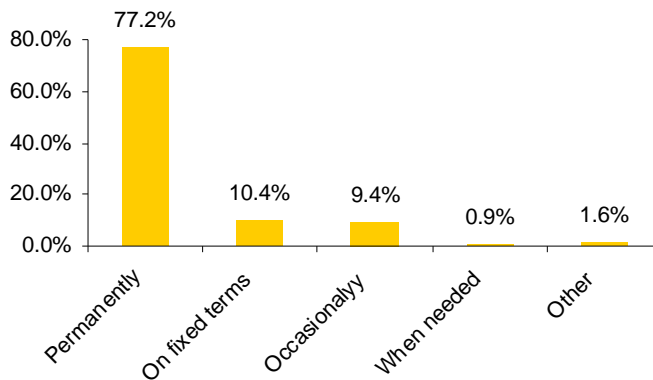


Figure 4. Informal caregivers in Spain: ¿How often do you take care of the elderly person?

### 4.1.2 Tasks, activities and duties carried out by informal caregivers

When asked about the type of activities they help the care recipient with (or, in some cases, assume to entirely do because of the care recipients' physical or cognitive situation). There are basically three types of activities:

- Housework: cleaning, ironing, preparing meals, etc.



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- Daily activities: going out in the street, shopping, going to the bank, paying bills, etc.
- Personal care: taking a shower, getting dressed, help to eat, etc.

Informal caregivers can carry out these three types of activities separately or all together. For example, 68.8% of them declare to help care recipients with all the three types aforementioned, 14.3% carry out only housework and daily activities; 2.9% carry out only daily activities and personal care; and 2.2% , perform only housework and personal care. As it was said, most carers combine all the three types, that is why 92.1% help those cared for with their daily activities, 83.9% do housework and 76.1% provided aid for personal care (Figure 5).

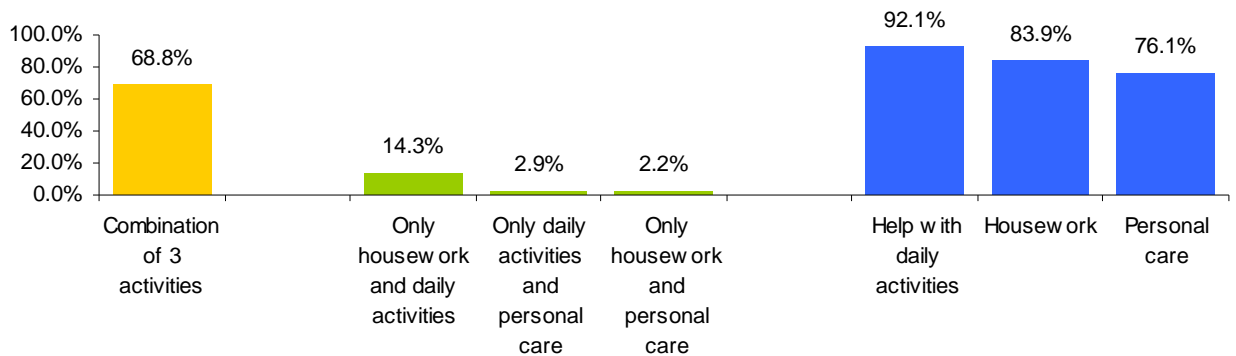


Figure 5. Tasks, activities and duties carried out by informal care givers in Spain.

No differences are detected by the care giver’s sex or age, but they do seem to be important according to the care recipient’s sex. As age increases, people need help to do many more tasks or activities. For example, both the 66-70-year-old ones and the 71-80-year-old ones need help mainly for 4-8 daily activities, but as age increases (81-90 and 90+ groups), care recipients need help generally for more than 9 daily activities.



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	Total (% column)	60-65 years	66-70 years	71-80 years	81-90 years	90+
1 activity	0.3%	1.9%	1.4%	0.2%	0.2%	0.0%
2-3 activities	3.1%	6.9%	4.7%	3.8%	2.5%	0.0%
4-8 activities	18.5%	18.5%	29.6%	23.4%	15.5%	5.7%
9 or more activities	77.8%	70.9%	62.8%	72.5%	81.8%	94.3%

There are not significant variations according to the care recipient’s sex, except in three specific activities: preparing meals, taking public transport and going out in the street. As can be seen in Figure 6, aged men are more likely to need help as regard preparing meals, while aged women are more likely to need help when using public transport or going out in the street .

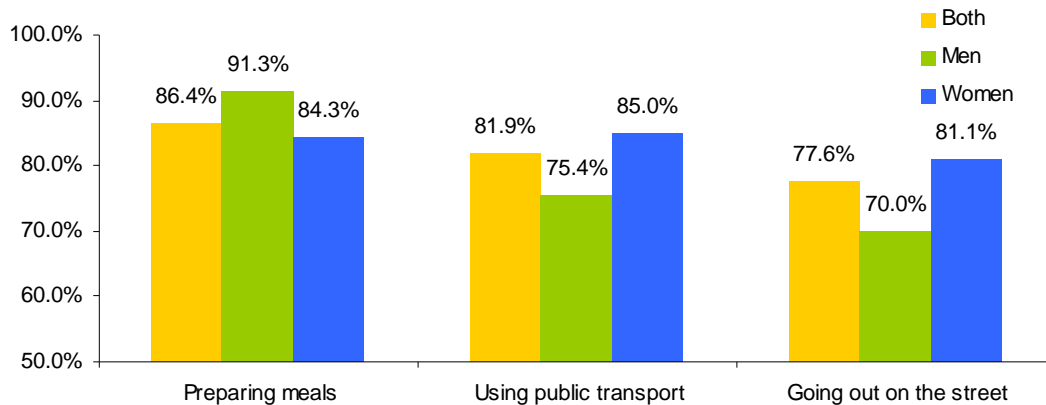


Figure 6. Spanish informal caregivers: Significant differences by sex for those activities aged people need help with.

#### 4.1.3 Qualification and Skills

Taking care of another person is not an easy task, especially if this person suffers from any particular disease. Caregivers can be either trained or not. In the case of informal caregivers, they are usually not trained, although public administration is doing great efforts to provide short-term courses on this matter available for the large scope of informal carers.

According to a study carried out by IMSERSO (2005), more than 65% percent of informal caregivers have gone through formal schooling at either elementary or high school level. Nevertheless, specific training on care-related issues is scarce.



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That is why it is interesting to analyse what informal caregivers say about the skills needed for the job they carry out. When asked about this subject, a significant percentage, although not very large, say that anyone can do their job (35%). Those who say that training is always needed are a bit less (32.6%). There is also a considerable percentage who believe that training is needed only when the persona cared for suffers from dementia (23.3%) (Figure 7).

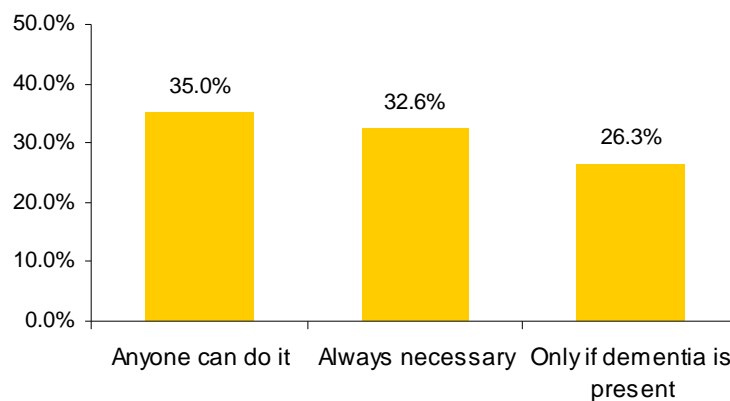


Figure 7. Spanish informal caregivers: ¿Is training on caregiving necessary?

### 4.1.4 Difficulties and challenges faced by care givers

Being such a hard job, caregiving is both gratifying and exhausting. There are many variables at stake, but scientific evidence has shown that caregivers are likely to suffer from health and mental problems (Dura, Haywood-Niler, & Kielcot-Glaser, 1990). There is also evidence showing that the care giver’s gender and age are likely to increase the risk of suffering from the so-called caregiver’s overload (Vitaliano, Russo, Young, Teri, & Maiuro, 1991).

For instance, in a study conducted by Crespo & López (2008) with 208 Spanish care givers (84.13% women, 15.87% men), researchers found that women tend to care for those with more severe situations of dependency, assume the most demanding tasks, are in conflict more often than men with carrying out their reproductive roles (family, housework, etc.), and spend more time providing care than men. In fact, Crespo & López (2008) found in their study that 74% of female caregivers felt overloaded, but only 45% of men felt in that way. On the reason to explain this abysm, they point out that female caregivers tend to have a greater perception of overloading, have worse personal resources than men (self-esteem, emotion-based schemes to face problems) and little social support.



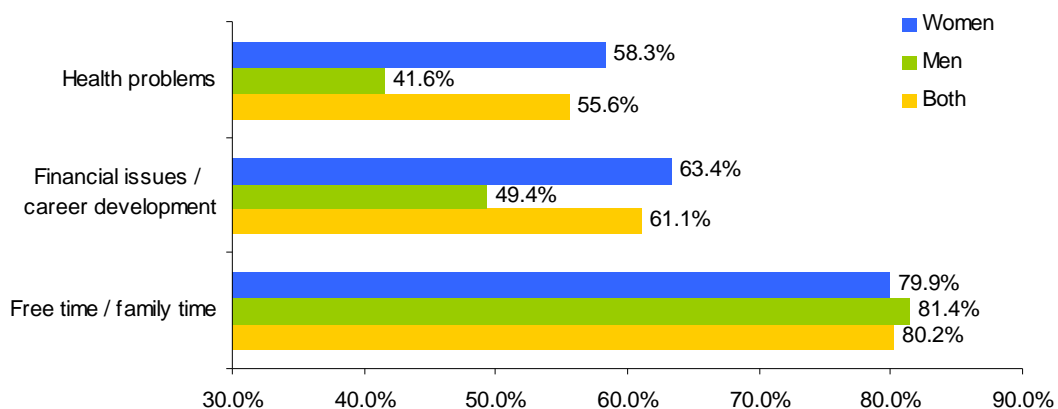
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Moreover, the medication intake was higher in female care givers (48.0%) than in male ones (16.0%) and suffering from depression was more common in women (26.0%) than in men (12.0%). More over, 68.0% of female caregivers were psycho-pathologically diagnosed, versus 46.0% of men (Crespo & López, 2008).

