EUROFAMCARE

Services for Supporting Family Carers of Older Dependent People in Europe: Characteristics, Coverage and Usage

The National Survey Report for Italy

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1 Introduction

by Sabrina Quattrini and Giovanni Lamura

This report focuses on the main findings of the National Survey carried out in Italy for the European research project EUROFAMCARE. In the following paragraphs an overview of the aims and overall methodology of the project will be described, followed by a preliminary introduction in the European survey's main features, and by an outline of the contents of the chapters making up this report.

1.1 Aims of the EUROFAMCARE (EFC) research project

EUROFAMCARE is an international research project funded for the period 2003-2005 by the 5th "Framework Programme for Research and Technological Development" of the European Commission (Key Action 6: The Ageing Population and Disabilities, sub-section 6.5: Health and Social Care Services to older People, Contract N° QLK6-CT-2002-02647, see website in: http://www.uke.uni-hamburg.de/extern/eurofamcare/).

As its subtitle clearly reveals – "Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage" – the project has mainly aimed at providing a comprehensive picture of the existence, familiarity, availability, use and acceptability of services or measures addressing the needs of family carers of older people in Europe. In this respect, an explicit objective has been to formulate empirically based suggestions at the following levels:

- at a *macro-level*, for the implementation of more organic and *carer-friendly* policies addressing family carers in Europe;
- at a *meso-level*, to promote an in-depth collaboration between service providers, local agencies and family carers, thus contributing to develop services better responding to the users' needs;
- at a *micro-level,* to better understand the interpersonal dynamics underpinning the caregiving phenomenon, in order to formulate recommendations to improve the carers' quality of life and by these means also the quality of the help received by the cared-for older persons.

A particular effort of the project was to identify those support services suitable to promote positive effects on the caregivers and/or preventing negative consequences and implications connected to the caregiving duties, by inquiring the carers' experience in using them, the reasons of non use and possible barriers to their access. The above objectives have been pursued by analysing in detail following aspects:

- the differential between support services availability and the carers' knowledge about it;
- the use and non-use of such services, and the reasons behind it;
- experience with and assessment of such services with respect to effectiveness and efficiency;
- the specific support needs resulting from individual family care situations, including the identification of a possible lack of valuable types of support or service characteristics.

From a pragmatic point of view, the EUROFAMCARE project aimed at using the research findings to promote a change in the care management process at various policy levels, in order to push social policies towards a more dialectic partnership approach between family carers, professional providers and cared-for older people.

1.2 Overall methodology of the project

The project involved six core countries representing the main types of welfare states existing in Europe (Germany, Greece, Italy, Poland, Sweden and the United Kingdom), where detailed empirical data on the caregiving situation have been collected by means of national surveys and analysed to produce six **National Survey Reports (NASUREs**), of which the present constitutes the Italian one. In further 17 countries (which together with the core countries composed the so called “Pan-European group”), only secondary data analysis on available literature and documentation related to support services for and needs of caregivers and dependent older persons has been carried out by appointed national experts. These provided a **National Background Report** (NABARE) for each of the 23 chosen countries, whose contents are available for download on the project’s website (http://www.uke.uni-hamburg.de/extern/eurofamcare/presentations.html), while a Pan-European Background (PEUBARE) report, containing a comparative synopsis of all NABAREs, has been released as a separate publication (Mestheneos and Triantafillou 2005). The information gathered by means of the NASUREs, NABAREs, PEUBARE and further, more specific data analyses have provided the premises to carry out a **Research Action (REACT**) phase, consisting in dissemination activities for and with family carers’ organisations, service providers and policy makers at a local, regional, national and European level, complemented by a **Socio-Economic Evaluation** and a **European Policy Analysis** (see the project’s website for more details).

1.2.1. The EUROFAMCARE National Survey

The EUROFAMCARE National Survey is actually compounded of three connected, but at the same time distinguished pieces of research, represented by a family carers “baseline study”, a “follow-up” study and a service providers survey (more detailed information regarding the execution of each of these in Italy will be provided in chapters 4, 8 and 9 respectively).

The baseline study

In each of the six core countries of the EUROFAMCARE project, a National Survey on about 1.000 primary family carers of older people aged 65 and over has been carried out in the first half of 2004, the main inclusion criteria being that caregivers were providing at least four hours of care per week. Carers have been stratified by kind of locality (metropolitan, urban or rural), representing different regions (four macro-areas in Italy), and interviewed using a Common Assessment Tool (CAT), inquiring several dimensions of the caregiving situation: burden of care, needs of the caregiver in relation to those of the older person, experiences in the use of the existing support services, conciliation of professional and caring responsibilities etc. The collected data have been entered in an SPSS based databank in order to create an integrated European dataset, which has been then analysed to produce six national background reports (NASUREs) – this document representing the Italian one – as well as a Trans-EUropean Survey REport (TEUSURE). These reports illustrate, both at a national and a European level, the situation of family carers as well as support services and policies addressing their needs, and provide a first picture of cross-nationally relevant typologies of family care situations.

The follow-up study

Twelve months after the baseline survey, the same family carers have been contacted again for a follow-up interview, mainly aimed at producing longitudinal data for a more in-depth socio-economic evaluation of the impact of caregiving on their conditions, and at estimating its consequences in terms of perceived quality of life, thus allowing a better understanding of European-wide politico-economic implications.

Service Providers Survey

The views of professional care service providers were also collected in the second half of 2004 in order to gather their experience with family care. Detailed information were in particular collected by means of semi-structured interviews to over 200 service providers (of which 53 in Italy), concerning services provided to carers and older persons, overall aims of these services, main benefits for family carers, problems experienced by family carers in accessing, cost of services, areas of family carers' needs not covered, assessment and monitoring of needs, examples of good practice, current challenges as well as service providers' strategies to implement future developments.

Interviews have been collected through face-to-face interviews or postal questionnaires submitted to the main representatives (or the delegated ones) of the most relevant care service organisations operating in the sites/regions where the Italian survey on family carers has been carried out, subdivided into the following categories: public social services; public health services; voluntary associations; religious associations; private services; caregivers' or older people's associations.

1.3. Chapters overview

This report illustrates the main findings emerged from the survey on family carers of older people and providers of support services, according to following chapters structure.

After the main purposes and articulation of the EUROFAMCARE project presented in this chapter, **chapter 2** introduces a bibliographical review of existing literature on the topic of support services for family carers of older persons and related themes. **Chapter 3** illustrates the contents of the questionnaire used to collect carers' interviews and the psychometric characteristics of the scales included in it. **Chapter 4** describes the sampling and recruitment procedures used to contact the 1,000 caregivers, and discusses the representativeness of the reached sample. **Chapter 5** provides a general overview of the sample of carers and related sample of older people (age, sex and other main socio-demographic features), and of the characteristics of the caregiving situation. **Chapter 6** proposes a typology of the main caregiving situations present in Italy, obtained using a cluster analysis approach. **Chapter 7** presents data on the use of the support services by caregivers and older persons, the experience and satisfaction by caregivers in using them, the factors associated with service use, the impact of the service use on the situation of the caregiver and the financial support due to the caregiving situation. **Chapter 8** illustrates the results of the survey carried out with services providers, comparing their point of view with that of caregivers, especially with respect to the types of support and characteristics of services considered as more important by the two groups of subjects. **Chapter 9** analyses the preliminary results of the follow-up study, focussing in particular on the changes occurred in the caregiving situation, in the level of disability of the older person and in the subjective outcomes for caregivers in service use. The report ends with **chapter 10,** which summarises the most relevant findings and political implications emerging from the survey.

2. State of the art of literature on family care of older people in Italy

by Maria Gabriella Melchiorre

2.1. Introduction: the needs of older people and their family caregivers

2.1.1. Population ageing statistics

Data from the 2001 census – carried out by the Italian Statistical Institute (ISTAT) and concerning the demographic structure of the Italian population – reveal a nation with an increasing life expectancy (reaching 76.8 years for men and 82.9 for women), where one out of five inhabitants are aged over 65, 8.4% are over 75 and one in 20 over 80 (Casadei 2003, ISTAT 2003). In the European Union, over-75 year old should increase by 24% between 2000 and 2010 (growing from 27,287,000 to 33,722,000), thus accounting in several countries, like Italy, for up to 14% of the population by 2030. This will contribute to a rise of the potential share of dependent individuals, the current share of over 65 Italians with severe disabilities being estimated between 10 and 20% of the total, and significantly higher after the age of 75-80 (Pesaresi & Gori 2004).

United Nations Organisation's data rank Italy second in the list of the world's oldest countries in terms of median age, just behind Japan (UN 2005: 58). Compared to the observed, high rate and intensity of ageing, social and economic structures have not always been capable of adapting at the same speed to support this pace of demographic change. In effect, the insurgence of chronic-degenerative diseases, apart from other causes of disability, have determined an increase in the number and change in the quality of socio-medical demands, that relevant structures are ill-equipped to meet. Population ageing therefore brings greater welfare demands, which have on turn an evident fallout on public spending (Ungaro 2002), especially on the cost of pensions (ISTAT 2003). The picture is even more critical when it is acknowledged that the incidence of poverty amongst older people is above average, reaching 13.9% (compared to the average of 10,6%) in families with at least one over-64 year old and a peak of 16.7% in household when more older people are present (ISTAT 2004a). In today's Italian society, therefore, the fragility of the family and its weakened capacity for care, together with the increased flexibility of employment and the precariousness of living arrangements, affect increasingly large strata of the population, rendering former certainties instable, especially in more vulnerable groups like the older people (Micheli & Ranzo 2003).

Inevitably this has been an incentive, for more than a decade, for a series of initiatives including the Italy's declaration of 1993 as the "European Year of the Elderly and Solidarity Amongst Generations" (Calvazara 1993), 1999 as the "International Year of the Elderly" by the United Nations (Boccacin 2000), 2001 as the "International Year for Voluntary Work" (Zanella 2001), until the Second World Assembly on the problems of ageing organized by the UN in Madrid in 2002, whose International Plan of Action aims to improve health and well-being in older age, also by means of better training of caregivers and support to carer families (Guiducci 2004; Pinzauti 2002), while a specific conference on "New welfare for the family", held in Bologna in 2004, examined prospects for "taking care of the family" within the International Year of the Family (Forum 2004).

2.1.2. Family caregiving

The demographic evolution occurring in Italy and other European countries, characterized by the simultaneous increase in average life expectancy and incidence of the elderly population, means that a growing number of families will be called upon to offer informal care for increasingly lengthy periods of time. Consequently, since it is traditionally the family network that mainly deals with the demand for care from its weakest members, this has created a significant “underground” sector of welfare work, unaccounted for and “internalised” by families and other relevant social networks, where there is urgent need for channelling of an adequate flow of public resources as well as of human and organizational support. In particular, the circle of relatives beyond the family nucleus is the chief source of support before public and private services, which appear to have limited capacity of intervention in this field (Bertolini 2002). Friends can also play an important role in caring (Himes and Reidy 2000), although it is unlikely they will assume relevant responsibility for caregiving, because of possible role conflicts. The presence of “good neighbours” is also sometimes reported (Pinotti 2004), as well as of the support from volunteer associations (Sansa 2004), especially in Northern Italy (where over 60% of all volunteer organizations are localized, ISTAT 2004b).

Therefore, even today, the family is the largest welfare institution in Italy (Giancaterina 2004). Indeed, it plays a fundamental role in the management of care and support of the more fragile, especially older disabled, so that the alternative of the institutionalisation is rarely preferred, and usually limited only to cases where the elder has no children living nearby, or these have serious health problems. Since the concept of “care” is a composite idea - which includes health and social care services, but also actions generated by affection, friendship and solidarity - support policies for the elderly must therefore take into account the work performed by relatives, and guarantee them adequate support so they can continue to care (Colombo 2002). That is why assessing caregiver needs must become a starting point for defining caregiver’s rights and support actions. A correct and efficient management of dependent patients has to place their family at the heart of the care system, taking into consideration the family system (Scaglia et al. 2001), since adequate solutions can only be planned if both the needs of the caregiver and of the care recipient are observed and understood, in their individual peculiarities and reciprocal points of interaction (Azienda USL di Cesena 2002).

Scrutiny of “caregiving families” means looking at relationship-level significance of “taking care” of next of kin who are not self-sufficient, affected by handicap, illness, psychological malaise. Thus, a first perspective for analysis may be the emotional sphere, examining the various family settings, quality of relationships prior to the critical event, the role of the formal care system and informal solidarity networks. A second perspective, called “dual forms of caring”, on the other hand, consists of looking at and understanding the needs of the caregiver and of the care receiver in their interdependence: this, in particular, allows operators to perceive needs that many be in contrast and develop mediation skills. Moreover, the ethical values developed in the caregiving family context must be supported, as they are a heritage of resources for ensuring the family shoulders its responsibilities (Taccani 2002).

As already identified in countless studies, if the support and care of fragile elderly family members is not adequately supported, however strongly it may be desired, there may be a significant deterioration in the quality of life for the chief caregiver, who risks being affected by high levels of emotional and psychological tension, until they, in turn, become a “second victim” of disabling pathologies that affect the elderly person, and consequently will need care themselves (Toseland and al 1995; Kropf 2000).

Traditionally there have never been specific policies for family caregivers in Italy (Polverini et al. 2004), although things have begun to change to some extent part in recent years. What is more, this state of affairs also allows limitation of public expenditure, since it is an alternative to hospitalization (Da Roit 2002a: 106). However, the debate on caregiver rights is growing and steps should be implemented for promoting assistance and support for family caregivers through socio-institutional services (Colombo 2002: 39-45).

The 2003-2005 National Health Plan (as in the previous 2002-2004 plan and the older 1998-2000 plans) pinpointed care for the chronically ill, the elderly and the disabled as a priority action area. “The elder lives better at home and in a family context. Often, however, the family has economic and logistic difficulties in offering home care to the elderly person needing assistance. So the family must be supported in this task” (National Health Plan 2003-2005: 18). The home is a significant setting for everyone, as it is not only where we reside but it is also, and above all, a place of belonging to a family and of family experience: the family, as the “caregiving playing field” is, in particular, an open system, a dynamic field. This suggests that it is opportune to provide a multidimensional description of requirements that meet and connect with all the resources available in the local community of the persons involved (Cantini et al. 2002). Rest-homes, on the other hand, are often units that cause uprooting and a sense of abandonment; any intervention policy must bear in mind problems of institutionalization, but also of remaining in the home. Encouragement of home care means fostering the elder staying with their family and in their home, through a network of services and solidarity (Bentivogli 2001).

Supporting the family in caregiving means understanding the physical and psychological difficulties, and accepting and supporting situations of sudden deterioration, economic and financial difficulties, serious health problems requiring trained personnel, problems caused by architectural barriers in the home (Cesena Health Authority 2002; Kropf 2000). In particular, symptoms of depression (White et al 2000) and stress often associated with “long-term in-home care for impaired older persons” (Whitlatch et al 2001) should not be underestimated. Extra costs, when the carer lives at a distance from the person being cared for, should also be considered, as this complicates managing time dedicated to paid employment (National Alliance for Caregiving Mature Market Institute of Met Life 2004). It is very important to consider the social setting within which both the caregiving and the support occur (Askham 1997), especially when people have other identities and are not just caregivers; in fact, support which helps them to balance their various roles may be just as important to their ability to continue caregiving as direct support to the actual caregiving (Hoerl 1997).

To promote adequate knowledge of carer needs so that their demands are properly classified in strategies for service reorganization, it is very important to proceed to a definition of caregivers’ socio-economic characteristics and to an analysis of the difficulties that they meet in the economic-financial, relational and human contexts. These conditions are extremely important when care is given within the family unit (CENSIS 1993). It should also be considered that the family often feels judged by other relatives as far as care given to elderly next of kin is concerned, and although subjected to heavy pressure that it is unable to manage, it often refuses help because it feels indispensable. Sometimes even friends lose touch, especially when there is an elder affected by dementia in the home, and this intensifies the devastation of the carer’s social contacts (Cesena Health Authority 2002).