	Caregivers' distribution	Perception of overload	Taking medication	Psychopathologically diagnosed
Women	84.13%	74.0%	48.0%	68.0%
Men	15.87%	45.0%	16.0%	46.0%

n=208  
 Source: Crespo y López (2008). Cuidadoras y cuidadores: el efecto del género en el cuidado no profesional de los mayores. Madrid: IMSERSO

In a wider study (IMSERSO, 2005) including 1,504 caregivers' findings were similar, 85.5% of care givers declared to face or suffer from at least one disease of problem. When asked to identify this problem, most of them referred to limitations to their leisure time and to having time for their family (80.2%), followed by problems dealing with financial issues or with not being able to fully develop a professional career (61.1%) and health problems (55.6%). If separated by sex, women (63.4%) claim to suffer from financial difficulties more often than men (49.4%). As regard to health problems, a similar situation takes place (women, 58.3%; men 41.6%). (Figure 8) Curiously, men more than women declare not to have enough time for themselves or for their families. Probably, gender roles explain a great deal of this response, being women the ones spending more time with the care recipient, they are less likely to see this as an invasion of their personal time, and more as a role they are expected to assume.





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Figure 8. Spanish informal care givers: Difficulties / problems faced by care givers according to sex.

### 4.2 Formal care givers

Although estimates for formal care givers are scarce in Spain, some studies have approached the matter as a very early stage of research. The fact that a great share of this sort of jobs are part of the informal market and the role of immigration make any attempt to describe and analyse formal care giving is extremely difficult.

IMSERSO (2005) tackled this situation in its ever-cited study “*Cuidados a las Personas Mayores en los Hogares Españoles. El entorno familiar*” (*Home based Care provision to elderly people in Spain. The family environment*). The study included 105 domestic workers who labelled themselves as care givers of an elderly person and who are paid a salary for their work.

Women formal caregivers are more frequent than their male counter parts. In the first national study carried out by IMSERSO (2005), results were conclusive: 96.6% women and 3.3% men. Concerning their age, they are slightly younger than informal caregivers because their mean age is 39 years old and those older than 60 years hardly are beyond 4% (Table 7).

It is also interesting to point out that more than 95% of formal caregivers have gone through some sort of schooling. There was also a significant share of people with university studies (11.6%).

Formal caregivers are more likely to be immigrant than the informal ones. Even though almost 60% are Spanish, we suggest that this percent must be regarded cautiously, not only because it might be out of date (2005) and the situation has changed, but also because evidence have shown that most illegal workers are under-registered in every survey or study. Yet, the important amount of people from Ecuador, Colombia, Peru and Bolivia suggest that immigrant formal care givers in Spain tend to be South American rather than from any other nationality.

<b>Table 7</b>			
<b>Profile of formal caregivers in Spain.</b>			
	%		%
<b>Sex</b>		<b>Education</b>	
Women	3.4	No studies - Illiterate	1.4
Men	96.6	Basic literacy	5.3
		Elementary school	31.9
<b>Age</b>		High school	46.4
younger than 20	0.5	University	11.6
20-29	17.9	Schooling unknown	2.9



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30-39	29.5	NA	0.5
40-49	31.4		
50-59	16.4	<b>Nationality</b>	
60-69	3.9	Spain	59.9
70 and older	0.5	Ecuador	13.0
Mean age	39.4 years	Colombia	6.8
		Peru	4.3
<b>Marital Status</b>		Bolivia	2.9
Single	27.1	Rumania	2.4
Married	48.8	Bulgaria	1.9
Widow	6.3	Dominican Republic	1.4
Separated	10.6	Other	2.0
Divorced	4.3	<b>Source:</b> IMSERSO (2005). Cuidados a las	
NA	2.9	personas mayores en los hogares españoles.	
		Madrid: IMSERSO.	

As said before, estimates for formal caregiving at home is very rare in Spain. In the aforementioned study by IMSERSO (2005), only 7% of the Spanish households surveyed had external aid for caring for an elderly person. This aid did not imply the absence of family caregivers when the formal caregiver was not present.

In most cases, extra aid was hired for housework and thus those carrying out this job are referred to as domestic workers, even though their job is linked to caring for the elderly person. These formal care givers work mainly on a hourly basis (27.1%) or part time (26.6%). Those who work full time can be split into those not living in the household (23.2%) and those who do (22.7%).

Most of those working full time and living in the care recipient’s home are immigrants. This explains why 73% of these workers do not enjoy social security (IMSERSO, 2005)

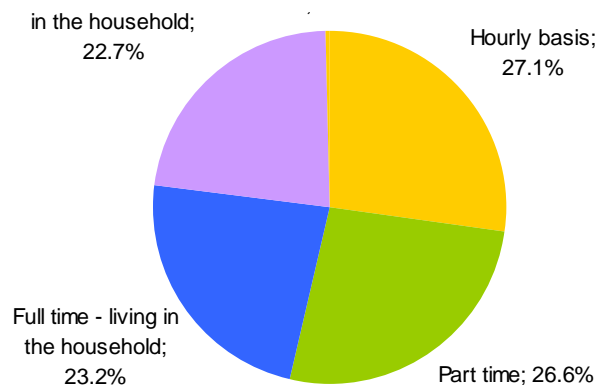


Figure 9. Spanish formal caregivers' time distribution.



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Caregiving is a very demanding job. That is why 71.0% of formal care workers are entirely devoted to taking care of the elderly person, limiting the professional and income potential. Those working as formal carers on fixed terms only represent 24.2% and those working seasonally reach 4.8%. Out of this 71% working only as formal care givers, most of them are the sole type of aid the elderly person has (39.1%).

Formal caregivers carry out their job along the day, most work only on mornings (31.4%), but a large share do an all-day-shift (29.0%). A great percent do both mornings and afternoons (23.7%). On average, they work 7 hours a day and they have taken care of the elderly person for more than 1 year (69.0%).

**4.2.1 Specific training and training needs**

When asked about specific training for taking care of some else, most caregivers declare not having gone through any form of training (70.0%); the rest have either taken a short course or read by their own. On the reasons to explain their weak training, they believe they do not need any training (42.0%) or have not even thought about it (32.0%) Most of formal caregivers believe that specific training is needed to care for another person (40.0%); however, a large share (29%) believes that “any one can do it”. Many caregivers suggest that specific training is necessary only for specific situations (27.0%), such as those cases when the one cared for suffers from dementia or his/her degree of dependency is important.

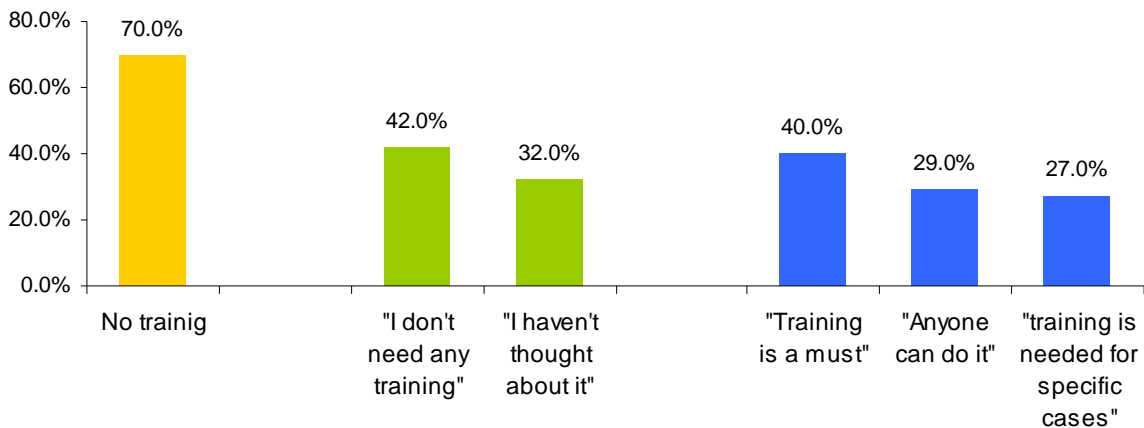


Figure 10. Training: needs, opinions and perspectives for Spanish formal caregivers.

As regards to the activities they do or help with, 70% of them declare to help care recipients with housework (cleaning, ironing, preparing meals, etc.); daily activities (going out in the street, shopping, going to the bank, paying bills, etc.) and personal care (taking a shower, getting dressed, help to eat, etc.): 9.2% , perform only housework and personal care; 7.2% carry out only housework and



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daily activities; and 2.9% carry out only daily activities and personal care. Nevertheless, most carers combine all the three types: that is the reason why 89.4% do housework, 84.5% provide aid for personal care, and 83.1% help those cared for with their daily activities (Figure 11).

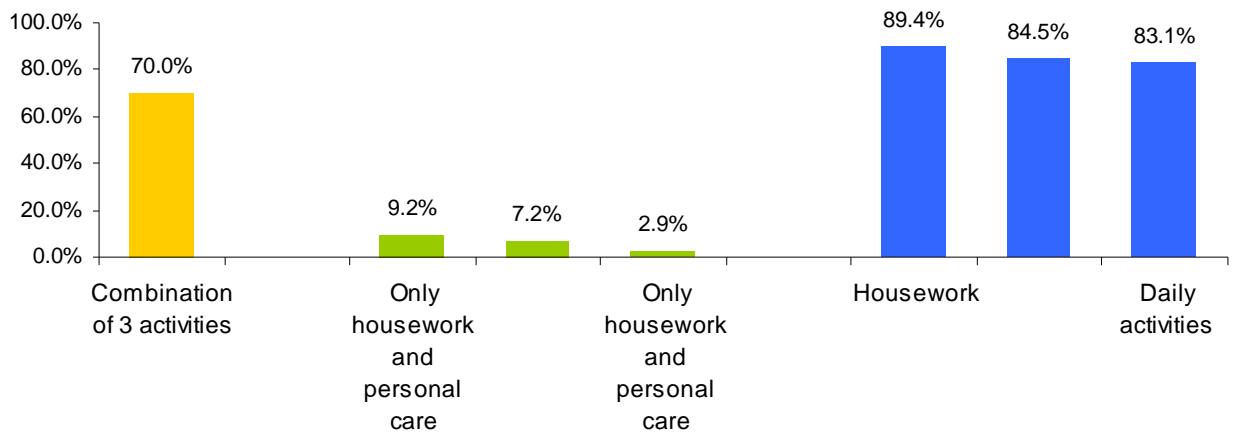


Figure 11. Activities and tasks carried out by formal caregivers in Spain

#### 4.2.2 Available resources for care givers in Spain

When someone is diagnosed with Alzheimer’s disease, all those people around them get involved. Care givers, both formal and informal continuously declare not having enough information about the disease and about the resources available to mitigate the burden and load they go through when caring for some with AD.