It is also known that the caregiver commitment is prevalently sustained by women, especially wives and daughters (Stone et al 1987; Kropf 2000; England 2001; Laditka & Laditka 2001), in particular when dependence, involves daily routine. In fact, most “home care” is undertaken by female figures and, in particular, those aged from 50 to 69, who shoulder heavier domestic workloads (on average in excess of 30 hours a week). Family caregivers are prevalently women aged between 50 and 75, with close family ties with the elderly person they look after; the caregiving commitment tends to vary from 20 to 45 hours a week and, of course, increases as the elder becomes less self-sufficient (Cossentino & Innorta 2004). So it is the female caregiver who suffers most from loneliness for loss of contact, lack of time for herself and feeling obliged to stay at home for long periods because there is “no one” to take over her caregiving role, even temporarily (Cesena Health Authority 2002).

The tendency to keep non-self-sufficient older people at home as long as possible, favoured by European and national political currents, presupposes and often takes for granted the presence of this support provided by female relatives. However, this appears increasingly unlikely, at least in the forms that prevailed in the past, since women aged between 40 and 65 – figures traditionally involved in person in family care – are now participating in larger numbers in the labour market. Furthermore, there are other factors such as the smaller average size of a family nucleus and slackening of intergenerational bonds. The domestic and family workload, which weighs on several age groups of the female population, therefore appears as an outright problem of caregiving sustainability, especially when domestic routine combines with a paid job on the labour market (Cossentino & Innorta 2004).

So observation of family social policies is called upon to deal with the compatibility for women of caregiving and working on the open market. The woman’s role began to be considered a “double presence” in the 1970s (Balbo 1978; Saraceno 1998) and there are many socio-cultural and economic factors that have led to the “breaking of the vicious circle of interchange” between family and welfare state. Two possible scenarios emerged: one envisaged the possibility for women to enter and/or leave the labour market with utmost flexibility, in a context that safeguarded their social rights, not as citizens, but as wives or mothers; the other was based on a parental leave system to foster the co-presence of productive work, and work for the market, with a more symmetrical organization of family workload (Di Nicola 2003). Caregivers often experience conflict arising from their attempts to balance the caregiver role with other social roles. This conflict is especially relevant for adult daughters who make up a significant percentage of caregivers for elderly relatives. Their other roles are typically mother, wife, and employee, hence Elaine Brody’s term, “Women in the Middle.” (Stephens et al 2001).

Problems increase for caregivers who are involved with sufferers of dementia. An Italian study measured and compares use of and satisfaction with medical and social services, in addition to subjectively perceived needs of family supporters of patients with probable or possible Alzheimer's Disease (AD), and family carers for elderly people who do not suffer from dementia (Dello Buono et al 1999). Carers for the older people suffering from AD were significantly more involved in providing care than supporters of those not affected by dementia. Assessment of family health, social relations and financial status showed significantly lower levels in AD supporters than in supporters of non-AD elderly.

Caregivers are adults or older people who also have to deal with other personal, family and social demands. So care strategies must be identified or an organization must be set up to offer support to the family system in the difficult and delicate caring task, with focus on a communication process with the family and functioning of the actual family system (Taccani et al 1999). The definition of family caregiving in the population must include instrumental help provided for functional disabilities in care recipients, as well as additional factors such as financial support, emotional support, employment foregone to provide caregiving, and the arrangement and payment of formal caregiving services (Horowitz 1985).

2.2. Services and monetary transfers for older people and caregivers

In Italy there are few ad hoc services for caregivers, and of the few that do exist, even fewer are actually used. They are chiefly monetary benefits of which there are several for the elderly and their use often translates into indirect relief for caregivers.

2.2.1. Services for older people that provide support to caregivers / Indirect services for family caregivers

In Italy there are supports for family caregivers through health and social services for the elderly (Polverini et al 2004). We have:

- Community services: General Practitioner (GP), SAD (Home Care Service), Programmed Home Care Assistance (ADP) - medical home care provided to patients who are unable go to their GP's surgery - and Integrated Home Care Assistance (ADI), offered to terminal patients or those affected by severe pathologies; home medical treatment and rehabilitation;

- Community Care Centres: with an organizational function, stores applications and assesses needs (in the form of Assessment Units), with the aim of integrating users into the welfare services network.; Day care ("protective" care) services are welfare structures that offer rehabilitation and recreational services, personal care and hygiene services for partially disabled elderly in semi-residential accommodation (http://www.comune.castelnovo-di-sotto.re.it/INFORMA/urpsitoweb5.nsf/ServTerrCentroDiurno/$first?OpenDocument).

- Residential care in residential facilities (RSA for non self-sufficient older people and residential facilities for self-sufficient or partially self-sufficient older people) (Tomassini et al 2004).;

- Acute care in hospitals, Home Hospitalization (OD: the activation at the patient's home of a number of diagnostic and therapeutic services generally provided in hospitals) (Lamura et al 2001: 103-107).

Home care for the non-self-sufficient elderly is the type of assistance preferred by all governments, both as targeted care for assisting older people in their daily lives and as home care that ensures nursing and rehabilitation. The extent of home care differs widely from country to country in Europe: in Northern Europe more than 10% of the elderly receive home care, whereas in the South less than 3.5% do. The trend is to intensify home social and health care services, with more flexibility in providing services and a greater coordination of provided services (Fogli-etta F., 2004). As integrated home care is classified as part of socio-medical integration, alongside semi-residential and residential care, it is found in numerous regulations: in attachment 1c to DPCM (Prime Minister's Decree) of 29/11/2001, which considers three micro levels within the macro level relative to territorial surgery and home care, envisaging care services at the person's home - ADI and ADP, socio-rehabilitative services for the disabled, socio-medical service for terminally ill and AIDS patients -; in the "Act to address and coordinate socio-medical services" (DPCM 14 February 2001), which identified ADI as a service targeting the elderly and those suffering from chronic-degenerative pathologies; in Art. 22, Law 328 of 8/11/2000, which pinpoints home care as one of the essential levels of social services (Pesaresi F., Gori C., 2004). In Italy the "home help" category includes people who do the housework and help with personal care (hygiene, getting up and going to bed, dressing, eating, bathing) (Polverini F. et al., 2004).

The day care service is viewed as one of the most adequate answers to the needs both of elderly patients and of their families (Taccani P., 2001). In CENSIS research on caregiving to patients affected by Alzheimer's Disease findings state that it is considered the most useful service by 30.7% of the sample but, at the same time, 27.8% of the same respondents define it as the most inadequate service (CENSIS, 1999; Vaccaro C.M., 2000). Integrated day centres are also useful, where the impaired elder is taken during daytime hours to be cared for, and to receive a series of medical and social services, including assistance with personal hygiene. When a family nucleus is not available but the mature person is sufficiently independent, they can also live alone in their own homes (Cesena Health Authority, 2002).

As far as residential care in Italy is concerned, in 1999 there were 2.7% institutionalized elderly compared to 9.4% in Iceland; so our country denotes a lower level of development for assisting the elderly in residential structures (rest-homes, sheltered housing and RSAs), like Greece, Portugal and Spain (Pesaresi F., Gori C., 2003). Nonetheless, Italy is the European country with the far lowest number of elderly placed in residential facilities or cared for by territorial and home services; furthermore, there is the economic burden, often unbearable for families, of maintaining an elderly person who is not self-sufficient in a unit (Lazzarini G.V., 2004). It should be considered that general recourse is made to a facility when the elder's health deteriorates considerably, or when the carer is no longer able to assist (Albert S.M., 2000). Moreover, family caregivers who place a loved one in an institution report relatively high levels of depression, anger and anxiety, and many continue to experience these negative consequences up to three years after admission of a relative (Whitlatch C.J. et al, 2001).

For partially self-sufficient and seriously ill patients, therefore, there are only two solutions: placement in a facility or recourse to non-EC women (Cesena Health Authority, 2002). In Italy 13% of families have an elderly relative in the home and often the person is not self-sufficient: in 88% of cases, the caregiver is a relative; in 9.8% the family receives the support of operators or *minders*; in 2.4% of cases, the elder is entrusted to a care structure (Caretta F., 2003). A CENSIS report, "Gli anziani e la salute" [health and the elderly], presented on 22 September 2004, stated that in Italy 2.4% of over-65s have a live-in minder (CENSIS, 2004), a percentage that rises to 7.65% for over-85s; moreover, according to ISTAT 2003 Report findings on the resident population, in Italy there are in excess of 260,000 older people with home help. This figure reaches its greatest concentration in Central Italy: 3.6% against 1.7% on the Northwest and 1.4% in the Northeast. In the South, 2.8% of elderly have minders, twice the number found in the North; it should be remembered that in these areas it is less likely that a person will be placed in an institution and that there are levels of non-self-sufficiency that are much higher than the national average. In fact, in Southern Italy and in the case of disabled elderly patients, the inadequacy of care structures means it is not unusual to resort to the employment of so-called "minders" (privately paid caregivers) (Polverini F. et al., 2004). This occurs mainly to ensure night care in hospitals, but in some residential units it can also be "suggested" for everyday routine care, justified by alleged lack of staff (Polverini F., Lamura G., 2004: 3). Foreign "minders" are almost invisible, silent presences in countless families, employed chiefly for helping with the elderly, and are a crucial component in Italy's overall social caregiving system. The phenomenon presents many traits of "hidden welfare", still largely characterized by the scarcity or lack of regulation, the widespread skirting of social security and tax laws, with failure to safeguard both the caregivers, who are generally foreigners, and the care recipients (Lazzarini G.V., 2004). The possibility of maintaining a functional equilibrium between our demands for caregiving and the availability of immigrant women to meet those demands, lies for the most part precisely in this different perception of the status of a home help: a subordinate activity that Italian women refuse with increasing frequency, a means of emancipation for immigrant women. "Useful interlopers" is the definition that pinpoints this widespread ambivalence for the need for a precious and vital service, and the perception of social and cultural distances. The belief, and the hope, is that immigrants, and this applies to family helpers too, are perennially just passing through (Lazzarini G.V., 2004). Employment that involves almost all immigrant women is helping out in the home, and this is not so much a vocation that these women have, as the response to the need expressed by the families. Labour demand from Italian families over the last 15 years has extended, in no uncertain terms, from caring for the home to caring for people, especially the elderly disabled, sick and or non-self-sufficient (Spinelli E., 2003). Very often the medium-high cultural level of these immigrant women, and their good knowledge of Italian, has made it possible to avoid modules of pre-training guidance (D'Ottavi A.M., 2003).

Another figure to mention is the "*health and social guardian*", in other words specialists who act as a point of reference for the older people living alone, and whose role is to assess and satisfy the needs of these users, applying to institutional health and social services networks, and friendship and solidarity networks (Cesena Health Authority, 2002). They identify and resolve situations of greatest need and difficulty in the elderly, with some simple, direct actions, like taking them to the doctor, buying medication, shopping, etc, which are concrete expressions of "home care" (Barbarani G., 2004a). The guardians are managed by a central operations unit that monitors activities, and they undergo basic training so they are able to identify dangerous situations that arise in critical moments during the year. They are an innovative model of taking responsibility for elderly members of society (Discalzi A., Del Prete C., 2004). The new role of "health and social guardian" has recently been introduced by Milan Municipal Council (Polverini F. et al., 2004), with the function of identifying needs of elderly people in difficulty, through their daily contact with those living in a specific district, and the relevance of such a scheme is further enhanced by the fact that it links up with another project of great welfare relevance: the "counselling bureau for the elderly", implemented with the aim of taking charge of situations which place elderly people at risk, and supporting caregivers in their problem-solving difficulties throughout their caring. (http://www.governo.it/GovernoInforma/Dossier/anziani_caldo/caratteristiche.html.).

So the services network is a fundamental point for offering rational assistance and is based on the presence of the *UGV* (geriatric assessment unit that evaluates how to implement management of each subject), ADI (useful for keeping subjects in their own home), day centres (semi-residential units for helping older people with social and health problems), sheltered housing (residential units that now only take in the chronically ill), RSA (nursing homes, strongpoint in the services network, with flexible organization). Then there are hospitals, which offer geriatric day clinics that are also fundamental for rehabilitation processes (Cucinotta D., 2002).

In particular, the UVG is a dynamic factor is assisting the elderly, called upon to valorise the contribution of the informal support network, both for assessment and for providing resources, (Bavazzano A. et al, 2004), especially in caring for persons affected by dementia, with the need for specific essential care levels for diagnosis, for dealing with behaviour disorders, and for staff training. Multidimensional evaluation (a UVG activity) is now a validated work methodology in geriatrics and, with an interdisciplinary approach and standardized instruments, aims to identify problems and resources in the health, psychosocial and functional context. The scope is to formulate a global treatment plan for the individual, with results that can be verified and measured in time (Veneri L. et al., 2001). For some years now, paths for guaranteeing adequate assistance on discharge have been sought (protected discharge), within which the geriatric assessment unit has a pre-eminent role (Tagliavini A. et al., 2001).

2.2.2. Services for caregivers

The five service areas identified in the National American Family Caregiver Support Program (Older Americans Act Amendment of 2000, Title III-E) are: information to caregivers about available services; assistance to caregivers in gaining access to these services; individual counselling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles; respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; supplemental services, on a limited basis, to complement the care provided by caregivers (Whittier S. et al., 2002). Effective actions for positive impact on caregiving families have, in fact, focused on education programs to impart basic caregiver information, community-based services to alleviate the demands of caregiving, psycho-educational support groups to facilitate adaptation amongst family caregivers, family counselling/therapy to resolve serious family conflicts or problems, and policies to address the concerns of caregiving families at social level (Toseland R.W. et al., 1995).

Special services for family caregivers in Italy are (Polverini F. et al., 2004).:

- *Free at point of use*: training courses on caring, counselling services for family caregivers, support or self-help groups for family members, helplines offered by associations for family members, internet services.

- *Completely privately paid*: regular respite home service (supervision of the elderly for a few hours a day during the week), temporary respite home service (substitution of the family carer for brief periods of time, for example, a week).

Another distinction is between services providing a break (home and residential services, day services outside of the home, leisure-social activities and holidays for caregivers) and non-breaks services (training, transport, information, helpline). In particular, there are gaps in information on services offering breaks to caregiver families. The challenge continues to be ensuring more equitable access to respite services, across all caregiving situations and communities, and for authorities to demonstrate appropriately that more caregivers are really being offered respite (Banks P., Roberts E., 2001).

Respite care programs are designed to offer temporary or periodic relief from the time demands of caregiving by providing care for recipients who are cannot be left alone due to mental or physical impairment. Respite is a secondary benefit received by the caregiver of a service provided to the care recipient. This relief affords the caregiver the opportunity to attend to other tasks, such as shopping and other errands, doctor’s appointments, relaxing and socializing. Respite services are categorized into three main forms: in-home care, adult day care, and overnight respite(Whittier S. et al., 2002; Kropf N.P., 2000;). In-home respite consists of someone providing care at periodic intervals in the care recipient’s home for a specified amount of time, while the primary caregiver is away or occupied by other activities. The type of care that is most useful to the caregiver will depend on the caregiver’s and care receiver’s needs. Early use of respite care is especially important if caregivers are to receive the greatest positive impact. Early intervention has been shown to relieve more caregiver stress and other negative outcomes than respite services offered after the caregiver has been providing care for many years. Moreover, research indicates that regular, ongoing use of respite services, in contrast to intermittent, inconsistent use, can result in lower levels of caregiving-related stress, reduced feelings of overload and burden, and better psychological wellbeing (Toseland R. et al., 2001).

Respite care services in Italy are defined by Art. 16 of Law 328/2000, but they are of residential or semi-residential nature, in the form of temporary stays in institutions or community care centres, while there are no noteworthy examples of respite care services implemented in the cared-for person’s home, excepting the “companionship” service provided by conscientious objectors employed by municipal social services, for a few hours a week (Polverini F. et al., 2004).

2.2.2.1. Education and training

Certain programs and services are particularly helpful to caregivers, like *Education,* which provides caregivers with information about caring for older people (information on the normal ageing process, medical information, community resources data, how to interact with professional and medical staff) (Kropf N.P., 2000). *Education and training programs* strive to help caregivers by educating them about resources and by teaching specific problem solving and coping techniques. Teaching specific caregiver skills that are clearly operationalized, practiced, and used to resolve real-life problems, have been found to produce significant problem-solving changes in outcome measures directly related to those skills. For example, nine-week behaviour treatment

teaching programmes for caregivers decreased their symptoms of depression (Whittier S. et al., 2002).
Training today is more important than ever (Angelini A. et al., 2003: 163-164), and must stand as an effective service, whose core issue is the analysis of training requirements. The elder may not only make use of the training, but may also train other older people or people interested in acquiring the expertise (Dal Ponte A., 2001). Families also require training and support so they can acquire specific caregiving abilities, since caregiving requires a perfect professional reference model and opportunities for ongoing training, to avoid the depersonalization of care interventions, carelessness, neglect (Colombo G., 2005). In this respect, the WHO has identified 80 chronic illnesses where patient and caregiver knowledge is fundamental (Cucinotta D., 2002).

In Italy there are various examples of training courses for caregivers. In Liguria, a region with a high number of elderly at risk of developing non-hereditary dementia pathologies, the “Progetto Caregiver” scheme has been implemented, as a synergy amongst various social and health authorities and institutions, to provide families caring for sufferers of dementia pathologies with support and training opportunities for caregiving, including the support of a multidisciplinary framework consultation text (Costanzi C., 2004). AUSER, ARCI, the pensioners of CGIL, CISL and UIL, the “San Lazzaro Nord” social centre in Bologna, have organized a course on assisting the elderly affected by dementia or by significant impairment. The course is held on a weekly basis and targets relatives, welfare services staff, voluntary workers. Lessons are held, on a rotating basis, by nursing professionals, social workers, physicians, psychologists, animators, and even by an architect, who deals with the issue of managing domestic spaces (AUSER, 2002; ARIS, 2002). It should be noted that Bologna has offered courses since 1996, dealing with problems faced by families with dependent non-self-sufficient older people, and therefore aimed at persons who offer home care to older relatives, with the objective of alleviating the psycho-physical and ethical problems that this type of caring involves. The courses also deal with the personal dimension of the individual and seek to develop a sense of the family and good neighbourliness in the participants (Avallone A., 2001). At the Umberto I Polyclinic, in Rome, training courses have been organized with the objective of restoring an adequate level of psycho-dynamic functioning for the family, by dissipating the anxiety and psychological resistance that forms when faced with the impact of a family trauma (Silvestri A. et al., 2001). Then there is a special training course on the potentiality of music for older people and Alzheimer sufferers, targeting the members of the patient’s family and sector operators (Ausl-Comunità Montana Taro Ceno, 2003).

Again, to meet halfway the caregiving needs for the non-self-sufficient elderly, Rome’s Università Cattolica centre for promotion and development of geriatric assistance (CEPSAG), under the patronage of the Focolari movement, organized an intensive course for 160 hours of theory and practice, designed for the relatives of the elderly, as well as minders and voluntary workers (AUSER, 2004a). Other examples of courses for caregivers are in Trento and Rovereto (A.D.A., http://www.uiltn.it/servizi/ada.html), providing important information and news, a useful tool for the elder’s caregiver, whether this be next of kin, a voluntary worker or a professional minder (including foreigners), to prepare and also defend oneself by being better equipped to deal with stressful situations and burn-out that carer and cared-for will encounter. The lessons dealt with medical-nursing, geriatric, therapeutic and psychological issues in caregiving, as well as with the services network activated on provincial territory. The intention was to make available the information needed by users so that it was easier for them to access and make use of a number of useful services that are not well-known and for this reason not exploited to the full. The two carer courses in Trento and Rovereto were organized as 12 two-hour lessons, and the interest and participation of those who enrolled proved their success. Participants were able to voice their doubts and problems, even if they were personal, in the numerous breaks for debate. There were also many insistent requests to repeat the initiative and the positive results obtained encourages continuing this project and perhaps extending it, organizing courses that are not occasional, but ongoing, not only in Trento and Rovereto, but also in the larger provincial towns and all localities that show interest.

Guides and manuals of practical and medical-nursing advice for those who provide home care for the older people who are not self-sufficient, prepared precisely for those looking after elderly family members, and therefore for home help and next of kin, who may be in difficulty even for small actions in the elder's daily routine (Del Savio G., Bernardini R., 2004; Silistrini N., 1993; Degan M., 2003). There are also popular manuals targeting the relatives of dementia sufferers. Caring for these invalids, in truth, requires a constant commitment that can be very trying for the caregiver, in particular when there is an emotional involvement with the patient. The suggestions provided by the manuals can offer practical solutions and help for dealing with daily problems, in the awareness that even before taking care of these patients, caregivers have to take care of themselves (Emilia Romagna Regional Authority, 2000). In this context there are also some useful compendia of exercises for memory stimulation that can be used by individual or group programmes for memory reactivation, designed after relatives meeting in self-help groups suggested they would be a good idea. Caregivers to persons suffering from cognitive deficit should, in point of fact, aim to safeguard the independence and identity of the relative for as along as possible (Quaia L., 2001). Worth mentioning is the manual edited by Alzheimer Europe (Alzheimer associations in: Great Britain, Denmark, Austria, Luxemburg, Belgium, Italy, Spain) and financed by the European Commission; the Italian edition was published by the Alzheimer Italia Federation. This volume, fruit of the life experiences of thousands of Alzheimer sufferer families, throughout Europe, targets caregivers and all professional operators. It touches on the themes of information about Alzheimer's Disease, how the illness starts, the sufferer's needs, the caregiver's needs, financial and legal issues, news about Federazione Alzheimer Italia (Federazione Alzheimer Italia, 1999). Another useful guide for the family is a volume, downloadable from the website: www.italz.it/DOCS, produced by Brescia Local Health Authority, to help persons caring for dementia sufferers. The index includes an analytical description of Alzheimer's Disease; problems and treatment; the role of the family, local services (Bianchetti A. et al., 1998).

More important information can be gleaned from “Il Quaderno n. 6”, published by the Bottega del Possibile Association, addressing those who assist and care for the sick, the disabled and the elderly. Mainly these are family members, operators who offer home or institutional care, but also includes voluntary workers. Day after day, the energies of these caregivers are subject to the wear and tear of commitment and fatigue; sometimes the sensation of no longer being able to perform their caregiving. Help must be given to those who help. The various contributions in the volume deal with different aspects of caregiving: responsibility in services to the person; working with the family; the caregiving context; service policies and instruments supporting caregivers (La Bottega del Possibile, 2004). Then there are manuals that also target the foreign caregiver. In point of fact, the presence of foreign minders in Italian families, a conclusive solution and consequently frequently adopted, as well as being destined to increase, means that there is a need for training that will help minders to deal with their difficult task, and help relatives to ensure their expectations are met. These guides intend to foster the integration of immigrants, providing general information about Italy; ample space is given to the language aspect too, but chiefly to the prevalently operational part, with practical indications on the various aspects of assisting persons who are not self-sufficient, explaining in basic terms how to be a carer, not a nurse, but a person with common sense, able to read signals of suffering and interpret the needs of the person (Baratella P., Tecchio M., 2004). Several training activities, including language courses, have been activated for immigrants, for instance the Serdom Project (Socci M. et al., 2001; Toniolo Piva P., 2002a:76). Lastly, it should be remembered that there is an up-to-date manual for designing without architectural barriers: the publication was edited by Emilia Romagna Regional Authority, and is based on the most recent legislation, with technical indications and advice from sector experts and associations for the disabled. Solutions presented are accompanied by illustrations from a CD-Rom (Fantini L., 2001).

Preparation for future caregiving is also very important (so far this has received little research attention) as it can help to reduce stress or to maintain long-term physical or mental health (Sorensen S., 1997). At the pre-caring stage or later, information on the services available, on symptoms, on what to expect, etc., can empower caregivers or increase their sense of control and lessen their sense of burden (Schutz C., 1997).

2.2.2.2. Counselling and advice

It is fundamentally important to provide for emotional support to family caregivers (Nankervis j. et al., 1997), through counselling that may include, but is not limited to, traditional psychotherapy, individual problem-solving, couples counselling, group counselling, and family treatment. Counselling, whether conducted in an individual, group, or family format, typically strives to relieve caregiver depression and/or anxiety, resolve pre-existing personal problems which complicate caregiving, placate conflicts between the caregiver and recipient, and/or improve family functioning (Whittier S. et al., 2002).

The development of the culture and emerging of behavioural sciences, chiefly psychology, have brought methods where the relationship used is formal and deliberate, alongside the forms of informal assistance. This is how psychotherapy was born, also offering “lightweight” methods that are grouped together as “counselling” (Brusco A., 2003). Counselling is a psychological technique that is based on dialogue and relationships of trust and esteem that arise between a person in difficulty and the counsellor. The latter take on the role of friend, of a sage, who helps the person in need to examine their situation and resolve it without trauma (Danon M., 2000). There is a growing presence of sociologists with management, consultant and freelancer roles in the socio-medical structure, acting as cultural and community intermediaries, by listening to the needs and unease of the elderly and their families (Polinelli R., 2004). “Gerocounselling”, in particular, involves physical, social and emotional problems in the elderly, embracing gerontology and geriatrics, and focalizes the interaction between the elderly person and the “gerocounsellor” (Burlingame V.S., 1995).

In the territory of San Donato Municipality, near Milan, the social cooperative “Solidarietà and progresso” has set up a project named **“**Support Services for Caregivers”, presented in 2001, pursuant to Regional Law 23/1999 “Regional policies for the family” (Polverini F. et al., 2004). The service is free and aims at providing caregivers with forms of support such as information service, counselling and advice, and first assessments of the project seem to be positive about the impact on caregivers wellbeing (Corradini M.G. et al., 2002: 214-221). In another Northern Italian city, Modena, a counselling service for caregivers of the elderly being discharged from hospital has recently been implemented (Polverini F. et al., 2004).

2.2.2.3. Self-help support groups

Support groups are amongst the most popular and most prevalent interventions available to caregivers. In general, support groups are designed to provide informal peer support, information about diseases and disability, and referrals for caregiver support services. Support groups are often affiliated with a social service or non-profit agency targeted to help older adults and their families, and frequently are led by peers or paraprofessionals. Studies have shown that participants in support groups typically evaluate these programs as quite useful and helpful (Whittier S. et al., 2002). Support groups give caregivers a place to socialize with others, vent feelings, and get away from providing care for a few hours (Kropf N.P., 2000).

Self-help groups play a strategic role in facilitating the permanence of older people in their life setting, fostering the process of normalization and dealing with unease within the community, supporting the caregiver in their functions of safeguarding the person in difficulty. Four phases have been pinpointed in the work process: contact with relatives; welcoming of participants with communication at verbal and non-verbal levels; establishment of informal networks amongst caregivers outside of the group; verification of the experience through report cards, for guidance of any furtherance (Giorgetti M., Rozzi G., 2004). Specifically, the objective of the self-help group for caregivers to dementia sufferers is that of getting Alzheimer sufferer families to recognise the instruments each of us has inside and which, if adequately used, are able to improve quality of life. The group is invited to focus attention on each single participant, leading them to discover needs, plans, desires. Self-help does mean helping oneself and referred to a group, it means helping other members who are part of the group. In this way, the relative will realise that they can escape isolation and will find courage because they interface with people who are in the same situation. If the group works well, the relative will take control of themselves and of their needs, feel less isolated and unhappy, as well as more open and willing to make contact with the world at large (Salmoni G., 2002).

In several parts of Italy, mutual help groups for people who have lost a relative have grown and become a very important social resource (Polverini F. et al., 2004), since professional people and social services are not always able to respond to the complex needs linked to death (Pangrazzi A., 2002: 7). Self-help groups are composed of people who share the same situation and who can offer psychological and emotional support to families with a dependent relative. An experience worth mentioning is that of the Ancona group “Teniamoci in contatto”, which began in 1999 in the context of the “Care synergy” service, aimed at families living with an elder. Apart from the increase of expertise, reduction of stress and self-management, one of the group’s aims was to create opportunities for women risking social isolation to meet, face up to the relationship with illness and death of an elderly person (Cotoloni G., 2004). To support older people affected by dementia, and their families, Cesena Municipal Authority organized not only territorial psychological support and assistance, with the circulation of information and activation of places for “overnight respite” in the services network, but also home meetings and self-help groups, fostering the establishment of a territorial association of next of kin, in other words a “resource centre for the elderly”, which offers guidance for services and help (escorting to services, delivering medication and shopping etc) through volunteers (Cesena Health Authority, 2002).

If the primary drive found in literature for training self-help groups can be pinpointed in the attempt to adapt to a stressful situation, they cannot be excluded from forms of legitimization and recognition within a favourable context (in particular if formed by the families of elderly with serious problems of physical and/or mental autonomy): apart from providing a resource for social policies, the groups are places or spaces that demand significant participation and emotional commitment, and the leader takes on the role of guiding to independence, which helps participants to master their experience better (Taccani P., 2004a). WHO promotion policies outline self-help groups as efficient tools for restoring responsibility and initiatives for safeguarding personal and community welfare to the citizen, avoiding passive delegation to institutions and professionals. This also transpires from the many directives of social policy adopted by the European Union, as well as by more recent sector regulations circulated at national level. Social support networks, whose subjects are, simultaneously, producers and consumers, self-help groups, unite citizens who share a an identical problem of discomfort and suffering which, if shared, will create expertise for social expenditure: this leads to a concrete collaboration with social services, institutions and professionals, in whose framework social workers may play an active role as promoters and facilitators of empowerment (Amadio T., 2004).

2.2.2.4. Telephone support/services

In Italy, telephone support is provided mainly by relevant pressure groups involved in promoting support measures for family caregivers; they are organizations and associations for the elderly and for families of dementia sufferers (Polverini F. et al., 2004). Some of them also play a relevant political back-up role, for instance the no-profit organization A.U.S.E.R (a voluntary association for elderly care), which recently published the “manifesto of caregiver rights” (AUSER 2001a:28) and promoted a national conference on the topic of “Supporting caregivers for the rights of the persons cared for” (Sarno P., 2001: 25). A crucial role in this sense is also played by the Italian association of Alzheimer victims (AIMA) and the Italian Alzheimer Federation (AI).

There are about 500,000 Italians affected by Alzheimer, with peaks of 20% in the over-80 population (AUSER, 2004b); this is an illness that changes the lives of sufferers and families. The “Tempo Alzheimer, azioni di sostegno alle famiglie” [Alzheimer time: support actions for families] project was established as a joint venture with Cantù Municipal Authority, AUSER and Fondazione RSA “Garibaldi Pogliani”, to raise awareness of the pathology and offer support. It is the first project of its sort in the province of Como and it provides concrete help to families, a foothold for help in finding one’s bearings amidst the sufferer’s many needs. In point of fact, the service envisages the opening of an info point and creation of a helpline that assists in getting the most out of the territory’s welfare services; the helpline will be run by volunteers from AUSER (AUSER, 2004b). The Pronto Servizio Anziani “Filo d'Argento” helpline for the elderly, promoted and financed by Lombardy Regional Authority, in collaboration with a network of volunteers, also headed by AUSER, is another commendable scheme. Active 24/24, offering replies to requests for information and providing a friendly ear for the older citizen (Barbarani G., 2004b). “Pronto Alzheimer” in particular, is a helpline organized by the Alzheimer Italia Federation, providing information or just the chance to chat or let off steam (Federazione Alzheimer Italia, 2003). AIMA (Italian Alzheimer’s Disease Association) also offers a helpline (Telefono “A”), set up in 1998 as a scheme by operators at the Sant’Eugenio hospital in Rome. A survey undertaken on the retrospective assessment of data gathered in the period 2000-2001, compared with those of 1998-1999, showed that sufferers and their relatives did have needs (for various kinds of information, psychological support, legal and social protection) which required a multidisciplinary type of feedback, including telephone helplines (Arcangeli F. et al., 2001).