According to a study carried out by Fundación Alzheimer España (2007) and other four European organisations, including with 1,181 caregivers from Spain, France, Germany, Poland and Scotland, inaccurate information about the disease was pointed out as one of the main difficulties faced by caregivers (37%). Half of caregivers highlighted that information on the evolution of AD was not sufficiently provided by health staff. Even more, 34% declared not to have received any information on the medical treatment available for AD.

In this study, only 4.0% of caregivers were given information on the resources available and 8.0% were told about associations and support groups for AD patient’s families. That is why, 80.0% of caregivers request more information on resources and services (80.0%) and medical treatments available for AD. (47.0%).

Resource and services have been aiming patients, but not necessarily caregivers. Although recently there have been a change towards a more comprehensive and

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inclusive perspective. For instance, **home assistance** is a service usually provided by local public administrations, including home aid, tele-assistance and other financial support for reparations, informal care givers, meals to go and assistive technologies. Publicly supported home assistance services covered 753,995 elderly people in 2007. This figure represents both direct help for dependent elderly users and for family care givers (Imsero, 2008).

**Respite centres** offer temporal stays in residential setting, which is another type of service to help both dependent elderly persons and their carers as it provides a time free from care giving. In 2007, there were 4,561 beds in 724 residential settings for respite services (Imsero, 2008). The most common service is the so-called “a weekend respite” provided for families taking care of relatives on weekdays.

Support groups and Family Associations are the main resources available for care givers in Spain. Founded in 1991, the *Fundación Alzheimer de España* is the largest **national NGO** grouping family and care givers of people suffering from Alzheimer’s disease. It provides support and guidance to families and carers on the medical development of the disease, the resources available in their town, recent calls for provision of financial support, information on networks of smaller or local associations, and in general, has struggled for making AE a public health issue. Resources are limited, but the publication of a e-newsletter and several e-Guides on Alzheimer make this NGO the Spanish focal point on the web for informal care givers ([www.fundacionalzheimeresp.org](http://www.fundacionalzheimeresp.org)).

Another large, national NGO is the INAFA (*Asociación de cuidadores y familiares de enfermos de alzheimer y demencias afines*). Founded by care givers and people with early-stage dementia, it aims at providing counselling, legal assistance and nursing services to families. Some of the centres of INAFA are equipped with a respite centre and some other develop a programme for children living with people suffering from dementia ([www.inafa.es](http://www.inafa.es)).

Almost every Spanish region has its own association of families and care givers of people suffering from EA. In San Sebastian, for instance, AFAGI (*Asociación de familiares de enfermos de Alzheimer de Gipuzkoa*), was founded in 1991 to provide counselling, legal support, sociological and economical perspectives on AE, medical dissemination, networking and making invisible care givers visible to society and public authorities.

Some specific initiatives have taken place recently. For example the GAM project, backed by Ingema and Fundación Matia (San Sebastian, Spain), is a psycho-educational training programme for AD care givers to improve emotional management. The purpose is to modify negative emotions care givers may have when taking care of AD patients. GAM is an input to the RING Kit to be developed later on in the project.



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ICT-based resource and services are recently taking position and settling as a common and general choice. Internet has made knowledge expand faster than ever and care givers are more and more using internet to fill the gap health practitioners have not been able to satisfy. Thus, e-forums for care givers are webbing the web in Spain:

- Social / Learning communities:
  - Emagister.com: There are 3 groups devoted to Alzheimer’s Disease, their carers and social implications: Grupo de Geriatria (717 members); Foro de Alzheimer (737 members); and, Grupo de Alzheimer (25 members).  
<http://grupos.emagister.com/grupo/search?q=alzheimer&sa=Buscar&idGrupo=1300&scope=T>
  - Facebook: The largest social e-community, there several groups aimed at both patients and carers, whether they are family or non-relative. Some of the groups are: Alzheimer's Society (7,156 members), The Alzheimer Project (1657 members); Links a páginas en Español sobre la Enfermedad de Alzheimer .
  - Red Cross: Through its website, it provides up-to-date information on resources and services for families and caregivers  
[http://www.cruzroja.es/portal/page?\\_pageid=659,12329695&\\_dad=portal30&\\_schema=PORTAL30](http://www.cruzroja.es/portal/page?_pageid=659,12329695&_dad=portal30&_schema=PORTAL30).
- e-Learning and Open Universities: Supply is endless when it comes to distance training for care givers. For example, some of the courses available are:
  - Distance training on caring for AD patients (Cursos de cuidador de enfermos de Alzheimer a distancia):  
<http://www.aprendemas.com/cursos/cursos-cuidador-de-enfermos-de-alzheimer-a-distancia-234048.html>
  - Oficial Certificate for AD Patients Care givers (Cuidador de Enfermos de Alzheimer – Curso Oficial):  
[http://www.formazion.com/cursos\\_curso\\_cuidador\\_de\\_enfermos\\_de\\_alzheimer\\_curso\\_oficial\\_distancia-46642.html](http://www.formazion.com/cursos_curso_cuidador_de_enfermos_de_alzheimer_curso_oficial_distancia-46642.html)
  - Distance training for caregivers of AD patients (Curso de cuidador enfermos de Alzheimer a distancia 2010):  
<http://cursos.universia.es/cursos/1/3b8ce-cursos-cuidador-enfermos-de-alzheimer-a-distancia.html>



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### **4.2.3 Legal regulations in Spain**

ACT 39/2006, of 14th December, on the Promotion of Personal Autonomy and Care for Dependent Persons

This law took effect on the 1<sup>st</sup> of January of 2008, and it was the first time in the field of the socio sanitary system that it was regulated and guaranteed the provision of care to persons with dependency. This law allowed the access to a wide services catalogue in order to cover the provision of care to this population. To guarantee the implementation of the law a specific system was created: the System for Autonomy and Care for Dependency, as mentioned this system guarantees the basic conditions and common content to which the Act 39/2006, of 14th December refers; serves as a common ground for the collaboration and participation of the Public Administrations, in the exercise of their respective competences, on the subject of the promotion of personal autonomy and protection for dependent persons; optimises the public and private resources available and contributes to improving the living conditions of citizens.

The System is configured as a network for public use that integrates on a coordinated basis, both public and private centres and services. The fact of integrating the centres and services referred to in this article in the System for Autonomy and Care for Dependency shall not bring about any alteration in the legal regime applicable to their ownership, administration, management or secondment to other bodies.

In the following lines there is described the catalogue of services provided by this law:

1. The Catalogue of services includes the social services for the promotion of personal autonomy and care for dependency, according to the terms that are specified in this chapter:

- (a) Services for the prevention of situations of dependency and for the promotion of personal autonomy.
- (b) Personal Alert System.
- (c) Home Help Service:
  - (I) Housekeeping tasks.
  - (II) Personal care.
- d) Day and Night Centre Service:
  - (I) Day Centre for older persons.
  - (II) Day Centre for persons under the age of 65 years.
  - (III) Day Centre with specialised care.
  - (IV) Night Centre.
- e) Residential Care Service:



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- (I) Residence for dependent older persons.
  - (II) Centre offering care for dependent persons, according to the various types of disability.
2. The services listed in item one are regulated without detriment to the terms of article 14 of Act 16/2003, of 28th May, on the Cohesion and Quality of the National Healthcare System.



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Besides the listed before there are another articles related to financial benefit. In the next paragraphs they are described:

Article 17. Financial benefit linked to service.

1. The financial benefit, which shall be received on a regular basis, shall only be granted when it is not possible to access a public or subsidised attention and care service, depending on the degree and level of dependency and on the beneficiary's economic status, in accordance with the terms of the convention held between the General State Administration and the Autonomous Community in question.
2. This personal financial benefit shall in any case be linked to the acquisition of a service.
3. The competent Public Administrations shall supervise, in any case, the purpose and use of these benefits to verify compliance with the purposes for which they were granted.

Article 18. Financial benefit for care in the family setting and support for non-professional carers.

1. On an exceptional basis, when the beneficiary is being cared for in the family setting and when the conditions laid down in article 14.4 are met, a financial benefit for family care shall be acknowledged.
2. Following agreement by the Territorial Council of the System for Autonomy and Care for Dependency, the conditions qualifying for this benefit shall be established, according to the degree and level acknowledged for the dependent person and his/her economic status.
3. The carer must comply with the rules on affiliation, registration and contribution to the Social Security that are laid down in the regulations.
4. The Territorial Council of the System for Autonomy and Care for Dependency shall promote initiatives to support non-professional carers, which shall include training and information programmes and measures to cater for rest periods.

Article 19. Financial benefit for personal assistance.

The purpose of the personal assistance financial benefit is to promote the autonomy of the severely dependent persons. Its objective is to contribute to the hiring of a personal assistant, for a number of hours, in order to provide the beneficiary with access to education and employment, as well as a more autonomous life in the exercise of the basic activities of daily living. Following agreement by the Territorial Council of the System for Autonomy and Care for Dependency, the specific conditions for qualifying for this benefit shall be established.

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Article 20. Amount of financial benefits.

The amount of the financial benefits regulated in the articles in this section shall be agreed upon by the Territorial Council of the System for Autonomy and Care for Dependency, for subsequent approval by the Government by means of a Royal Decree.

## **5. REQUIREMENTS ANALYSIS IN THE RING PROJECT**

The project aims to improve the quality of life of the caregivers, to strengthen its position in the labor market and contribute to social cohesion with a relapse on assisted people, family and on social and health services. To increase the skill level of the group at risk, we intend to transfer the product formed by:

- a. the Spanish program "Psychoeducational programme focused on the emotional well-being of the Alzheimer's caregivers" based on an innovative methodology of psycho-social intervention, useful to hoarding and enhance the skills, communication and behaviour of people in initial or permanent training.
- b. The book of relief for palliative care (Sospiro Foundation - Cremona). Dvd with movie fragments on the supportive relationship (Maderna Centre - Stresa). The final product, an aggregate, called "Ring Kit" will be used as a tutorial in the training module on supportive relationship.

In order to gather caregivers (informal and formal) and trainers' needs within the Ring project two, *ad hoc*, questionnaires were created, one for caregivers and another one for caregivers' trainers. Formal and informal caregivers were defined as follows: **Formal Caregiver** is a paid worker in a Nursing Home /Rest Home, a paid outworker, or a volunteer who cares for the elderly and is remunerated only with a refund of expenses. Instead, the **Informal Caregiver** is a family member or relative who cares for the elderly at home or in a Nursing Home/Rest Home, and who is not remunerated with a refund of expenses.

The caregivers' questionnaire was composed by different sections: Type of caregiving, identification of needs: psychosocial area, identification of needs: organizational area, identification of training needs, and sociodemographic characteristics (see appendix 1). Trainers' questionnaires consisted of questions related with their perception about caregivers needs on training (see appendix 2). A total number of 311 questionnaires from caregivers and 106 from trainers from 4 different



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countries (Turkey, Romania, Italy and Spain) were collected. In the next section, the results from the questionnaires are outlined.

## Results from the questionnaires

### 5.1 Caregivers

A total of 331 questionnaires from caregivers were collected in four countries: Turkey, Romania, Italy and Spain. Caregivers were distributed into two groups: formal or informal. A total of 204 formal caregivers and 127 informal caregivers were interviewed. The distribution of caregivers by country is the following: Turkey, 60 questionnaires from formal caregivers; Romania, 10 formal and 6 informal caregivers; Italy, 117 formal and 107 informal caregivers; and, finally, Spain, 17 formal and 14 informal caregivers.

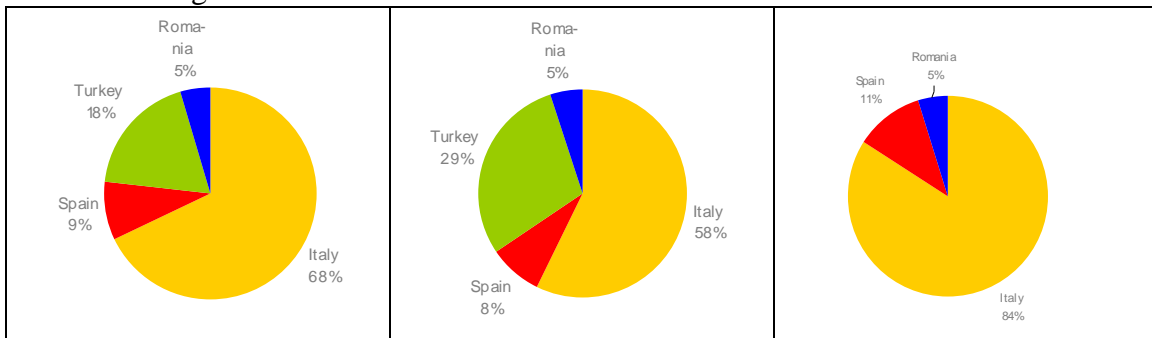


Figure 12. Total Caregivers by Country.

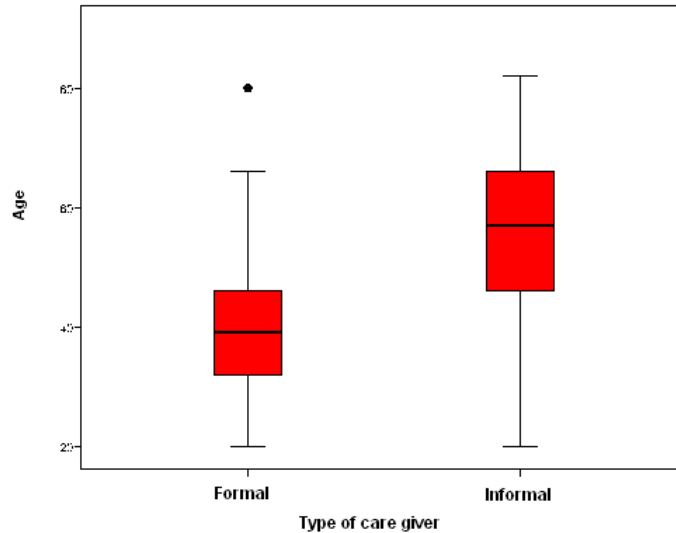
Figure 13. Formal Caregivers by Country.

Figure 14. Informal Caregivers by Country.

If we take a look at the ages of all the caregivers, it is particularly interesting to note that formal caregivers are in general younger than informal caregivers. As can be seen in Figure 6, informal care givers’ age range is much larger than the one for formal caregivers. In fact, there are several 80+ informal caregivers. For example, 50% of formal caregivers range from 32 to 46 years of age, 50% of informal caregivers range from 46 to 66 years of age (Figure 6). This situation confirms the wide spread hypothesis that informal care giving is a life course process.



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**Figure 15: Caregivers' age distribution.**

### 5.1.1 Informal caregivers

#### *Description of the sociodemographic data of the informal caregivers*

Data were gathered from 127 informal caregivers; yet, only 124 of the respondents did answer this question. The mean age of informal caregivers was 55.62 years (SD=14.47), ranging from 20 to 82 years. Being the range too large, it is better to re-distribute the data into age groups: one for the 20-40 year-olds, a second group for the 41-60 year-olds and a third group for the 61+ year-olds. This will show a better description of the groups and will lower the deviation (14.47 years).

The largest group is the 41-60 year-olds (43,5%), followed by the 61+ group (39,5%). The 20-40 group is the smallest one (16,9%). As can be seen, care giving is mainly a “grown-ups” thing, as young caregivers are not as numerous. Mean age for the 20-40 group is 32.76 years (SD=7.04), for the 41-60 group mean age is 51.94 years (SD=7.11), and for the 61+ groups, mean age is 69.47 years (SD=6.35)



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Table 8. Informal care givers’ mean age

Table with 2 columns: Num-ber, % and 2 rows: All Informal care givers, Informal care giver by age group

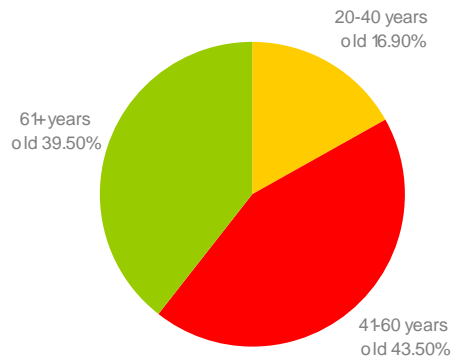


Table with 2 columns: Age group, and 3 columns: Number, Percentage, Mean Age (years)

Figure 16: Informal caregivers by age group.

As can be seen in Table 9, most caregivers are women (83.9%) and this is so for every age group and country, although in the 41-60 group and the 61+ group men tend to increase their participation as informal caregivers, probably because they engage in couple relationships, a less likely situation in the 20-40 group.

The case of Romania is particularly remarkable as no male caregivers were interviewed at all (no informal caregivers, either female or male, were interviewed in Turkey) and neither did 61+ care givers. On the contrary, both Italy and Spain included males in all the age groups. Concerning elderly caregivers, in the case of Italy, there were some male 61+ caregivers.

These figures confirm that the feminization of care giving is still a major gender divide in every country.



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<b>Table 9. Informal care givers' age groups according to gender by country</b>									
	Number	% (row)	Country % (row)						
			Romania		Italy		Spain		
<b>All care givers</b>									
Female	104	83.9%	6	100%	85	82%	13	93%	
Male	20	16.1%	0	0%	19	18%	1	7%	
Total	124	100.0%	6	100%	104	100%	14	100%	
<b>20-40 year olds</b>									
Female	17	81.0%	4	100%	12	75%	1	100%	
Male	4	19.0%	0	0%	4	25%	0	0%	
Total	21	100.0%	4	100%	16	100%	1	100%	
<b>41-60 year olds</b>									
Female	47	87.0%	2	100%	36	86%	9	90%	
Male	7	13.0%	0	0%	6	14%	1	10%	
Total	54	100.0%	2	100%	42	100%	10	100%	
<b>61+ year olds</b>									
Female	40	81.6%	0	-	37	80%	3	100%	
Male	9	18.4%	0	-	9	20%	0	0%	
Total	49	100.0%	0	-	46	100%	3	100%	

When asked about who they live with, most care givers stated that they lived with the person they care for (55.6%) (Table 10). This is not a general situation in all the countries. Although the numbers are small, the cases of Italy and Spain are different. While in Italy almost half of the caregivers live with the care recipients, in Spain more than 84% of all the informal caregivers interviewed in this country live with the care recipients (Table 10).

Concerning the relationships of between the care givers and the care recipient, most of caregivers were either the care recipient's daughter (42.9%) or spouse (23.8%). (Table 6) Just a few percent were the recipient's son, a fact that reinforces what was stated seen previously as the feminisation of caregiving. Then, informal care giving is mainly a "family matter" as 85.7% of care givers are in one way or another family-related to the care recipient: spouse, daughter, son, daughter-in-law, or sister (Table 11).