Alzheimer’s Disease, and other forms of dementia, have significant impact on patients and family caregivers. Various types of research, with the aim of examining the impact of helplines that provide information, instructions and counselling for caregivers of dementia sufferers, show that horizontal telephone contact helps to increase the use of services and cut down stress and depression levels (Coyne A.C. et al., 1995).

2.2.2.5. Internet services

Most of the (very few) existing websites for caregivers, such as existing telephone support services, are especially dedicated to families of Alzheimer and psychiatric patients. An innovative project, implemented in the European context, is the Progetto CRONOS, addressing persons with Alzheimer’s Disease and their families, with a website devoted entirely to the project (Polverini F. et al., 2004). Besides providing information on the disease, the site also offers e chance for discussion and confrontation amongst doctors, families and care providers, and useful information for caregivers about the various services (http://212.38.48.166/main.htm). There is also the Alzheimer Italia Federation website, which offers information about its activities and provides an index to Alzheimer resources on the internet (Federazione Alzheimer Italia, 2003).

Help contacts in internet forums, integrated IT-welfare systems as a tool for prevention, assessment and planning; E-Government, E-Nursing, E-Service, E-Care; computerising citizen records for the assistance processes, general medicine and information technology (AA.VV., 2003): Italy is still in the early stages, but there is no doubt that technological advances may improve results for caregivers. Home videos, computer programs, telephone services, and online education and support are just a few of the many ways technology may enhance services. The few studies to date that have looked at the effectiveness of technological programs have generally given positive results (Whittier S et al., 2002). It is important to understand the value of the various types of technological interventions in order to use them appropriately for the development of future caregiving interventions (Coon D. et al., 1999).

2.2.3. Monetary transfers for older people and caregivers

Services for non-self-sufficient older people and caregiving families in Italy consist in extensive distribution of cash handouts both at national level (disability pensions and companionship allowances) and at local - regional and municipal - level (care allowances) (Gori C., 2001a). In the Italian, mainly cash-oriented, care system, support measures available to caregivers are: care allowances, measures for working caregivers and tax deductions (Lamura G. et al., 2003).

2.2.3.1. The National Act 328, 2000

This law, for the reform of social services, aims at promoting home care for keeping older people the place where they have always lived, wherever possible (Minguzzi P., 2003: 80, 84). In 2001, pursuant to Art. 18, comma 2 of Law 328/2000, a national plan of interventions and social services was presented. One of the objectives of the plan was to support dependent and disabled people through home services, thus valorising family responsibilities. Regions must direct policies, provide support, and develop the supply of care services (Polverini F. et al., 2004).

For social services, Framework Law 328/00 introduced forecasting of Essential Services Levels (Liveas), defining the interventions that constitute precisely the “minimum essential level”, and involve various planning levels (national, regional, local) in this (Meloni G., 2003). With circulation of Law 328/00, the municipal authorities are called upon to define an integrated system of welfare policies and services, standardised and equal at national level, as the motivation for public policies (Del Todesco Frisone S., 2003). This, alongside the introduction of a range of instruments and through a series of schemes (care benefits, home help, respite services, fostering, student loans, tax rebates) that would make the field of services for the person more flexible and innovative (Battistella A., 2002). There was to be explicit interest for the family, taken as the protagonist of an integrated welfare system, valorising and supporting care responsibilities. So there are numerous possible operating directions, even if national and local policies will have to deal with the enormous gap between family needs and community feedback, which, in Italy, has been the consequence of public disinterest for many years for the family as an institution (Castegnaro A., 2001).

Numerous local and regional authorities are involved in the registering and analysis of resources available for implementation of territorial social policies deriving from implementation of Law 328/2000, which reformed assistance. The transfer of the resources envisaged by the Law to regional authorities and preparation of area plans for designing and implementing services and schemes at local level, prompted identification of overall available resources (Da Roit B., 2002b).

In particular, Article 15 of Law 328/00 deals with the theme of "home support for non-self-sufficient elderly persons": the framework law thus adopts the theme of home care, which must be supported through the activation of integrated health and assistance schemes, to support families with next of kin in difficulty, and through appeal to co-responsibility of subjects present in a given territorial and community context. Home care, in its various forms, is one of the actions considered essential: this stands as a significant goal for the principle of affirmation of the dignity of the inform and right to care (Anfossi L., 2001).

2.2.3.2. Monetary transfers

At State level, no benefits are provided directly to family caregivers, except for those paid to persons "fully dependent from support provided by others", with the explicit aim of contributing to extra care costs deriving from these situations of need. In the last few years several local administrations (i.e. municipal, provincial and regional authorities) have introduced forms of monetary support directly addressing family caregivers (Polverini F. et al., 2004; Melchiorre M.G. et al., 2000). This trend reflects the aim of both relieving caregiver burden and, at the same time, reducing the tendency to resort to institutionalization, which has a high financial impact especially on municipal budgets, which pay the part of the monthly residential facilities fee covered by the elder (Lamura G. e al., 2001; Credendino E., 1997).

While the State care benefit is issued only on the basis of necessity, being non-means-tested, municipalities and regions provide families of dependent older people with grants based on need and income (Polverini F. et al., 2004; Da Roit B., 2002d: Da Roit B., Gori C., 2002: 131-133). Legislation describes these contributions as measures to help families, but often they are used to purchase private care from the illegal care market (Gori C., 2002:28; Battistella A., 2002: 2). Besides which, these allowances are insufficient to cover the entire remuneration of caregivers, which is guaranteed through funds from the beneficiary's family or from the beneficiaries themselves, in other words families in a better financial situation are mostly inclined to get help from the private care market (Gori C., 2002: 25; Lamura G. et al., 2003).

With regard to "care benefits", Law 328/00 introduced two main typologies of "ticket" for purchasing services: social voucher and care allowance. These are social intervention instruments of great interest for municipal and health authorities, and for private subjects (Battistella A., 2002). The most widespread form of care benefit is however the attendance allowance

2.2.3.2.1. Attendance allowance

The attendance allowance is distributed as a set amount, independently of income and composition of the family nucleus, to the completely disabled population who are unable to walk without the permanent help of a helper, or who are unable to perform the routine actions of daily life and thus require continuous assistance. Exceptions are the impaired who are institutionalized in public structures and have been so for over one month (National Health Plan 2002-2004).

The attendance allowance is paid by the INPS (National Institute for Social Security) and cannot be concurrent with other similar benefits. It is updated annually by the Ministry of the Interior and for 2005 is 443.83 euros a month (http://www.provincia.torino.it/sportellosociale/anziani/sg001). Attendance allowances actually serve to integrate the income of the elderly and in Emilia-Romagna they are a major element of cash transfers. In the case of an elder who is a beneficiary of an INPS attendance allowance, any other care allowance amounts issued will, in any case, be halved (Cossentino F., Innorta M., 2004).

A CENSIS survey (CENSIS, 1999) of 802 relatives of patients diagnosed with Alzheimer's Disease (national sample), shows that families pay out of their own pocket for most of the services required and services connected to welfare, whereas there is little public spending. One of the most popular services is precisely the attendance allowance (34%), whereas admission to welfare structures and rest-homes is hardly noticeable. Moreover, over 30% use paid home help, but little use is made of day centres and ADI. The services judged most useful are medical centres specific to Alzheimer's Disease, home helps, home medical care, economic benefits and tax relief, family associations, respite stays (CENSIS, 1999).

2.2.3.2.2. Social voucher

The social voucher is an economic provision supplied by the public authority to assist users, and can only be used for purchase of specific services provided by professional caregivers (Battistella A., 2002), and therefore by providers (public or private), authorized (accredited) by the public authority, who operate as competitors amongst themselves (Gori C., 2001b). So the service voucher, which can actually be described as a ticket that can only be used to purchase specific services (Battistella A., 2002), is a coupon for economic support that will allow families or the elderly themselves to buy, where they decide most opportune, the service they need. This mechanism has the advantage of activating a market of service providers, but in any case entails the institution having to inform and assist those involved in the choice, and in knowing how to accredit and assess suppliers correctly (Polverini F. et al., 2004).

The social voucher is intended to offer economic assistance to the family who is offering self-sufficient home care (Plantamura A.M., Dotti C., 2002). Some believe that this is the best instrument for guaranteeing the quality of the service (Da Roit B., Gori C., 2002: 137), because by having to 'intercept' the vouchers that users can spend, the disbursers are stimulated to improve their capacity to offer precise responses according to the needs (Battistella A., 2002: 2). The downside of this provision is the short time of assistance received (limited to the length of the service) compared to the actual needs (Battistella A., 2002: 4).

Lombardy Regional Authority, specifically, offers: a welfare voucher, an economic contribution, not cash but a "purchase voucher", which can be used only for buying integrated socio-medical home care services offered by professional and qualified figures (professional caregivers); the social voucher, not cash but a "purchase voucher", which can be used only for buying services of a social type offered by social operators (non-professional caregivers) (Calchera B., 2004).

Service vouchers, on the other hand, are a tool designed to allow even persons with a heavy family commitment, in particular women, to attend a course (http://www.atipici.net/formazione/voucher_alta.asp). The loan, up to 1000 euros, is intended to cover all or part of the costs for caring for children, elderly parents or the disabled. Only those persons who have applied for and been issued with a training voucher will be entitled to apply for a service voucher. Advanced vocational training vouchers are individual financial contributions, offered by Emilia-Romagna Regional Authority office for professional training, for planning and entering advanced vocational training courses aiming to create high-profile, highly specialized professional figures, or refresher courses for expertise and know-how already acquired in significant work experience. A voucher is issued for the partial coverage of registration fees for one of the courses chosen by the beneficiary of those offered in the Advanced Vocational Training Courses Catalogue. Advanced vocational training vouchers are for both employed and unemployed, young and mature age groups, who must be resident in Emilia-Romagna. The candidates, specifically, may be university graduates (four-year, three-year, specialization), or may lack a university degree but have been in full-time employment for five years and intending to take a specialization coherent with their professional development; if they are not graduates and are not in employment, they must hold other certificates or qualifications required for being admitted to advanced vocational training for professional enhancement.

2.2.3.2.3. Care allowance

A care allowance is basically a financial contribution to the elderly (or their families) that pays for assistance. The user is free to spend the allowance as desired and it is intended to act as economic acknowledgement of the care offered by a family or by a social support network (Battistella A., 2002), with reference to persons who are not self-sufficient and who would otherwise have to be institutionalised. In some measure the allowance is also used for purchasing private caregiving. This contribution is issued at regional and municipal level, by municipal authorities or local health authorities (ASL) as an alternative to services for the person, at home or in an institution, and is paid to caregivers or used to pay for private care. Cash instead of care therefore, is the revolutionary aspect of this allowance (Gori C., 2001b:12; Toniolo Piva P., 2002b).

The care allowance, or therapy benefit, thus has the objective of promoting home care and reducing requests for admission to residential structures. The allowance amount varies and is generally correlated to income and the needs of the non-self-sufficient person and the family. The municipal public relations (URP) or social services offices must be approached to find out whether the municipal authorities actually envisaged this sort of support and how to apply for it (http://www.provincia.torino.it/sportellosociale/anziani/sg001).

From the mid-1990s, care allowances became very popular in Italy and the phenomenon was chiefly concentrated in the centre-north of the country, more widespread in municipal authorities (social services) than in local health authorities. The main reason why the allowance was so scarce in the centre-south may be pinpointed to the improper use made in that area of the attendance allowance, often used as a “hidden” policy for shoring up income and, in any case for aims that were not those foreseen (Gori C., 2001b).

In 2000 almost one third of Italy’s municipalities with 50,000 inhabitants were issuing care allowances, and application requisites were not only the psychophysical but also the economic conditions of the applicant. Often, however, the care allowance was little more than a cash transfer, since it is not supported by a personalized intervention plan (Da Roit B., 2002c).

In a country characterized by a rather scant range of public services, the allowance was considered an acknowledgement of the daily work performed by caregivers, otherwise left to their own devices in dealing with such an exacting commitment (Taccani P., 1999). So it seems important to underscore the widespread approval that care allowances earn with relatives involved in the care of the non-self-sufficient elderly. On the other hand the research sphere - in Italy as in other countries - tends to look with suspicion on this measure, and to underscore the negative consequences that the care allowance produces on the lifestyle of caregivers, usually women, committed to helping the elderly person. In point of fact, this type of intervention serves to acknowledge the work, almost always undertaken by women, within the family sphere, but it may have the negative effect of legitimizing a caregiver role for women, called upon in a structural manner to find a solution to a relative’s welfare needs (Battistella A., 2002). In substance, it is thought that the economic contribution acts as a strong incentive to “stay at home”, devoting themselves to caregiving instead of seeking paid employment on the labour market. Such a choice may not reflect the true inclination of the women involved and produces negative consequences on the professional opportunities that these persons might have had in the future. The provision of this allowance as an alternative to services to the person might, in that perspective, even increase the workload for caregivers, with negative effects on their quality of life (Saraceno C., 1995).

An aspect that is also present in other countries but has particular significance in explaining the development of care allowances in Italy, is to do with the activation of public policies. It is no secret that in our country enormous difficulties are encountered when implementing a social or health policy. The development of home care, hoped for at length by many but struggling desperately to become a concrete reality, stands as an emblematic example of the aforementioned difficulties. For the public sector, it is not only far cheaper to provide an economic benefit but also simpler and faster than providing services to the person, whether they be home or residential care. The lesser difficulties that arise during implementation are consequently very important for explaining the widespread use of care allowances in Italy (Saraceno C., 1995).

So municipal authorities use care allowances far more than they do service vouchers. In point of fact, whilst the use of service vouchers is a way of managing services, use of allowances is actually another expression of traditional family income integration, which has no expectation of assessment in terms of impact of efficiency. Moreover, it is easy to understand how the care allowance can represent a way of containing costs; in point of fact, all the local authority has to do is issue allowances that are less than the cost of keeping a mature citizen in a facility or of setting up new structures, leaving the users or their families with the task of pinpointing an organizational solution able to guarantee the required assistance at a cost compatible with the amount received (Battistella A., 2002).

2.2.3.3. Provisions for working caregivers

The extremely limited social security benefits allotted to activities carried out by family caregivers are mainly intended for persons employed in the labour market. Relevant references to legislation are (Polverini F. et al., 2004):

Law 335, 8 August 1995: Article 40 states that for pensions issued exclusively by the state contribution system, periods of abstract credit (25 annual days of paid leave for an upper total limit of 24 months throughout the entire working career) are available, also for leave to assist children from six years onwards, spouses and parents, as long as they cohabit (Lamura G. et al., 2003);

Law 53, March 8 2000: Article 4 states that any worker has the right to paid leave for three working days a year in case of death or documented severe disability of the spouse or relatives twice removed. In addition, the employees of private or public companies can ask for up to two years of continuous or fragmented unpaid leave for severe and documented family reasons, for example in the case of workers with dependent next of kin requiring care (Lamura G. et al., 2003);

Law 104, February 5 1992: this law states that the working father, mother, relatives twice removed, involved in caring for another severely disabled and dependent family member, has the right to three days of paid leave per month, throughout an entire working career.

Legislation for measures to support employed family caregivers (rights to leave, rights to job-sharing, part '-time work, etc) in Italy is incomplete and fragmentary (Polverini F. et al, 2004). The opportunities offered are often really only accessible to public service employees, since people working in private employment risk "jeopardizing their jobs" if they seek to apply for them (Tarabelli D. et al., 2001: 251).

2.2.3.4. Tax concessions

Medical costs for assistance (medical, nursing, rehabilitation services, for technical-welfare operators dedicated to direct care of the person, for prostheses and aids) are tax deductible, for 19%, from income tax (IRPEF) due. Deductions are applicable for amounts above 129.11 euros. The disabled and invalids, or their relatives, who are not subject to the 129.11 euro limit, can also deduct costs for walking aids and for computer aids (armchair, artificial limbs, construction of ramps, ambulance transport, fax, modem, computer, etc), as well as for modifications to cars to suit the person's impairment. The disabled who require installation of special devices like ramps, slides and lifts that assist them in daily routine, are entitled to deduct 36% of the cost of these interventions for removal of architectural barriers from their annual tax declaration. The disabled are also entitled to a reduction in VAT (value added tax), which is charged at 4% (http://www.intrage.it/rubriche/salute/lasanitainitalia/detrazioni/index.shtml (Finance Act 2005).