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**Table 10**  
**Do caregivers live with those they care for?**

Yes
69
55.6%
No
55
44.4%

**% (country)**

**% (country)**

By country

Romania
3
50.0%
3
50.0%

Italy
55
52.4%
50
47.6%

Spain
11
84.6%
2
15.4%

**Table 11**  
**Caregivers' relationship with the care recipient**

	Number	%
Spouse	30	23.8
Daughter	54	42.9
Son	11	8.7
Daughter-in-law	8	6.3
<b>Yes</b> Sister	5	4.0
Caregiver	6	4.8
Others	12	9.5
<b>No</b>		
Total	126	100.0



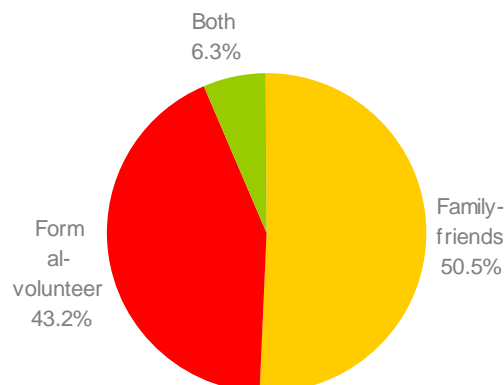
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Regarding their nationality, this is not a very useful variable for informal caregivers since they are by large related to the care recipient (Table 6). In fact, most informal caregivers share the care recipient’s nationality (Table 7). More than 95% are Europeans, whether from the East (6.3%) or from the West (89.7%). Only did a small share of informal caregivers come from Latin America (4%) and they lived in Italy and Spain. (Assigning oneself to Eastern or Western Europe was a self-perceived assumption by the respondents.)

Country	Western Europe	Eastern Europe	Latin America	Total
Romania	6	0	0	6
Italy	102	2	3	107
Spain	11	0	2	13
<b>Total</b>	<b>119</b>	<b>2</b>	<b>5</b>	<b>126</b>

In summary, most informal caregivers were female (83.5%), lived with the care recipient (55.6%) and were either the care recipient’s daughter (42.9%) or spouse (23.8%).

On average, caregivers have been caring for someone else for four years now. Although the variability is great, ranging from 1 month to 27 years. They spend an average of 11.95 hours a day (SD=8.59) on care giving. The main help received in the care giving task was given by family or friends (50.5%) and by formal or volunteer staff (43.2%). A minor share of caregivers (6.3%) stated getting both formal and informal support.



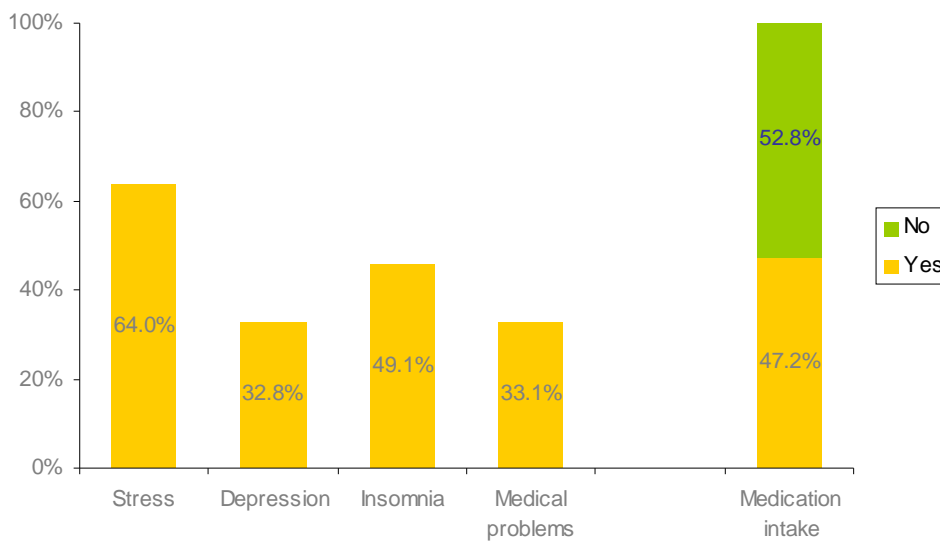
**Figure 17: Who do care givers get support from?**

*Descriptive results from the psychological and medical problems*



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Regarding the question if they had some psychological and medical problems in the last year, the results show a high frequency of these disorders among the caregivers that participated in this study. Thus, the informal caregivers interviewed pointed out the following problems: stress (60%), depression (32.8%), insomnia (41.9%), and medical problems (33.1%). They referred to consume medication to afford such problems in the 47.2% of the cases. (Figure 17).



**Figure 18: Psychological and medical problems faced by care givers and their use of medication for these problems**

#### *Training needs of the informal caregivers*

When asked about training, there is an outstanding result as only 24.6% of informal caregivers have ever received any sort of training, against 75.4% that have never had any type of training. For those who have had some kind of training, the average time this training lasted was 41.26 hours (SD=149.47). Yet, the variability of this result is so large (SD=147.47), that is it is better not to take this figure as a good indicator of quality and duration of the training informal caregivers have gone through (Figure 19).

Regarding their participation in a self-help group, only 28.3% of them have ever participated in one them (Figure 19). The situation is similar in every country (Romania, 33.3%; Italy, 28.0%; Spain, 28.6%)



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**Figure 19: Training received and participation in self-help groups.**

### *Identification of needs: psychological area*

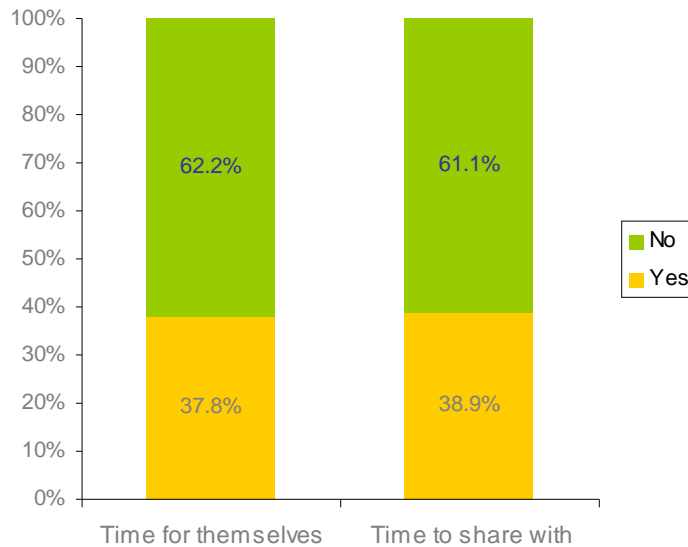
Concerning the perception of spare time caregivers have, the vast majority of them (62.2%) think that they do not have enough time for themselves and 61.1% consider that they do not have enough time to share with family members and friends (Figure 20).



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**Figure 20: Caregivers' time use.**

### *Identification of needs: Organizational area*

In this respect, most of the informal caregivers interviewed believe they need support. Thus 74.4% of caregivers estimate as valuable to ask for help and formal support. When asked about the type of support they would ask for, these are the results: housework (47.5%); personal hygiene (40.8%); administration-related tasks such as paying bills, legal aspects, etc., (26.9%); Public financial support (25%), nursing (23.3)%, and finally other type of help such as taking care of children (16.8%). Respondents were able to choose from more than one choice.



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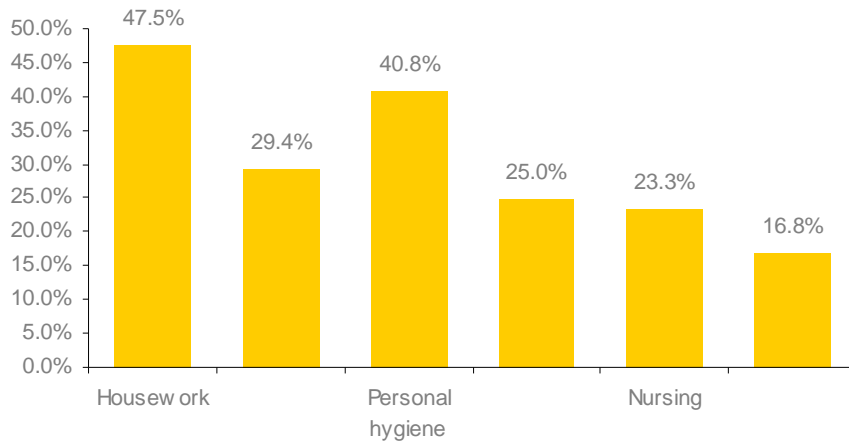


Figure 21: Type of help identified by informal caregivers

#### Identification of needs: training

In this respect, 90.6% of informal caregivers find meeting with others in the same situation interesting and 76.4% find psychological and emotional support to be helpful. A large share of caregivers (92%) considers having more information about the disease as interesting as its evolution. In addition, most (91.9%) caregivers would like to be informed about how to relate with the person they are caring for (Figure 22).

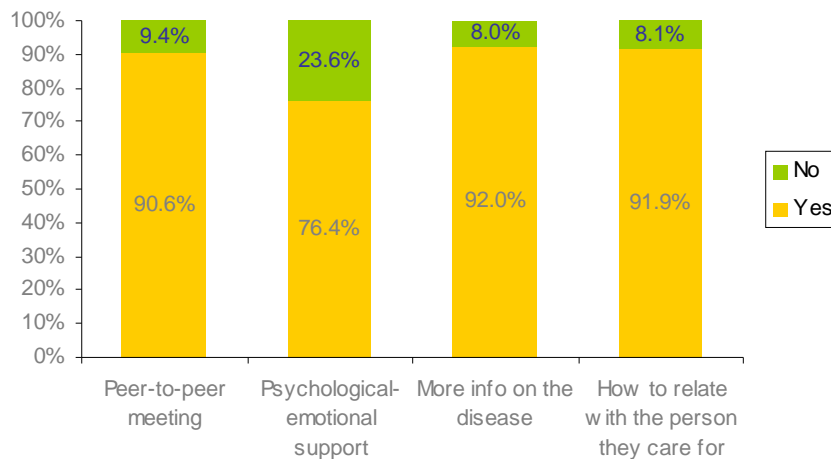


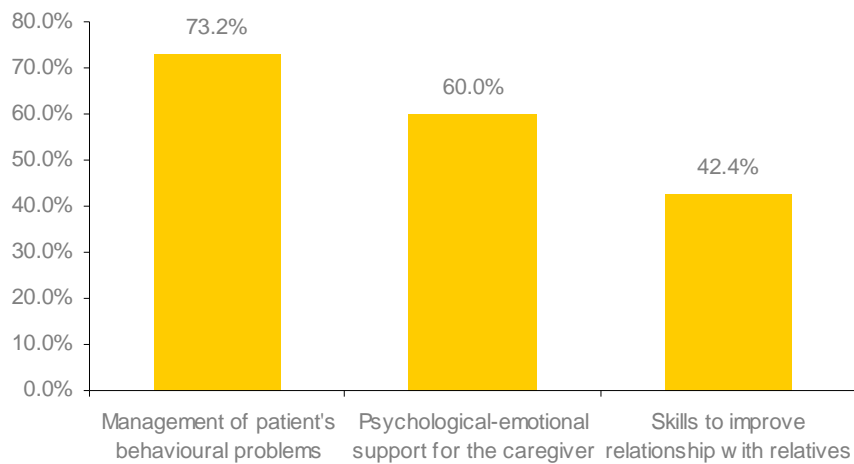
Figure 22: Areas of training identified by informal care givers

As regards to the topics they deem as the most interesting topics to be trained in, these are skills on to the management of the behavioural problems of the patient (73.2%), psychological and emotional support for the caregiver (60%) and skills to improve the



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relationship between the caregiver and other people (42.4%) (Figure 23). These results can be related to those referring to the psychological and medical problems they identified (see Figure 18) and their use of medication to face these problems. Let us recall that 64% of caregivers feel stressed because of the work they do. Therefore it is not surprising that they request training on management of the behavioural problems of the person they care for, or on psychological and emotional support for the caregiver or on skills to improve the relationship between the caregiver and other people. It is then evident that they request training related to the psycho-medical problems. Besides stress, they also pointed out depression (32.8%) and insomnia (49.1%) (see Figure 18).



**Figure 23: Main topics for training identified by informal caregivers.**

How to provide training to informal caregivers is one of the most important aspects for the RING project because it directly deals with the project's strategy and methodology. When asked about the means by which they would like to be trained in, informal caregivers ranked meetings with professionals in the first place (73.4%), then training courses (55%), followed by booklets (41.7%), specific websites (31.4%), TV and radio (26.5%), DVDs (26.3%) and other means (5.1%). Respondents were able to choose from more than one choice (Figure 24). These preferences are to be seriously taken into account for the training stage of the RING project.



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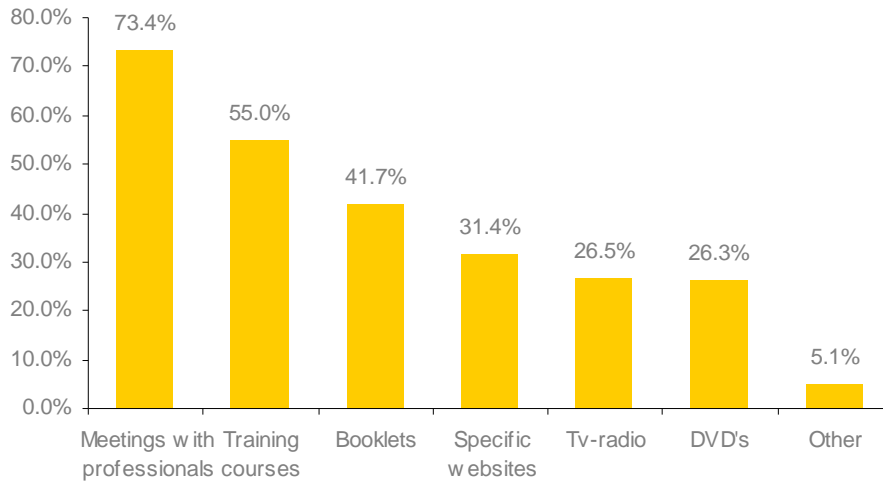


Figure 24: Means of training preferred by informal caregivers.

### 5.1.2 Formal caregivers

#### *Description of the sociodemographic data of the formal caregivers*

Data were gathered from 204 formal care givers; yet, only did 199 of the respondents answer this question. Their mean age was 39.44 (SD=10.40), ranging from 20 to 80 years, although 80 years old is a “strange” age as the next younger age is 66. Let us recall the informal care givers’ mean age for comparison purposes: 55.62 years (SD=14.47). That is almost more than 16 years of difference, let alone that there were more frequent cases of 60+ caregivers in the informal group than in the formal group.

Being again the range too large, it is better to re-distribute the data into age groups: one for the 20-40 year-olds, a second group for the 41-60 year-olds and a third group for the 61+ year-olds. This will show a better description of the groups and will lower the deviation (10.40 years).

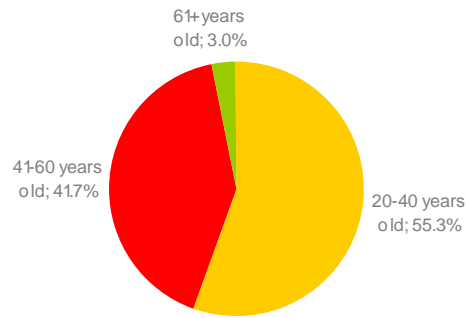
We find in these group younger carers than the ones found in the informal group. For instance, the largest group is the 20-40 one (55.3%), followed by the 41-60 group (41.7%). The 61+ group is really small (3.0%), including six cases, all of them from Italy. Concerning their mean age, the results are as follows: for 20-40 group it was 32.24 years (SD=6.21), for the 41-60 group it was 46.98 years (SD=4.93), and for the 61+ group it was 67.17 years (SD=6.52) (Table 13 and Figure 25).



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**Table 13**  
**Formal care givers’ mean age**

	Num-ber	%	Mean Age (years)
All formal care givers	199	100.0	39.44



Formal care giver by age group

20-40 years old	110	55.3	32.24
41-60 years old	83	41.7	46.98
61+ years old	6	3.0	67.17

**Figure 25: Formmal caregivers by age group.**

Most formal care givers are female (77.3%), which means that male caregivers’ share is greater in the formal group than in the informal one. In the case of Romania, all formal caregivers are female. Turkey is the country with the largest percent of male formal care givers. Moreover, 61+ formal caregivers were only found in Italy. In summary, we can see younger ages for the formal caregivers than for the informal.

	Number	% (row)	Country % (row)							
			Turkey		Romania		Italy		Spain	
<b>All formal caregivers</b>										
Female	153	76.9%	34	56.7%	10	100.0%	94	83.9%	15	88.2%
Male	46	23.1%	26	43.3%	0	0.0%	18	16.1%	2	12.8%



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Total	199	100.0%	60	100.0%	10	100.0%	112	100.0%	17	100.0%
<b>20-40 years old</b>										
Female	82	74.5%	22	50.0%	10	100.0%	41	89.1%	9	90.0%
Male	28	25.5%	22	50.0%	0	0.0%	5	10.9%	1	10.0%
Total	110	100.0%	44	100.0%	10	100.0%	46	100.0%	10	100.0%
<b>41-60 years old</b>										
Female	67	80.7%	12	75.0%	0	100.0%	49	81.7%	6	85.7%
Male	16	19.3%	4	25.0%	0	0.0%	11	18.3%	1	14.3%
Total	83	100.0%	16	100.0%	0	100.0%	60	100.0%	7	100.0%
<b>61+ years old</b>										
Female	4	66.7%	-	-	0	-	4	66.7%	-	-
Male	2	33.3%	-	-	0	-	2	33.3%	-	-
Total	6	100.0%	-	-	0	-	6	100.0%	-	-

As regard who they live with, most formal care givers did not live with the care recipient (78.7%). This is the most common situation as formal care givers tend to be not family-related to the care recipient. Therefore, it is interesting to describe those who did live with the one they care for (21.3%). These are 43 formal care givers who are generally women (77.2%) and live mainly in Italy (72.1%) and Spain (23.3%). In Romania, only do two formal care givers live with the care recipient and none did so in Turkey (Table 15).

**Table 15**  
**Do formal caregivers live with those they care for?**

<b>Yes</b>	
%	
<b>No</b>	
%	
All formal care givers	46
	77.2%
156	22.8%
<b>% (country)</b>	
	<b>Yes</b>
	<b>No</b>
	<b>Total</b>
	<b>43</b>
	<b>100.0%</b>

**Table 16**  
**Informal care givers living with care recipient**

	<b>Number</b>
	%
<b>Gender</b>	
Female	40
	93.0%
Male	3
	7.0%
	<b>Total</b>
	<b>43</b>
	<b>100.0%</b>



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**% (country)**

By country

			<b>Country</b>	
Turkey	0.0%	0	Turkey	0
60		38.5%		-
Romania	4.7%	2	Romania	2
8		5.1%		4.7%
Italy	72.1%	31	Italy	31
81		51.9%		72.1%
Spain	23.3%	10	Spain	10
7		4.5%		23.3%
			<b>Total</b>	<b>43</b>
				<b>100.0%</b>

On average, caregivers have been caring for someone else for 4 years now and the average hours per day dedicated to caring was 9.83 (SD=6.05).

When approaching their nationality or continent of origin, there are two possible approaches: one taking into account the four countries and another one splitting into two groups: a group for Turkey and Italy, and a second group for Italy and Spain.

If we follow the first case, we can see that most formal care givers are Europeans, on a second place they are from Latin America and then from Eastern Europe (Table 17).



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<b>Table 17</b>						
<b>Formal caregivers: Continent of nationality (numbers)</b>						
<b>Country (%)</b>	<b>Western Europe (50.0%)</b>	<b>Eastern Europe (21.3%)</b>	<b>North Africa (2.5%)</b>	<b>Latin America (24.8%)</b>	<b>Asia (1.5%)</b>	<b>Total</b>
Turkey	60					60
Romania	10					10
Italy	31	43	5	33	3	115
Spain				17		17
<b>Total</b>	<b>101</b>	<b>43</b>	<b>5</b>	<b>50</b>	<b>3</b>	<b>202</b>

What about the relationship between formal care giving and immigration? If we take data from Table 17, the relationship seems very weak. Yet, it is a mistake to take all countries altogether. That is why it is better to split into two groups: a sub-group for Turkey and Italy, and a second sub-group for Italy and Spain. The first sub-group (Turkey-Romania) is composed by all European caregivers. This is so because these two countries are not immigrants’ destination, so caregiving is mainly carried out by nationals of the country. On the other side, the second sub-group is formed by two countries (Spain and Italy) which are immigrants’ destination and where non-national population is usually employed in low-qualified jobs.