Medical and assistance costs, however, are allowable expenses (on gross income before calculation of tax). Specifically, a disabled person or member of the family may deduct from declared income (pre-tax) for the annual tax returns both the total spent for medical costs and the amount spent for health and social security contributions paid for private caregivers. The upper limit for allowable expenses is 1,549.37 euros pa (Law 342/2000). (http://www.intrage.it/rubriche/salute/lasanitainitalia/detrazioni/index.shtml - Finance Act 2005; Da Roit B., Gori C., 2002: 117).

It should be pointed out that tax relief for those who have disabled next of kin and make use of the legal labour market for care, seems to offer more substantial benefits to taxpayers with higher incomes, since this is a tax allowance (taxable income is reduced) and not a deduction (tax payable is reduced) (Lazzarini G.V., 2004).

2.2.4. Other financial provisions

Amongst the other major monetary provisions existing in Italy, there is a "worker's disability allowance" and a "worker's disability pension" (Polverini F. et al., 2004).

Worker's disability allowance is issued by INPS to employees and self-employed workers, who have paid at least five years of pension contributions, affected by a physical or mental infirmity which reduces their working ability to less than one third. The amount depends on contributions paid and, in any case, cannot exceed minimum pension amount.

Worker's disability pensions are granted to workers who are no longer able to work. The amount of the pension varies depending on taxes paid up to that moment, which are then supplemented with a contribution calculated up to retirement age.

2.3. Contexts that lead to an increased/decreased use of services

Various factors influence the use of services but these are mentioned only in non-Italian bibliographic references. A survey performed with reference to 293 care recipient/caregiver dyads in a Canadian province (Strain Laurel A., Blandford Audrey A., 2002), found the most frequent reasons for not using many services to be the state of health of the care recipient in terms of disability and illness (Broe G.A. et al., 2002), and the presence of family and friends providing care. It should be noted that economic poverty is one of the risk factors for loss of health amongst the elderly, and despite new social policies, poverty is still a reality in the life of a significant percentage of elderly men and women (Castelletti F. et al., 2000).

In particular, the findings of a study of 483 elderly Mexican-American women (John R. et al., 1997) identified functional disability in instrumental activities of daily living (IADL) as predictors of most significant use of services, accompanied by scant assistance provided by members of the family. With regard to use of service centres for the elderly, living alone and participating in social groups is a significant factor. The physical handicap variable is specifically correlated to the use of home care (Ozawa Martha N., Tseng Huan Y., 1999), whilst persons with dementia tend to use personal assistance services and make use of one or more home services, in a greater measure than caregivers and respective cared-for without cognitive handicaps (Hawranik P., 2002). Depression also leads to greater use of health resources by elderly patients, in terms of examinations, lab tests and x-rays (Luber M.P. et al., 2001).

Then, if the considerable needs of the elderly are assessed, following discharge from hospital or in the post-hospital period, it emerges that families provide most assistance; although there is frequent use of formal services, and nursing care is frequently required for bathing and personal hygiene, but this is limited to areas of greatest need, like transport, housework and shopping (Morrow-Howell N., 1998). When a geriatric patient is nearing discharge date, the type of home or residential care required must be assessed (De Moliner M., 2000) and so-called "protected discharge" (Aimonino Ricauda N. et al., 2003) has to be organized. Nevertheless, post-hospital and day clinic services are lacking and these are really the types of assistance most suitable as an alternative to hospital, especially for the elderly (ARIS, 2003).

Of the factors associated to requests for respite services (interviews with 458 caregivers for Alzheimer sufferers), the most significant were those already mentioned, including the burden of caregiving and presence of other caregivers (Kosloski K. et al., 2001; Strain Laurel A., Blandford Audrey A., 2002). In particular, reduced informal support and the specific lack of offspring are an important risk factor, especially for elderly women, as far as the probability of using rest-homes and home health care is concerned (Aykan H., 2003).

2.4. Barriers to use and gaps in services vs. features that services should have

Research into the themes of health and social services, focusing on those of long-term health care on a community basis (home care, transport, home help, nutrition, as well as centres for the elderly, information and support services, day care for older people) (Krout J.A., 1998) examines differences in comprehensibility, availability, acceptability, quality and cost, indicating the factors that could also explain specific barriers to use. Other authors (Whittier S. et al., 2002) identify five key elements when analyzing why caregivers may not be using services: availability (by family caregivers in their community), accessibility (with regard to physical location and structure of services), appropriateness (to the caregiver's needs), acceptability (culturally appropriate and acceptable to the caregiver), and affordability (that include financial costs and other costs in terms of time, effort, potential loss of confidentiality, and potential family conflict).

The elderly have particularly intense, ongoing relationships with health services: traces of this can be found in the growth trend seen in notifications to the tribunals for patients' rights that often refer to difficulties in understanding the meanderings of the National Health Service. All too often, not knowing how to get one's bearings or who to approach are an even bigger hurdle than the actual illness, and in these cases it is the family that shoulders the responsibilities and burdens that are not theirs to shoulder. There are plenty of problems: long waiting lists; forced discharge by hospitals; difficulty in accessing rehabilitation or long-stay structures, or home care services; impossibility of getting free medication. There are few investments and closing down of small hospitals does not guarantee that something better will take their place (Inglese S., 2002).

In effect, knowing whether or not specific services exist is one of the chief barriers to their actual use (Cox E.O. et al., 1988; Shibusawa T. et al., 2001). Many caregivers are not very familiar with services and this suggests that social operators can play a vital role in providing information (Toseland R.W. et al., 1999). However, it does happen that the general practitioner gives no information or gives the wrong kind (Cesena Health Authority, 2002), when in reality the physician should be the chief link to care services, which are interconnected and rooted in the territory, able to meet the health and social needs of elderly citizens (Fini M., Silvestri A., 2003).

It is precisely the general practitioner, together with the geriatrician, who should direct the patient to the various services offered by the network, first for the diagnosis and subsequently for the effective care and any rehabilitation. So families do not receive support - for information and on how to access regulatory tools that can sustain them – from the family physician, a subject who is quite often not seen as a reference figure, whereas the specialist physician is mentioned more often as a source of information (CENSIS, 1999).

So procedures for receiving care and aids are slow and not facilitated by the presence of the general practitioner. Moreover, procedures for admission to a facility or for receiving home care are characterised by their bureaucratic complexity, sluggishness and long waiting lists (Cesena Health Authority, 2002). Sometimes the decision to keep elderly next of kin at home, even if they are not self-sufficient, is a forced choice due precisely to the very long waiting lists for rest-homes (Possenti R., 2003). Long waiting lists are the main problem of the public health system. In fact, for 63% of the interviewees (CENSIS, 2002), they represent the most serious problem; further problems are the low quality of services (30%), the lack of adequate assistance for elderly non self-sufficient and disabled people (19%), and the excessive economic burden of health costs to be borne by citizens (14%).

Shortening waiting lists is one of the main strategic projects outlined by the National Health Plan 2003-2005, as well as enhancing care of chronic patients, the elderly and the disabled, and urgent and emergency services, creating quality hospitals, promoting healthy lifestyles and correct use of medication (National Health Plan 2003-2005). In order to deal with the problem of long waiting lists, several measures have been taken by different local health authorities, pursuant to Legislative Decree 124\998 art. 3, which states the adoption of measures aimed at reducing waiting times for specialist visits, ordinary admission to hospitals and day clinic facilities (Polverini F. et al., 2004).

Lazio Regional Authority, specifically, has prepared a plan for shortening and abolishing waiting lists for specialist examinations and priority diagnostic tests. The plan was put together by a work group comprising regional council offices, local health authorities, and FIMMG (Italian federation of general practitioners), and associations like “Cittadinanza attiva”. It intends to allow family physicians the possibility of booking services for patients who are in serious/priority conditions directly at the unified regional booking centre, online or by freephone (ARIS, 2004). Piedmont Regional Authority, on the other hand, has set aside 20 million euros for local health authorities and authorities who manage welfare services, with the aim of abolishing rest-home waiting lists by defining individual schemes that privilege keeping non-self-sufficient older people in their own homes. The provision includes diversified interventions such as home care, granting of a care allowance to support home care, supply of semi-residential and residential respite beds in structures (ARIS, 2004).

The problem of long waiting lists, evidenced also by the Third Report on health policies for chronic diseases (Inglese S. et al., 2002: 18), is strictly linked to the problem of costs (see § 5.2). (Polverini F. et al., 2004). The use of the National Health Service in Italy is subordinated to the payment of a prescription charge for the user to have access to public expenditure. However, when a person is over 65 or when they suffer from an officially recognised “chronic and disabling disease”, the prescription charge is waived. Additional costs are mainly connected with the phenomenon of long waiting lists (Polverini F. et al., 2004).

Another cost barrier is that for hiring a minder. In this respect, the Multiscopo ISTAT survey on “Families and daily life” (Cossentino F., Innorta M., 2004) found that about 25% of the elderly with disabilities make use of a private home help and/or caregiver service. When the elder really is lacking in self-sufficiency and needs attention several times a day, as well as more or less constant minding throughout the 24-hour time span, the cost of private care on the legal market is prohibitive. In this situation, characterized the public system's evident deficiency in protection, a demand for caregiving emerges, expressed by the families, who seek figures able to guarantee a presence for the entire day, at an accessible cost. This demand is met by the existence of a specific flow of migrant women, which has brought about the so-called "minder" phenomenon. Board and, above all, lodging are made available by families for a foreign minder, and in any case are a fundamental part of the contract: in point of fact, the elderly person often lives in a home that is too big for their requirements. The offer of lodging for a minder is not perceived as an excessive cost for families and thereby represents a "salary bonus" that allows them to spend less on the minder's wages; on the other hand, it allows the minder to resolve the accommodation problem, which would otherwise have prohibitive costs, incompatible with the final aim of the emigrant's plans, if it was to be dealt with on the open market.

The same ISTAT survey (Cossentino F., Innorta M., 2004) highlights how families faced with the need to find external support for care of an elderly person who is not self-sufficient, decided not to place the person in a residential structure for two main reasons. The first reason was the desire to act in the best interests of the elderly person, and whose best interests are perceived as being closely linked to the possibility of keeping the elderly person "in their own home". The other reason is, in fact, the sustainability of the financial impact of a residential structure, which are considered excessive. Unfortunately, when self-sufficiency ceases completely, the best solution is the RSA, whose cost is often high, however, and only partially sustained by facilities, whilst the excess must be paid for by the families (Cesena Health Authority, 2002).

On the subject of the cost of services, on 12 May 2004, a presentation was held in Brescia of findings from the research entitled "The municipal network of social services for the elderly", commissioned by the municipal office for social services' statistics unit (Gorlani P., 2004). The aim was to obtain a complete map of services offered to the elderly in the decade 1991-2001. The data gathered showed that the number of older people contacting social services is increasing by 500 unit pa and that 70% of the older people receiving care are women. The problem of cost is therefore a dilemma for the future: in point of fact, municipal authorities spend about 24 million euros pa and data show that the requirement is to help keep the elderly person in their family for as long as possible, enhancing home care services (SAD) and helplines, day-care services and sheltered housing, with greater involvement of the voluntary sector. Again, with regard to costs, during a conference organized in Rome during the 15th anniversary of the Centre for Medicine of Ageing, it was underscored that the increase in disabling pathologies and disabilities in general, brought a growth in health requirements and a need for greater resources to meet these needs. So it will be necessary to extend integrated home care services to achieve better quality of life for the elder and savings for health service coffers, considering that a day spent in hospital costs about 500 euros, whereas a day of home care costs about 50 euros (Antini C., 2002).

In brief, managers of the current network of services to the person declare an acceleration of costs, compared to state and regional intervention, whose fees users cannot meet: the financial endowment, available as general funds (for care policies, for non-self-sufficient elderly, etc), fails to meet the objectives and principles of the care model outlined by Law 328/00 (Bertolini E., 2004). Not to mention the high costs of new technology products (comfort devices and technical aids) that are of great help both to the elder and their families, but whose advantages are offset by the fact that in a great majority of cases, the users themselves have to buy such devices out of their own pocket (Marcellini F., Gagliardi C., 2000).

With particular reference to caregivers of dementia patients, during the EPOC (Equality in the Provision of the Care at Home) project, financed by the European Commission in the context of projects for equal opportunities, implemented between 2000 and 2001 by Alzheimer Europe, the use of services and, in particular, motives behind failure to use services, were explored. A high percentage of men, both husbands and sons, simply replied that the elder had no need of them; other motives, however, were indicated as cost and a reluctance to ask. Besides which, more men than women did not know how to request services, whereas women were often faced with refusals from the patient to accept outside help (Possenti O., 2003). Also with regard to dementia, several barriers that impede the use of mental health services include: lack of appropriately-trained professionals, lack of services targeted to the specific mental health care needs of the elderly, and a medical bias that prefers intervening with medication (Robert J., Maiden Ph.D., 2003).

In rural areas, these problems are further exacerbated by having fewer mental health care facilities and professionals available, especially psychiatrists, to provide adequate service (Benson E., 2003).; so serious transportation problems restrict the elderly individual's access to services (even when the services are available) (Krout J.A.,1998). In effect, and in a context not purely targeting dementia patients, but more in general, transport services can be significant in defining programmes that meet the elder’s travel needs, and lack of transport is a further obstacle to the use of welfare services (Smith L.D. et al., 2002; Rittner B., Kirk A.B., 1995; Kosloski K. et al., 2001). It should also be considered that opening day centres for the entire day and providing users with means of transport to reach them, must be correlated to achieve improved exploitation of these centres, which would also improve financial results (Reifler Burton V. et al., 1997).

Another barrier to the use of services may be the architecture of the home (Cesena Health Authority, 2002). In this respect, a key point in the rehabilitation treatment plan is certainly adapting the home to the level of functionality and individual needs of the elder. The architectural barriers present in homes may even influence the rehabilitation performed in the A.D.I (Sparagna N. et al., 2001). In point of fact, a home should be designed to meet the needs of the ageing person, where it is important to prevent furniture becoming a barrier and where technology may offer intelligent solutions, so that care of an elderly person is increasingly linked to the family and always less “residential” (Rossignati M., 2002). Sadly, the problem of overcoming architectural barriers is a phenomenon destined to increase significantly, as the population of older people increases, and this will affect all Western countries, who share this population ageing process (Marcellini F., Gagliardi C., 2000).

Lastly, it should be emphasised how even geographical, cultural, social and lifestyle variations can discriminate against subjects in the use of various types of services. Several Multiscopo surveys of families, undertaken in Piedmont between 1994 and 1995 (Vannoni F. et al, 1999), show that in point of fact the tendency to contact the family physician for a health problem is more common amongst the less well-educated and, moreover, increases amongst classes with fewer resources (white-collar middle class, lower middle class, blue-collar) and amongst employees. The fact that the upper middle classes and the self-employed categories use their GP less, is not so much due to a tendency to avoid bureaucracy by going to ER, but rather recourse to private healthcare, where it is often easier to achieve a faster diagnosis and treatment. There are also significant differences in recourse to the family practitioner depending on the altitude and demographic extent of the municipality of residence. For an equal number of chronic illnesses, inhabitants of non-metropolitan mountain communities are reluctant to make regular visits to their doctor. So Multiscopo data show that the Piedmontese demonstrate social differences in accessing health services; in particular there is a massive restriction, for less well-educated families and less well-off social classes in accessing private structures, which the authors explain as a lack of awareness that there are private services contracted by the health service, and as a lack of cultural and interpersonal resources for dealing with the bureaucratic hurdles created by the system. Bearing in mind the critical points of our health service, above all long waits, the high number of bureaucratic phases and lack of guidance from the family practitioner, then greater demands on the public health service by the less wealthy sector of the population becomes a discrimination. So access times are the chief amplifiers for inequality in the accessing of health services, since their sum puts a strong brake on the process with which patients find answers to their health queries (Vannoni F. et al, 1999).