As can be seen in Table 18, when taken only Italy and Spain, and taking out Western European caregivers, this is a more realistic picture of the proportion of immigrant informal caregivers. Most of them are from Latin America (49.5%) and from Eastern Europe (42.6%). These results indicate that a increasing number of immigrants are becoming more and more the formal caregivers of impaired persons in some industrialized countries in Europe. North African and Asian informal caregivers are unusual, perhaps due to cultural reasons. Yet, the grounds to reach a conclusion on this issue must be must further analysed.

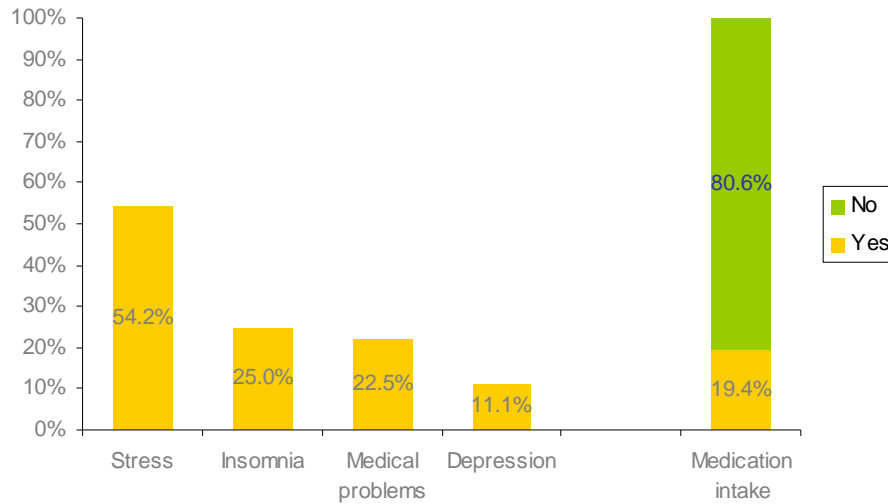
<b>Table 18</b>						
<b>Formal caregivers in Italy and Spain. Continent of nationality.</b>						
<b>Country (%)</b>	<b>Western Europe</b>	<b>Eastern Europe (42.6%)</b>	<b>North Africa (5.0%)</b>	<b>Latin America (49.5%)</b>	<b>Asia (3.0%)</b>	<b>Total</b>
Italy	31	43	5	33	3	84
Spain				17		17
<b>Total</b>	<b>31</b>	<b>43</b>	<b>5</b>	<b>50</b>	<b>3</b>	<b>101</b>



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***Descriptive results from the psychological and medical problems***

The most frequent problem thought formal caregivers was stress (54.2%), followed by insomnia (25%), medical problems (22.5%), and in the last place depression (11.1%). In relation to the drug intake for the treatment of these disorders, 19.4% answered yes when asked if they were in treatment for these psychological and medical problems (Figure 26)



**Figure 26: Psychological and medical problems faced by formal care givers and their use of medication for these problems**

***Training needs of the formal caregivers***

A large number of formal caregivers had received training (72.1%). This training lasted on average 307.66 hours (SD=397.62). As regard taking part in a self-help group, only a small share (24.6%) of the formal care givers takes part in one of them (Figure 27).



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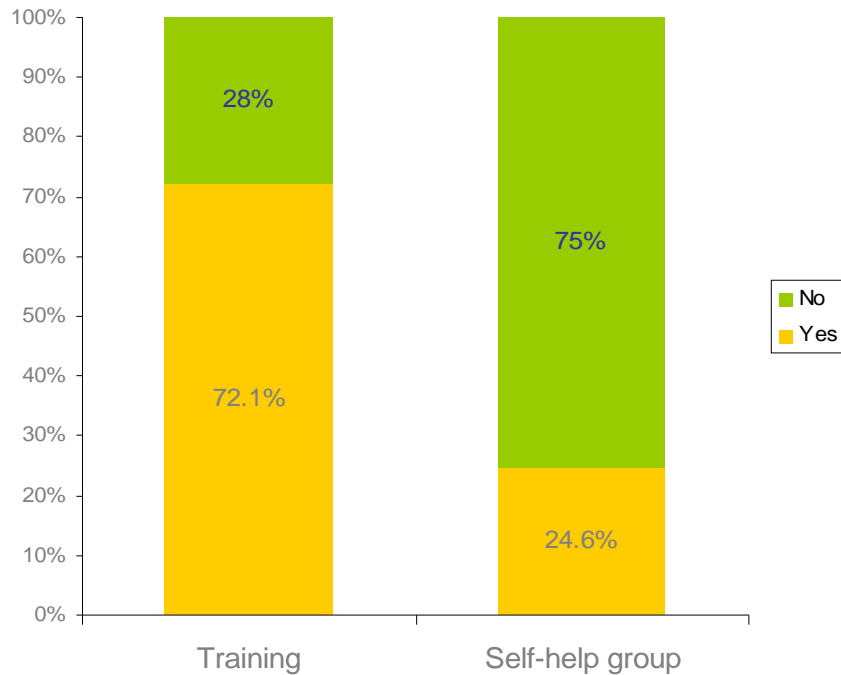


Figure 27: Informal care givers: Training received and participation in self-help groups.

### *Identification of needs: psychological area*

Half of the informal caregivers perceive having enough time for their own activities (49.3%) and enough time to spend with their family and friends (46.1%) (Figure 28). These figures are a bit higher than the ones found in informal care givers (see Figure 20), which stated 37.8% and 38.9% respectively. Let us recall that most informal care givers live with the one they care for (56%, See table 10) and 84% are family-related. Thus, it is more likely that formal caregivers perceive to have more time for their own and for their own people.



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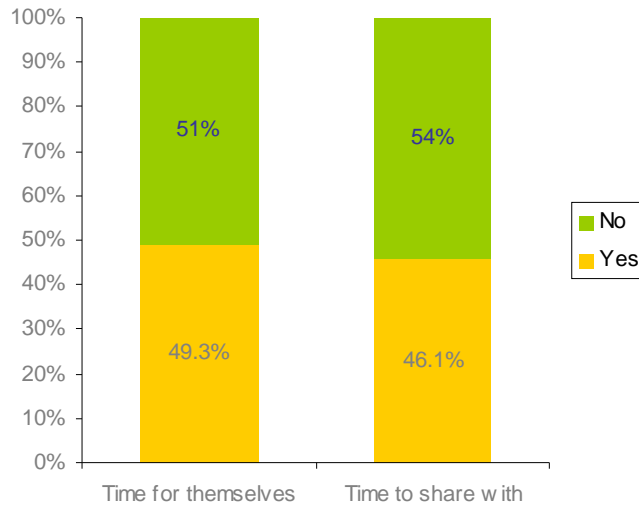


Figure 28: Formal care givers' time use.

#### Identification of needs: Organizational area

In this respect, the vast majority of caregivers think that they would like to ask for more formal support. In the organizational area they consider of interest to have support in the following areas: Nursing (54.9%), Housework such as cleaning, shopping, etc. (50%), administration including bank, doctors' appointments, legal issues, etc. (40.1%), personal hygiene care and help with activities of daily life (16.7%), Public financial support from the Government (15.5%) and other kind of help, e.g. help with child care, other elderly people (14.4%) (Figure 29).

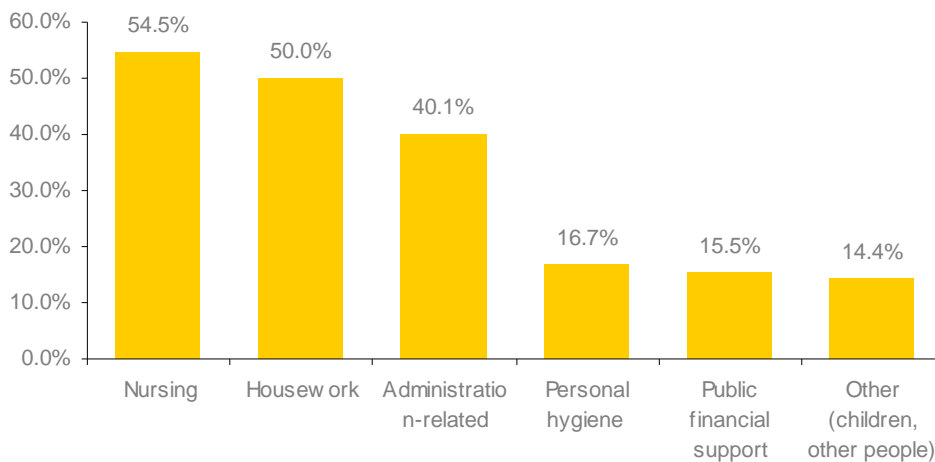


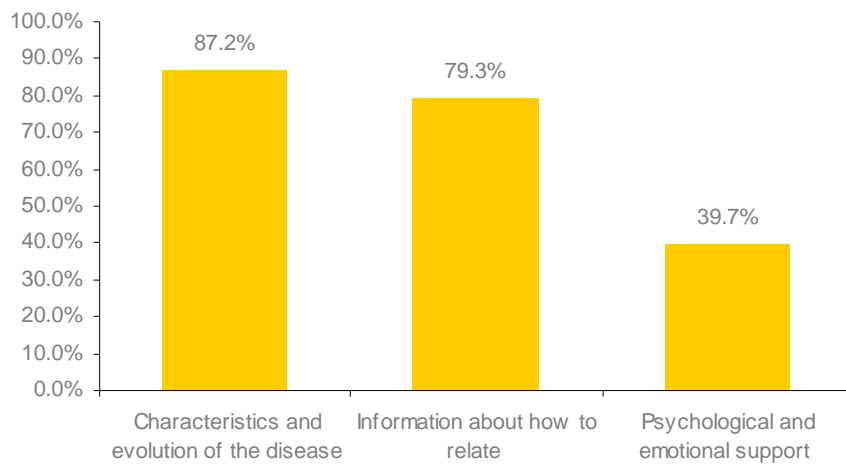
Figure 29: Type of help identified by formal caregivers



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***Identification of needs: training***

It is of interest to know the training needs of this population in order to provide them with useful tools to cope with their daily activity. In this sense the 87.2% of the formal caregivers estimate of interest to more information about the characteristics and evolution of the disease of the person they care for, to have more information about how to relate to the person they care for (79.3%) and to get psychological and emotional support (39.7%).