Other research (on elderly women in the United States, on the basis of the 1990 U.S. Census data and empirical health care data) found that gender, residence in a rural area and poverty were risk factors for decreased access to health care services, lower use of services in general and poorer health (Barnes N.D., 1999). Specifically, elderly women in rural areas, compared to those in urban areas, live in greater poverty levels, worse housing conditions and with less access to medical and social services (Kivett V.R., 1997). Residing in rural areas also means that families do not get information about services for non-self-sufficient elderly who are entitled to it, that there is a failure to be familiar with services activated by local authorities and rights assured by law, lack and/or difficulty in obtaining adequate information about the possibilities and quality of socio-institutional aid, failure to be familiar with associations to contact to request this type of assistance (Cesena Health Authority, 2002). As far as gender is concerned, male caregivers with lower education levels are frequently ignorant of the availability of day centres, day clinics and formal support services (Strain Laurel A., Blandford Audrey A., 2002). The lower the education level, therefore, the lower the use of services (Ozawa Martha N., Tseng Huan Y., 1999).

The relationship between social participation and use of services was the subject for research that also confirmed how members of groups with high levels of participation and/or cohesion tended to adopt similar ways of using services, differing from those of other groups with different characteristics. Consequently, acting on the group's internal dynamics, it is possible to influence the use of the actual services (Delisle M.A., 2001).

Another aspect to consider, on the subject of social participation and barriers to use of services, is certainly the user's ethnic origins. In actual fact, interventions should be geared to the specific needs of particular caregiver populations. The needs of dementia patient caregivers differ substantially from the needs of other caregivers, in the same way as culture and ethnicity also need to be considered in designing services for caregivers (Whittier S. et al., 2002). Studies on barriers to use of services for mental health by elderly Afro-American and Hispanics (Biegel D.E. et al., 1997) focus attention on lack of trained staff, the inability of physicians to address the elderly in ethnic minorities, the lack of staff specialized in cultural differences. In this light, it is worth mentioning the conclusions of the MEC (Minority Elderly Care) project (presented 9 December 2004, at the European Parliament), organized by the PRIAE in the context of the fifth QoL Action Line research programme (population ageing and handicaps), and financed by the European Commission. The findings state that there is a need to prepare common strategies to improve services for minority elderly (EURAG, 2005). The Police Research Institute on Ageing and Ethnicity (PRIAE), founded in 1998 and awarded the Jean-Khan 2003 prize, should also be mentioned. It is involved in the improvement of quality of life (income and pensions, health and social care, living conditions) for the elderly in black and ethic minorities in Great Britain and Europe, thanks to targeted projects in various fields (research, information, services, training and consultancy), as well as working with sector organizations (EURAG, 2004).

Further studies (Cotrell V., Engel R.J., 1998), which examined the impact of informal support on the use of formal services by caregivers to dementia patients, showed that informal support could be an important factor for overcoming prejudices against formal services. So informal support performs important mediating function for professional support and for various types of services.

2.5. Formal and informal support: an indispensable synergy

Informal care activities in families, their capabilities in terms of material resources and substance of social networks, are a crucial node for the obvious connections to the system of public policies and formal services (IReR, 2002). If family care and assistance strategies continue to be private initiatives, detached from the institutional welfare network, all the weight of assistance for the elder is left on the shoulders of the family. This is how two parallel “services markets” come to be generated: the first, based on the family but lacking in guarantees: the second, sustained by the public authority but “reserved” for that minority of the population that belongs to the sector of the weak (Di Santo P., 2003).

ISTAT’s Multiscopo survey - “Families and daily life” - shows precisely the fragmentation of caregiving, mainly when an elderly person who is not self-sufficient and lives at home , supported by informal unpaid work, legal and paid work, underground or semi-underground labour. The context is a reflection of overall segmentation in the services to the person sector of the labour market (Cossentino F., Innorta M., 2004). Another ISTAT Multiscopo survey - “Health conditions in the population” (Cossentino F., Innorta M., 2004) – found that elderly disabled who live at home are not necessarily fully dependent on their families, and are often supported by day centres, home care services (SAD), and integrated home care. However, in all three cases, public intervention does not appear as a real taking of responsibility for the elderly (unlike residential-type interventions), but as a series of actions, of a few hours a week, supporting care activities offered prevalently by the elder’s family.

Faced with this scant public back-up, in just 15 years, from 1983 to 1998, the number of families paying for private services has soared; this market comprises predominantly individual workers, has developed prevalently as underground labour and involves a growing number of foreign workers (Da Roit B., Gori C., 2003). This is a phenomenon that has reached significant proportions throughout Europe, in particular in southern states like Italy, Spain and Greece, where the public system of services to the person is weak, and is a complicated challenge that calls into play various interventions: social, labour and immigration policies. Decision-makers involved in social policies, in reality pay little attention to the private care market; however, just recently some realities have begun to offer new actions for training private operators, accreditation of people who provide assistance, creation of information and advice services to foster the coming together of supply and demand, issue of allowances to families to encourage regularization of private operators (Da Roit B., Gori C., 2003). In this respect the tiny space given over to private assistance by social services Framework Law 328/2000 is emblematic (there is merely reference to the 2001 Finance Act’s provisions for tax relief for families who pay for private care). The Law shows an evident contradiction between the intention to define characteristics for a new Italian welfare system, with a complex consideration of all subjects involved, and the failure to consider one of the most important of these subjects (Lazzarini G.V., 2004).

In other words, in the case of elderly disabled, formal services are usually only brought into play as a last resort (Horowitz A., 1985). Employment of formal service providers, when utilized, is often in conjunction with informal hands-on help; families continue to provide care even where formal services are used (Nadine F.M. Lambert J.D., 1997), and they are the primary informal sector group (Beach D., 1997). At formal sector level, service organizations (both medical and social) influence the course and consequences of family caregiving, as do social institutions, and their policies and service provisions (Beach D., 1997). The relationship between formal and informal support is becoming increasingly important for those involved in caring for older people; as the latter become more dependent on formal services, there is a need for organized and efficient formal support networks that work well with family helpers (Lyons K.S. et al., 2000). The transition from family to formal help is difficult, particularly if there are disagreements within the family over the need for outside help. Interventions that reduce family tensions and increase the amount of help from the family also reduce care-related stress and delay institutionalization. To judge formal services as lacking the flexibility and personal quality of family caregiving, and with increasing severity of disabilities, may lead to unstable care arrangements (Mittelman M. et al., 1996).

There is no simple route to achieving effective synergy between formal care (public services) and informal care (relatives and neighbours). In Italy the concept of welfare is often tied to public intervention and/or voluntary services, and it is difficult to acknowledge the role of informal caregiving as a resource to be educated for aiding the patient. The concept of community care, on the other hand, has marked assistance philosophy's transition from institutional to community, creating a substantial burden for the community (Sodero C., 2004). In any case, nowadays even in Italy, professional and family care are no longer considered alternative solutions, but rather activities that must be rendered complementary through a combination of support measures for the latter, and aiming to provide professional services. Family caregiving is therefore to be considered an important element in the assessment of assistance measures to be implemented and the primary task of public services and volunteer associations is thus to sustain informal care provided by family and friends, so that these caregiving relationships continue to meet the more pressing needs of the elderly user. However, achieving a continuum between formal and informal is very difficult to implement, since it is tough going transforming care in the community into care by the community, especially if this means getting formal and informal caregivers to cooperate closely (Sodero C., 2004).

It is important to spread the word of a "culture of caring", to valorise the continuity-discontinuity transition from family caregiving to professional care, the reasoning on interweaving and connection between the two contexts, also because the needs of the users of these services are a dynamic reality (Colombo G. et al., 2004:168). For instance, one typical example would be temporary hospitalization, whose priority is a care objective, without neglecting the aid given by the family. In actual fact, temporary hospitalization must be seen as a moment for the relaunch and reassessment of the entire caregiving process, aiming to improve patient and family wellbeing, as well as reinstating the patient in a family context (Guaita A., Vitali S., 2004). However, styles of service approach to the family may vary; aid services might, in point of fact, even underestimate family caregivers and exclude them as an "obstacle" to the work of operators, involving next of kin only for information about the elderly relative (Taccani P., 2004b). In all honesty, public and private welfare interventions perceive the family as a reference scenario, a subject lacking expertise and specialization, so unsuitable for involvement in a care scheme, instead of seeing the family as a primary system with its own autonomy, capable of being not only the recipient but also the subject of social policies. As a consequence the family's attitude towards services may be one of claiming a right, rather than one of collaboration, and the service itself is provided in a one-sided manner to the elderly user (Paroni P., Rizzi M., 2004).

In the light of the changes that have recently begun to be applied to the welfare state, there is a quest for instruments for appraisal and new equilibriums, in particular for services to the person: decentralization of decision-making, pluralistic management and service localization, hand-in-hand with a process for revising the caregiving relationship, in which the user plays an increasing role as co-producer and protagonist (Giancaterina F., 2004). In a care culture centred around family involvement, support offered by relatives must keep pace with what is offered to the patient and, for instance, the work of an RSA cannot be limited to the sphere of the illness, but must extend to involving and informing the family, considering both the evolution of the disability and the mechanisms of family affections (Trecate F., Pozzati S., 1999). A residential facility for the elder must, therefore, have an ethics code based on the concept of responsibility – towards residents, family, local authorities and social services, territory and locale community – and with the person/resident at the centre of the code, as the holder of rights (Chiarle Prever F., 2005).

It is to be underscored that "In Italy at the moment much of the assistance to non-self-sufficient subjects comes in the form of financial support, often distributed without limitations or control over how it is used. This measure comes with a local offer of residential and home care services, which is still, however, scarce and covers a minimum part of care needs in the elderly population. So it is a system that is entrusted mainly to family caregivers." (National Health Plan 2002-2004). In reality, in Italy, the entire welfare system is characterised by a prevalence of cash allowances to families, traditionally the responsibility of the State, and to a lesser extent the responsibility of regional and municipal authorities for resources destined for territorial services and social actions (Da Roit B., 2002b). A system that is biased towards cash grants (Lazzarini G.V., 2004), based only on a handout to the citizen, will not resolve problems in families, but leaves them to their own resources, risking accentuation of social distinctions between who is able to get organized and those who do not have the financial and psychological possibilities to do so. Providing citizens with assurances is therefore one of the public authority's main responsibilities, according to Law 328/00, since the authority has the political tenure for programming, legislating and guaranteeing the services network and quality. In a universalistic welfare system, reception and information services acquire a fundamental role and function, like the social secretariat (Di Santo P., 2003). Conversely, economic aid supports but often isolates (Cesena Health Authority, 2002), and this gives rise to the need to attempt to combine cash allowances to families with provision of end services that will support informal and family caregiving (known as "cash and care") (Ranci C., 2001).

Florence Municipal Authority dealt with the theme of renewing services for the elderly. Florence is a city with one of the greatest numbers of older people in Italy and in Europe: the over-65s account for about 25% of the city's total population, and almost 4.5% of them are seriously impaired. The municipal authorities therefore decided to implement schemes whose scope was the reorganization, development and extension of the range of territorial services targeting home care, with the aim of encouraging home care for non-self-sufficient older people, encouraging next of kin to act as caregivers and also give them economic support, promoting quality of services and fostering greater integration (Uccello R., 2003).

It should be underscored that many interviews with caregivers and satisfaction surveys support respite services as effective action (Theis S.L. et al., 1994), but it is important for families to receive adequate amounts of help (Zarit S.H. et al., 1999). What helps - and what does not? We must also consider that some support helps caregivers and some does not. For example, other family members may hinder a caregiver's sense of control, and be a source of stress or conflict, and financial support may not directly support caregivers (Askham J., 1997). In fact, several caregivers report that their siblings refused to assist caregiving efforts because they disagreed with the caregiver's decision not to institutionalize their elderly parent (Cox E.O. et al., 1988).

2.6. Closing considerations

Today assistance to the elder is still focused on curing illness and limiting disability. The issue of overall and articulated need that is difficult to resolve is seen prevalently as "medical", whereas it is indispensable that the " needs of the family and the caregiver" also be considered, with reference to the daily commitment to assisting relatives who are not self-sufficient. It is also necessary to achieve cooperation between formal and informal, public and private, and within each type of network. Formal services must adapt to informal services and, as integration, informal services must reach a point of contact with formal services (Cesena Health Authority, 2002). Law 328/2000, on the reform of social services, has also attempted to redefine the boundaries between public and private, through a series of measures reformulated in the direction of public/private mix (Polverini F. et al., 2004). The same law highlights the principle of “horizontal” subsidiarity, whereby public authorities are obliged to support and facilitate organized voluntary schemes and not interfere with its decisions (Nocera S., 2002). In particular, whilst vertical subsidiarity is the expression of administrative decentralization, horizontal subsidiarity, identifiable in the role of private social arrangements, subsidiary and/or alternative to public authorities in the provision of services to the person, has generated significant changes in the user, with the consequent multiplication of issuing authorities and a need for “institutional” or “excellence” accreditation of services in private structures (profit and no-profit) (Fossati W., 2003).

This divide between the health problem and “existential” problems in the broadest sense, and between costs for society and costs for the family, will be further aggravated by the increasing drive for forms of “home placement”, in a vision of decreasing solidarity that leaves aside the social and economic reality of the families involved. This new form of assistance, which could be acceptable in many of its aspects, cannot fail to increase the commitment in terms of public authority spending, at least with regard to sufficient integration for the costs that the family itself has to sustain (CENSIS, 1993). It is important to affirm the elder’s right to stay in their life setting, in any case giving preference to home care, but in close connection with home care and support actions for daily routine, to prevent forms of institutionalization; it is equally important to foster a culture of “good-neighbourliness” at local, town and European levels, which reappraise the figure of the elder, on one hand, as being a resource for all society and increase intergenerational exchanges, and on the other restore the sense of collective and individual responsibility in relationships with weaker subjects, promoting forms of self-help, exchange of expertise, social protection systems at condominium and quarter levels. All this then becomes indispensable if referred to older people who live in particular isolation, lacking contact with informal aid services or networks, and therefore at greater risk (“hard to reach” older people) (Cutini R., 2005). So a new course for the reformulation of home care service should be developed to offset the failure to involve users and the scant public resources invested, which constitute a huge hurdle for individuals and their relatives (Goldoni L., 2003).

When Law 328/2000 was under debate, it was observed by some that more courage was required in offering forms of “guaranteed” protection to group of persons who “could not live without assistance”, so to speak (non-self-sufficient older people, persons with no fixed abode, abandoned children, etc) (Cutini R., 2001; Santanera F. et al., 2001; Cutini R., 2005). In effect, criticism and preoccupation has been voiced on the subject of welfare reform plans that cause an ethical impoverishment of the rationale behind welfare policies, and it is no surprise to see that the welfare state is currently enjoying a “bad press” (Zygmunt B., 2002). All welfare states are in difficulty for a number of reasons: the impossibility of forcing taxation over certain limits, the falling birth rate, the increase in average life expectancy and number of older people, increasing reduction of pension and social security contributions from the employed for the pensions of previous generations, expanding processes of unease and social exclusion. Crisis elements also arise from the lack of care and assistance services in our society, as in other western realities (Lazzarini G.V., 2004). Bureaucratic welfare reform has thus forced users to reconsider what services they will be offered: shorter timeframes and less rigid content, with new “flat” and “short” welfare organization models, where “short”, in welfare reform, refers to a state that reduces its responsibilities by limiting fixed or permanent guarantees, replacing them with temporary aid. Inequality is generated as a result” (Sennett R., 2004).

The relations between services and families are the crux of changing welfare that is increasingly "plural", welfare that must give more support to families involved in caregiving, which must regularize and stimulate plurality of offered services, which must support informal assistance networks and the voluntary sector, which tries new organization methods for services that include recourse to cooperation with the private sector (Paroni P., Rizzi M., 2004). The national health service must, in point of fact, prepare itself to meet growing demand for alternative forms of assistance, characterized by new provision methods based on principles of continuity for long-term care and integration of health services with social services. So strategic objectives include the increase of financial resources for providing health and social services for the non-self-sufficient, appropriate scaling of network nodes (home hospitalization, integrated home care, integrated day centres, nursing homes and rehabilitation facilities), and reduction of the number of improper admissions to hospitals for the acutely ill (National Health Plan 2003-2005). On the other hand, compared to other major European countries, Italy still stand outs out mainly for its lack of strong theory and provisions for dealing with the problem of failing self-sufficiency, a problem that is growing in size and which brings a great deal of unease to many impaired elderly and their families (National Health Plan 2003-2005).

So community social services, community care, development of urban social networks, service policies to combat exclusion, a work network are all important (AA.VV., 1996). In particular, the "network model" is a coordinated care system that contains support for persons in difficulty as far as welfare aspects are concerned and whose welfare scope is to provide appropriate assistance regardless of what is being offered by services (Oddo G., 2004), with higher quantities and better quality of home services, also through the offer of "graduated" services, in other words, with various types of welfare content (Anconelli M., 2001), and on the basis of the subject's situation, thus implementing the so-called "supply chain", which still offers actions for maintaining existing life context and residential-type services. The former covers economic and home assistance, helplines and domotic technologies, whilst the residential sector will included co-residence for reciprocal help, and hospital health and welfare residences (R.S.A.O.) (Malfer L., Zotta G., 2004).

It is fundamental to build a network of services as an alternative admission to an institution for families with an elder who is not self-sufficient (AUSER, 2001b), valorising each person's existing informal caregiving fabric, which is a real lifesaver used in cases of need, in the perspective of extended support (Bertolo E., Moretto A., 1998). In other words, family and services can meet around the illness of a member of the family (Campari A., Parisi G., 2002), and the latter must shoulder the commitment of an "extended user basin" (including family), and treat not just the need, but the "setting of that need" (Paroni P., Rizzi M., 2004:92). So, a reorganization of services is to be hoped for, intending to render them more perceptive of relative contexts (Castegnaro A., 1998), compared to the current Italian welfare system, based prevalently on interventions that target the needs of individuals, rather than the entire nucleus. However, current debate seems to be valorising families, considering them "active subjects for social policies" (Accorinti M., Carrera F., 1999), and base cells for primary services, which have their own independence with regard to each delegation to external operators (Franchini R., 2004).

The system of services for the person (young, old, sick, unemployed, families) is therefore a task that still has to be completed (Mozzanica C.M., 1999), and expected ageing of the Italian population in the near future will bring about an increased demand for residential care, taken not only to mean the request for adequate space, but also for innovative types of action and management in residential structures. The problem is delicate and urgent since public resources for health spending are very limited and this means that there will have to be an opening to the private market, new financial tools, adequate returns on invested capital. If there is a lack of effective response to residential needs for older people, the non-specialist market will prosper, with consequent fallout on the economy and inefficiency in the required services (Della Puppa F., Mostacci R., 2004).

So a welfare mix is needed to reconcile the elder's right to home care, with caregiving next of kin's right to work and socialise (Mattesini M., 2003), valorising informal care networks through promotion and support of self-help groups, and experiments with allowances integrated with welfare and home care services. Listening and supporting are the keywords to describe the shift from the individual to the typical collective of the welfare mix, which respects the welfare state by basing itself on new directions for services policies and the establishment of a "caring" model for the user/client, who is not just a bearer of questions requiring replies in the form of services ("curing"), but is also a bearer of resources (Giorgetti M., Bagarolo R., 2003).

In today's reality, the citizen cannot be left to hunt out useful services alone: they must be guided and access must be facilitated. Public administration will also have to stop considering the user an annoying obstacle and admit they are customers and resources; in welfare there is also a shift from a user provided with standardized products, to the "evolved consumer" who can choose (Lippi A., 2002). So it is to be hoped that there will be humanization of services, with respect for individuals, attention to the family, flexible organization and ongoing operator training. Consequently, humanizing means getting into the mindset for understanding human beings, observing the person suffers with respect and solidarity; it means making structures more appealing and encouraging the correct distribution of health resources, defining realistic treatment aims that are suited to the individual case, reinforcing the hope for a renewal of life even it appears impossible to go beyond the suffering of the moment (Bottino P., 2003). In the perspective of humanizing services it is therefore necessary to bridge the evident divide between existing clinical structures and people's needs (Delle Fave A., Marsicano S., 2004). The "dehumanization" problem of services, on the other hand, is strongly rooted in the private "market", as well as in institutional structures and public services, which are not always up to speed for operating in an acceptable manner (Lazzarini G.V., 2004).

In conclusion, long-term care providers must work with families to expand the capacity of family caregivers, who need all the help they can get to provide care; paid caregivers will be needed for those who have no family available to provide care (Friedland R.B., 2004). Improving caregiver wellbeing requires moving beyond the individual caregiver to organizational, community and policy levels. Future interventions should be directed at enhancing coordination amongst employer health care systems, churches, senior citizen centres, and other community-based organizations, in order to assist the family caregiver population more effectively (Whittier S. et al., 2002). However, precisely when the family performs the most intense care action in the most responsible way, strong cultural, social, political dynamics come into play, which tend to obscure and devaluate precisely this function: so the paradox is that the more the family uses its resources, the more it tends to close in on itself or is conditioned to do so. In this way, the great potentialities that underpin the culture and practice of home care and territoriality, too often transform into the culture and practice of narrow-minded familism (Lazzarini 2004).

3 Assessment Tool*

by Cristian Balducci, Kevin McKee, Barbro Krevers, Beata Wojszel, Eva Mnich and Costis Prouskas

3.1 Introduction

The Common Assessment Tool (CAT) used in the EUROFAMCARE study was developed over a period of several months. It comprises a series of items and scales that were developed by the partners specifically for this project, or selected for use from among a range of standardised and validated published instruments. Development was achieved through a series of meetings involving representatives of all partners, database searching for published instruments and evidence of validity/reliability, and extensive discussion via email. Once items/instruments had been selected, their availability in partner languages was determined. Where equivalent versions were not available in all languages, back translation was performed following established protocols. Formatting of the CAT took place, and the draft questionnaire was tested in two pilot studies carried out in each partner country. Following the first pilot study, substantial revision to the CAT occurred. The second pilot study indicated the need for further minor revision. The final instrument therefore represents a third version of the original. The Italian version of the CAT is available at: http://www.inrca.it/CES/QuestionarioEuroFamcare.pdf.

Items and instruments were developed by the partners or selected from the research literature with reference to a model of carer service use and quality of life as a guiding framework. Figure 1 presents this model. Derived from the work of Aneshensel and colleagues (Aneshensel et al., 1995), the model conceptualises the relationship between constructs that are hypothesised to impact on carer and elder service use and carer quality of life. Following further development, the constructs were operationalised in the CAT via a series of variable categories: *Elder's demographic and background characteristics; Elder's disability and need; Carer's demographic and background characteristics; Carer's caregiving situation; Carer quality of life (QoL); Financial circumstances; Service use; Characteristics and quality of services*. In addition, some variables in the CAT addressed issues related to the administration of the questionnaire. The CAT also included a project consent form. Finally, each EUROFAMCARE partner was allowed to include a small number of country-specific items in their own version of the CAT. The description of these items can be found in the partners' respective NASURs. The items and instruments in each of the above variable categories will be described in detail below. Where items/instruments were drawn from the research literature, the source will be referenced. Where no reference is provided, the item/instrument was developed by the partnership for the purpose of this study, or drawn from previous unpublished work of partnership members.

3.2 CAT Items and Instruments

3.2.1 CAT administration

A series of items were required to clarify the source of the data. These included the name of the interviewer (open response format) and the number of the interviewer (allocated via a national

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* This chapter represents an adapted version of Chapter 3 prepared at a European level for the Trans-European Survey Report (TEUSURE).

list). The country and country region were allocated a pre-set code, and the locality was indicated as metropolitan (1) urban (2) or rural (3). The data collection site was allocated a pre-set code, and each interview allocated a case number, which was the number of the interview carried out by each interviewer (i.e., the first interview=1, second interview=2, and so forth). The date of the interview was indicated (dd/mm/yyyy), and whether or not the elder was present at the interview (yes=1, no=2).

3.2.1.1 Mode of recruitment

This item, indicating the manner in which the respondent had been recruited, had eight optional responses: health or social care professional (1); priest/parish/religious organisation (2); door-to-door (3); voluntary organisation (4); advertisement (5); lists (6); other (7); and snowball (8). If other (7) was selected, the interviewer was asked to specify; and if snowball was selected (8), the interviewer was asked to additionally indicate which channel had produced the respondent (i.e., to enter the appropriate code (1-7) from the above options)

3.2.2 Elder’s demographic and background characteristics

Elder’s gender (male=1, female=2) and age (open response format) were identified, as were Elder’s nationality and ethnic origin (open response format). Elder’s marital status was categorised as one of married/cohabiting (1), widowed (2) divorced/separated (3), or single (4).

3.2.2.1 Elder’s residence and cohabitation status

Elder’s usual place of residence was categorised as at home (1), in a care home (2), in sheltered housing (3) or other (4); if other, the respondent was asked to specify. To determine Elder’s cohabitation status, the respondent was asked who Elder lived with. For each of the following options, the response categories were yes (1), no (0) and, where appropriate, not applicable (8): alone; with their children; with their partner; with paid carers (in their own home); with others (specify). For those Elders not living in a care home or with their carer, the respondent was asked to indicate the total number of people in the Elder’s household (including Elder), and, of those, how many were aged 14 years or less (both open response format).

3.2.3 Elder’s disability and need

The respondent was asked to identify the main reason the Elder needed care and support, and up to four other reasons.

3.2.3.1 Need for support

This construct was sub-divided into a series of domains: health needs; physical/personal needs; mobility needs; emotional/psychological/social needs; domestic needs; financial management needs; financial support needs; and organising and managing care and support needs. For each need, the respondent was asked to (a) indicate whether Elder required help completely (2) partially (1) or did not have a need for help (0); (b) to indicate who helped Elder with their need, checking all those applicable from the options of no one, the respondent, other informal carers, and services/support organisations; and (c) indicate (yes=1, no=0, not applicable=8) whether the respondent would like Elder to have more help to meet their need.

3.2.3.2 Mental health problems

The respondent indicated whether his/her Elder had any memory problems (yes=1, no=0). Those indicating ‘yes’ were asked if a doctor had given a cause for the memory problems (yes=1, no=0). Those indicating ‘yes’ were asked if the cause was dementia (1) or other (2), and if ‘other’ to specify the cause.

3.2.3.3 Behavioural problems

The respondent was asked a general question as to whether Elder suffered from any behavioural problems (yes=1, no=0). In addition, three items assessed the frequency of specific behavioural problems. These items were drawn from the behavioural component of BISID (Behavioural and Instrumental Stressors in Dementia; Keady & Nolan, 1996), and adapted. The items assessed ‘wandering in or outside the home environment or behaving in a way that endangers their safety’; ‘having difficulty holding normal conversation, having no insight into their problems, or becoming uncooperative with requests’; and ‘behaving in ways that you find upsetting’. Response options were ‘most of the time’ (3), ‘sometimes’ (2), rarely (1), or ‘never’ (0).

3.2.3.4 Dependency

A single item, drawn from the COPE questionnaire (McKee et al., 2003) asked ‘How dependent is the person you care for’, with response options ‘severely dependent’ (4), ‘moderately dependent’ (3), ‘slightly dependent’ (2), or ‘independent’ (1). Dependency was assessed in greater detail through the 10-item Barthel scale (Mahoney & Barthel, 1965), a 6-item IADL scale derived from the Duke OARS assessment (Fillenbaum & Smyer, 1981), plus an additional item on mobility. The six items drawn from the IADL scale assessed Elder’s capacity to carry out housework, prepare own meals, go shopping, handle money, use the telephone, and take medication.

For the majority of items, response options were ‘unable’ (0), ‘with some help’ (1), and ‘without help’ (2). For the two Barthel items assessing incontinence, the response options were ‘yes, frequent accidents’ (0), ‘yes, occasional accidents’ (1), and ‘no accidents’ (2). For the Barthel item assessing capacity to get around indoors, there were four optional response categories: ‘unable’ (0), ‘in a wheelchair without help or walking with major physical help’ (1), ‘walking with some help guided or supervised (2), and ‘without help, may use any aid’ (3). For the Barthel item assessing capacity to transfer from bed to chair, there were four optional response categories: ‘unable, no sitting balance’ (0), ‘major help, 1 or 2 people, physical)’ (1), ‘minor help, verbal or physical’ (2), and ‘without help’ (3).

3.2.4 Carer’s demographic and background characteristics

The respondent’s age (open response) and gender (male=1, female=2) were identified. Nationality and ethnic origin were determined, both with open response formats. Marital status was categorised as one of married/cohabiting (1), widowed (2) divorced/separated (3), or single (4). Membership of a religious denomination was determined (yes=1, no=0), if ‘yes’ the respondent was asked to specify (open response). Religiosity was determined by asking the respondent if he/she was ‘not at all religious’ (0), ‘quite religious’ (1), or ‘very religious’ (2). The respondent was asked if he/she had any children or grandchildren (response format for both items: yes=1, no=0), if ‘yes’ the respondent was asked to indicate the number of children (both items: open response). The total number of people in the respondent’s household, including respondent, was requested (open response), as was the number of those children aged 14 or less (open response). The respondent was asked to indicate their highest educational attainment (open response). The respondent also indicated whether he/she was currently in education (yes=1, no=0), and , if 'yes', the number of hours spent in education per week (open response).

3.2.4.1 Carer employment status

Whether the respondent was currently employed was established (yes=1, no=0), and, if 'yes' the number of hours work in an average week was established (open response). Occupation was categorised as: 'private sector employee' (1), 'public sector employee' (2), 'self-employed' (3), 'other, please specify' (4). An open response item asked for type of work. For *non-working respondents only*, an item asked whether the respondent's status was 'retired' (1), 'unemployed and seeking work (2), 'on long-term sick leave but intending to return to work' (3), 'a house-wife/husband' (4) or 'other, please specify' (5)

3.2.5 Carer's caregiving situation

An initial question determined the number of people of 65 years of age or older to whom the respondent provided support/care for more than four hours a week (open response). The number of hours support per week provided to Elder, the number of people not elderly to whom the respondent provided care and support, and the total number of hours of support/care per week provided to all people apart from Elder, were all determined as open response items. Relationship to elder was determined by a forced choice item (response categories: spouse/partner=1; child=2; brother/sister=3; daughter-/son-in-law=4; uncle/aunt=5; nephew/niece=6; cousin=7; other (specify)=8). The proximity of the respondent to Elder was assessed, using an item drawn from the COPE questionnaire (McKee et al., 2003) (response categories: in the same household=1; in different households but the same building=2; within walking distance=3; within 10 minutes drive/bus/train journey=4; within 30 minutes drive/bus/train journey=5; within 1 hour drive/bus/train journey=6; over 1 hours drive/bus/train journey=7). The typical week was assessed by asking the respondent to specify the periods they provided care or support for Elder for each day (Monday-Sunday): early morning (approximately 5 to 9 a.m.), morning (approximately 9 a.m. to 12), afternoon (approximately 12 to 5 p.m.), evening (approximately 5 to 10 p.m.), and night (approximately 10 p.m. to 5 a.m.). Duration of caring for Elder was assessed in months (open response)

3.2.5.1 Role inflexibility

Two adapted items drawn from the Social Restriction Scale (McKee et al., 2001) assessed this construct: The respondent was asked 'If you were ill is there anybody who would step in to help with Elder?' and 'If you needed a break from your caring role is there someone who would look after Elder for you?' The response options for both items were 'Yes, I could find someone quite easily' (1), 'Yes, I could find someone but with some difficulty' (2), and 'No there is no one' (3).