**Figure 30: Main topics for training identified by formal care givers.**

Regarding the topics they would like to be trained in, they address the following: skills to the management of the behavioural problems of the patient (60.8%), psychological and emotional support for the caregiver (39.7%) and skills to improve the relationship between the caregiver and other people (43.1%).

They would like to get this information by means of: Training courses (62.8%), meetings with professionals (58.8%), Booklets (31.7%), Specific websites (18.3%), DVDs (15.7%), TV, radio (10.1%), and other (4%).

**5.2 Trainers**

A total number of 106 questionnaires were gathered from trainers dedicated to offer training or support to caregivers in four different countries: Turkey, Romania, Italy and Spain. The distribution per country is the following: Turkey collected 5 questionnaires



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(4.7%), Romania 26 (24.5%), Italy 63 (59.4%) and finally in Spain 12 questionnaires were gathered (11.3%).

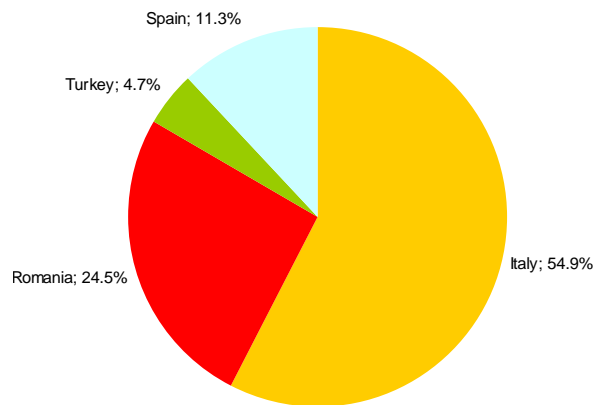


Figure 31: Distribution of the collected questionnaires by country

***Sociodemographic characteristics of the trainers***

In general the average age of trainers was 41.93 (SD=9.57) being the range from 24 to 60 years old. The majority of them were female (76.4%) against the 23.6% that were male (Figure 32).

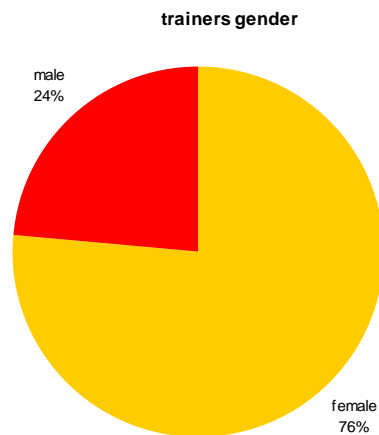


Figure 32: Trainers gender



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If we analyze the sex of the trainers by Country we found that again the majority of the trainers are female (Table 19).

<b>Table 19 Distribution by gender and country of the trainers</b>				
	<b>female % (country)</b>		<b>Male % (country)</b>	
By country				
Turkey	4	80%	1	20%
Romania	22	84.6%	4	15.4%
Italy	44	69.8%	19	30.2%
Spain	11	91.7%	1	8.3%

Concerning the profession of the trainers, they were mainly psychologists (26.4%), followed by nurses (24.6%) or physicians (22.6%), although a little proportion of them were social workers (9.4%) and other kind of profession (15.1%) (Figure 24).

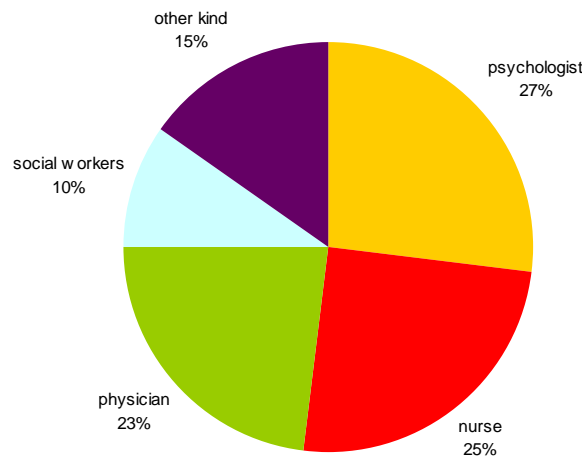


Figure 33: Trainers occupation

Usually, they had received training in the caring of the elderly with dementia (84.9%) and the most frequent place of work was a medical facility (52.8%), followed by a nursing home or rest home (24.5%), a voluntary organization 20.8%, an association 17.9% and, in the last place, a day care centre (15.1%).



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## *Kind of caregivers they train and methodological issues*

Answering to the question about the kind of caregiver they use to train, they are in contact more frequently with both formal and informal caregivers (44.3%), although there are some trainers that only train informal caregivers (34.9%) or formal caregivers (20.8%) (Figure 34). A huge amount of trainer’s lead self-help groups (61.3%), in their opinion, it is very important the training of caregivers (99.1%) and usually they assess in some way the effectiveness of their training (78.3%).

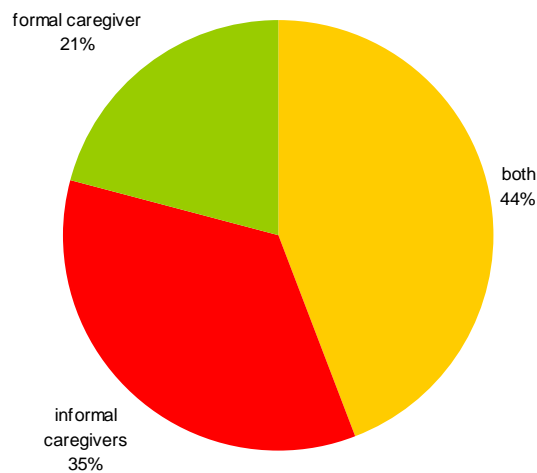


Figure 34: Kind of caregivers trained by trainers

## *Training needs of professionals*

In the questionnaire several questions related to trainers training needs were included. In general professionals consider of interest to improve skills on a specific context of their work (92.5%). Regarding the means by which they would like to be trained in this topics the answer that in the majority of the cases was that they would like to be trained in team work (84.9%), in addition to Multimedia tools (59.4%), Lessons (54.7%), Papery materials (51.9%), and Other menas (19.8%) (Figure 35).



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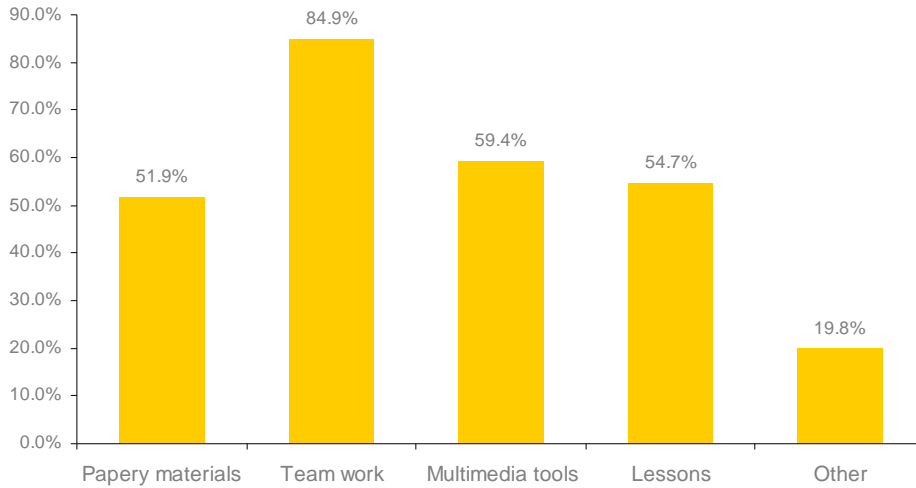


Figure 35: trainers training needs

In this section of the questionnaire another question related to the training needs of the caregivers was included. The question was which topics they find of interest in the training of caregivers. The main topics or fields they estimate interesting caregivers to be trained in were: Information about the disease and its development (83%), Skills to improve the emotional and psychological aspects of the caregivers (81.1%), Strategies for the improvement of the communication (70.8%), strategies to modify the behavioural problems of the care recipient (68.9%) and finally self-care of the caregivers (54.7%) (Figure 36).

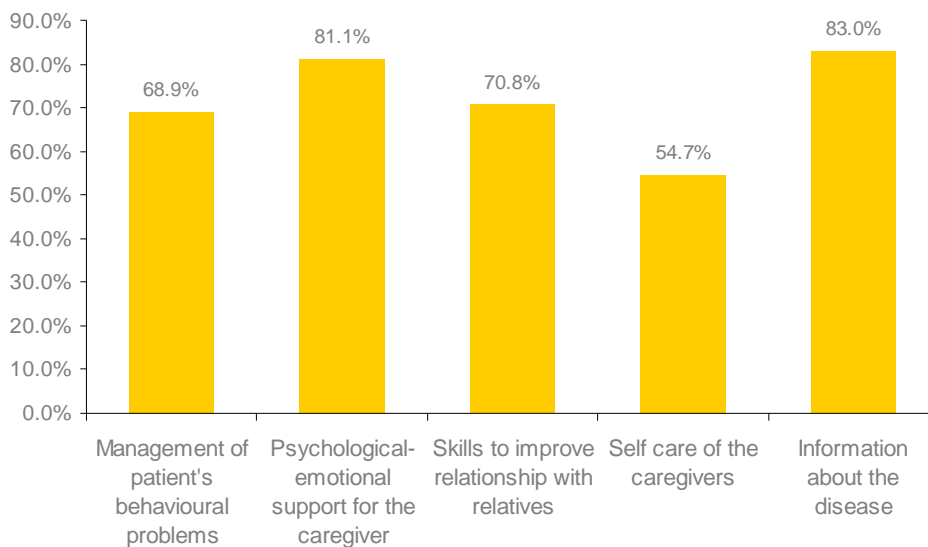


Figure 36: topics of interest in the training of caregivers



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