3.2.5.2 Decision to care

When prompted by the question 'what factors influenced your decision to care for Elder?', the respondent could indicate 'yes' (1) or 'no' (0) to each of a list optional factors, which included the following: a sense of duty; there was no alternative; the cost of professional care would be too high; emotional bonds (love, affection); caring for elder makes me feel good; elder would not wish for anyone else to care for them; because of my religious beliefs; I found myself in these circumstances almost by chance without making a decision; there are economic benefits for me and/or elder; a personal sense of obligation toward elder as a family member; other (specify). The respondent was also asked to specify the principal reason from those indicated.

3.2.5.3 Positive and negative aspects of care

The COPE Index (McKee et al., 2003) was used to assess the respondent's perception of their caring role. This 15-item instrument contains two subscales: a six-item Negative Impact scale, and a five-item Positive Value Scale. Three items also assess the perceived level of support received from family, friends, and health and social care professionals respectively, and one item assesses perceived financial difficulties. An example item is: 'Do you feel you cope well as a caregiver'. Response options for all items are: always; often; sometimes; and never. A 'not applicable' option is available for some items.

3.2.5.4 Future care role

Gilhooly's (1986) scales assessing carers' willingness to continue caring and their acceptance of institutional care were adapted and developed into two items addressing the respondent's perceptions of their future role. One item asked 'in the next year, are you willing to continue to provide care to Elder', with response options 'yes, and I would even consider increasing the care I give if necessary' (1); 'yes, and I would consider increasing the care I give for a limited time' (2); 'yes, I am prepared to continue to provide care if the situation remains the same' (3); 'yes, I am prepared to continue to provide care to elder but only if I have some more support' (4); and 'no, I am not prepared to continue to provide care to elder no matter what extra support I receive' (5). A second item asked ' Would you be prepared to consider elder's placement in a care home?', with response options 'no, not under any circumstances' (1); 'yes, but only if elder's condition gets worse' (2); and 'yes, even if elder's condition remains the same as it is now' (3).

3.2.5.5 Caregiving and employment.

Respondents were asked if 'caring for Elder has caused any restrictions to your working life or career'. For *currently employed carers*, this was quantified as a reduction of working hours (response options yes=1; no=0). Respondents selecting 'yes' were then asked 'how many per week' (open response) and 'what difference has this made to your income per month' (open response). Finally, the respondent was asked if the difference was positive (1) or negative (2). Restriction for *non-working carers* was quantified as 'I cannot work at all' (response options yes=1; no=0) and 'I have had to give up work' (response options yes=1; no=0). Non-working carers responding 'yes' to the last item were further asked 'how many hours per week were you working before you gave up work' (open response). Three further items (all response options yes=1; no=0) were asked of *all carers* regarding restrictions to working life or career: 'can/cannot develop professional career or studies'; 'can/could work only occasionally'; and 'other', with the instruction to specify if selecting 'yes' to the last item.

3.2.6 Carer quality of life

A single item assessing carer health was taken from the Short Form-36 (SF-36; Brazier et al., 1992). It asks the participant to record the general health status on a five-point scale, anchored by 'excellent' (1) and 'poor' (5). From the same instrument, a single item assessed overall quality of life for the preceding two weeks, with responses recorded on a five-point scale anchored by 'very good' (1) and 'very poor' (5).

Information on carers' psychological well being was gathered using the World Health Organisation-5 Well-being Index (WHO, 1998), a five item scale in which each item addresses an aspect of psychological health over the previous two weeks, and asks the participant to record how they have felt on a six-point scale, anchored by 'all of the time' (6) and 'at no time' (0).

3.2.7 Financial circumstances

Respondents were asked to indicate their net household income per month (specified amount=1; don't know =2; refusal to answer=3). Respondents selecting '2' or '3' to the item were shown a card indicating a series of income bands (country specific) from which they could indicate an approximate net household income per month (with 99 coded for non response). An identical procedure followed for the determination of the Elder's net household income per month. A further item asked if Elder received any pension or financial support of any kind from the state (response option yes=1; no=0).

3.2.7.1 Caregiving costs

The respondent was asked whether caring had resulted in any additional financial costs. Potential costs were indicated as 'adaptation of the home environment or furniture', 'travel costs'; 'special food', 'medicines'; and 'other (specified)' (response options for all items, yes=1, no=0).

3.2.7.2 Caregiving allowances

Four items (country specific) asked whether the carer or elder received financial support or allowances because of the care situation. For each item, the response options were 'Elder yes=1, no=0; Carer yes=1, n=0', dependent upon the appropriateness of the designated recipient for the respective allowance/financial support. An additional item allowed the respondent to indicate whether they or their elder received any other form of financial support (specified; response options as above). The total amount of benefits received for carer and elder were then required (open response format), indicated for both as per week (1), month (2) or year (3).

3.2.8 Service Use

Respondents were asked to exhaustively list the services used by themselves and their Elder in the previous 6 months. Separately for each service listed, the following questions were asked. First, whether the service had met carer's/elder's needs (mostly yes=1, mostly no=0). Second, whether the respondent or elder paid for the service when utilised (yes=1, no=0). Third, if the answer to the previous question was 'yes', to indicate the cost (open response) per unit (open response in terms of quantity such as per visit, per hour, etc.). Fourth, how often elder/carer used the service (open response in terms of time, e.g., daily, weekly, etc.). Finally, the number of the previously expressed units of the service that had been received by carer/elder in the last 6 months. Carers were asked if there were any services they or Elder still needed that they had stopped using (yes=1, no=0). Those carers responding 'yes' were then asked to specify up to the three most important services they had stopped using, and to indicate for each specified service whether the reason they had stopped using the service was because it was 'too expensive'; 'too distant'; because of the 'low quality of the service'; because it was 'not available anymore'; because carer/elder was 'no longer entitled to use it'; or 'other' (specified). A similar question protocol was used to identify if their were any services that the Carer or Elder needed but had not used so far (yes=1, no=0). Again, where the answer to this item was 'yes', the respondent was asked to specify up to the three most important services they had not used, and to indicate for each specified service whether the reason they had not used the service was because it was ‘too expensive’; ‘too distant’; because of the ‘low quality of the service’; because they ‘didn’t know about it’; because carer/elder was ‘not entitled to use it’; or ‘other’ (specified).

Respondents who used no services in the previous six months were asked to list the three most important reasons why carer/elder did not access services (open response). *All respondents* were then asked to list the three most important factors (e.g., people, organisations, facilities) that had been the greatest help to them accessing services; and the three most important factors that had caused the greatest difficulty to them in accessing services (both open response).

3.2.9 Characteristics and quality of services

A series of items were used to assess carers’ perceptions of the importance of different forms of caregiving support. Fourteen items were used to assess this domain. Each item was preceded by the statement ‘How important is support that gives you…’; an example item being ‘Information and advice about the type of help and support that is available and how to access it’. Each item had the response options ‘very important’ (2), ‘quite important’ (1), ‘not important’ (0), and for selected items ‘not applicable’ (8). A second component of the question asked for each item ‘Is this [support] currently being met?’ (response options mostly no=0, mostly yes=1). The respondent was then asked to rank order from all those forms of support indicated as ‘very important’ the three most important forms of support (Krevers & Öberg, 2002).

A series of items were used to assess carers’ perceptions of the importance of different service characteristics. Twelve items were used to assess this domain. Each item was preceded by the statement ‘How important are the following characteristics of a service for you…’; an example item being ‘Help is available at the time you need it most’. Each item had the response options ‘very important’ (2), ‘quite important’ (1), ‘not important’ (0). A second component of the question asked for each item ‘Is this [characteristic] currently being met?’ (response options mostly no=0, mostly yes=1, and for selected items not applicable=8). The respondent was then asked to rank order from all those service characteristics indicated as ‘very important’ the three most important service characteristics (response format adapted from Krevers & Öberg, 2002).

3.2.10 Country-specific items

The items discussed in this section were only incuded in the Italian version of the CAT. They were placed at the end of the assessment tool.

Carers were asked their opinion regarding the level of expenses associated to caregiving, with response categories being ‘low (not relevant)’ (1), ‘medium (tolerable)’ (2) and ‘high, so to create trouble’ (3). In case the latter response (3) was given, they were asked who reported costs (expenses)-related troubles, with response options to be chosen among ‘elder’ (1), ‘myself’ (2) – to indicate the carer him/herself – and ‘other family member’ (3), with more than one response option permitted. Carers were also asked to specify (if applicable) who helped to bear those costs (open response). Carers were then asked whether they were facing any of the following difficulty (more than one response permitted): ‘not able to rest during the night’ (1), ‘can not go out of home’ (2), ‘scared that something might happen’ (3), ‘sorry to see Elder in this condition’ (4), ‘loosing or reducing friendships’ (5), ‘can not go on holiday’ (6) ‘physically tired’ (7), ‘feeling emotional/psychological strain’ (8), ‘reporting the burden of costs to bear’ (9), ‘having lost or reduced amount of spare time’ (10), and ‘other’ (11), to be specified (open response). They were also asked which of the above mentioned difficulties was the most prominent to them. Following this, the carers were asked which sort of intervention could be useful for a working family carer, with the following responses available (more than one option permitted): ‘going in non paid leave’ (1), ‘going in paid leave’ (2), ‘possibility of working part-time, instead of full-time’ (3), ‘receiving a financial support to better organize caregiving’ (4), ‘receiving support from external personnel’ (e.g. professional carers) (5), ‘other’ (6) to be specified (open response). They were also asked which of the interventions above would be the most useful to them. A further question investigated whether the carers were taking advantage of any facility which helps to reconcile working commitment with caregiving (no=1, yes=2). If a ‘yes’ response was given, carers were asked to specify which facility they were taking advantage of, by choosing among ‘three days per month of leaving (Italian law 104/1992)’ (1), ‘leave of absence for caring reasons (Italian law 53/2000)’ (2) and ‘other facilities’ (3), to be then specified (open response).

Following this, carers were asked whether the older person is able to remember a series of seven events or circumstances such as ‘what happened yesterday’, ‘what happened last week’, ‘where things have been left’, etc., with response options being ‘usually yes’ (0), ‘usually no’ (2) ‘sometimes’ (1). The entire BISID scale (Behavioural and Instrumental Stressors in Dementia; Keady & Nolan, 1996, see also section 2.3.3) was then presented to carers. For each of eleven behavioural problems possibly showed by elder, carers were asked to report the relative frequency of the behaviour (1=never; 2=rarely; 3=sometimes; 4=often; 5=very often) and how much distressing it is for them (1=not distressing; 2=a bit distressing; 3=moderately distressing; 4=very distressing).

Carers were then questionned on the frequency with which they or other persons carry out a series of ten caregiving-related activities towards the older person, such as personal care/hygiene, drug administration, preparation/administration of meals, etc. Response options were ‘three or more times per week’ (2) and ‘more rarely’ (1). For each activity carers could indicate whether (a) they themselves carry out the activity, and/or one or more of the following persons: (b) ‘other family member 1’, (c) ‘other family member 2’, (d) ‘other family members’, (e) ‘neighbours’, (f) ‘friends’, (g) ‘home helper’, (h) ‘home helper from private organisations’, (i) ‘home helper from public organizations’, and (l) ‘volunteers’. For response options ‘b’ and ‘c’ the carers were asked to specify among the following categories: older person’s ‘husband/wife’, ‘daughter’, ‘son’, ‘daughter in low’, ‘son in law’, ‘sister’, ‘brother’, ‘nephew’, ‘niece’, ‘other’. For response options ‘d’-‘l’ carers were asked to specify the number of persons in each category.

Respondents were then asked their opinion about the possibility to temporarily place (e.g. some days or a week) the older person in a facility who provides for (non definitive) short periods of stay, with responses available being ‘no, not under any circumstances’ (1), ‘yes, but only if older person’s condition gets worse’ (2), ‘yes, even if the older person’s condition remains stable’ (3). After this, the carers were asked what the most useful period of stay would be, if these facilities would exist in their area. Responses were ‘even only for some hours per day’ (1), ‘even only for the week-end’ (2), ‘for some days’ (3), ‘for some weeks’ (4), ‘for some months’ (5). Following this an item investigated whether the carers, in case of older person hospitalization, had ever resorted to a private carer to ensure night care to the older person (1=no, never, 2=yes). If the response was ‘yes’, the carer was asked for how many nights (open response), the cost per night (open response), and whether the private carer was an italian citizen (1) or a foreigner (2). After this an item asked the carers whether, in case elder would need continued care and it would be impossible for them to give it, they would be ready to resort to a private foreign carer. Responses were ‘yes, I already do that’ (1), ‘yes, I would do that’ (2), and ‘I would do that only if I wouldn’t have any alternative’ (3), ‘No, I wouldn’t do that in any case’ (4), ‘I don’t know’ (5). Three further items were linked to responses to the latter question. In case the carers responded ‘yes, I already do that’, they were asked whether the foreign carer is ‘cohabitant’ (1), helps ‘during the day’ (2) or ‘during the night’ (3). If the carers responded ‘yes, I would do that’, they were asked to specify the reason, with responses being: ‘it can be useful both to the older person and his/her relatives who can not care' (1), 'these [foreign] persons do a useful job that few Italians would be ready to do' (2), 'it is economically convenient' (3), 'other' (4) to be specified (open response). Finally, if the carers responded 'I would do that only if I wouldn't have any alternative' or 'No, I wouldn't do that in any case', they were asked again the reason for their response, with options being 'I do not think it's a good thing to entrust ones family member to these persons' (1), 'only people with enough money can afford that' (2), 'this is a good solution only for the older person's sons/daughters' (3), 'I would prefer an Italian citizen' (4), other (5), to be specified (open response).

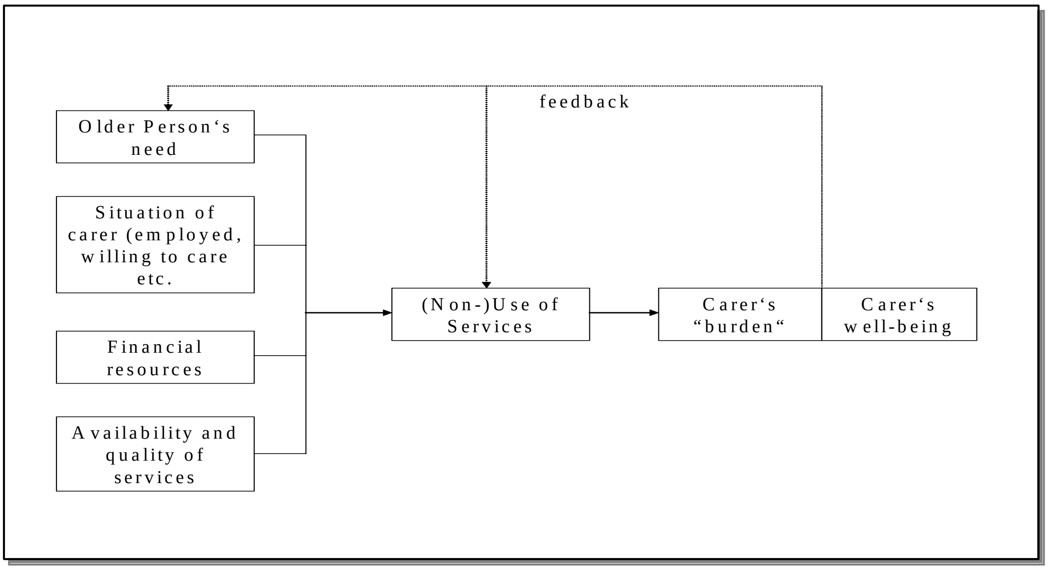
Seven items then followed, which investigated carers depressive sympomatology. These were taken from the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1982). The carers were asked to focus on their last week and to report the freqeuncy with which they experienced seven common symtoms of depression. An example item is: 'I still enjoy the things I used to enjoy'. Responses were given on a four- point scale, varying from '0' to '3' (highest frequency of the symptom).

In conclusion of the interview the carers were asked what is the main problem faced by people who care for a family member, and what is the most useful thing to help these people. Both items had an open response format. The carers were finally thanked for their collaboration.

3.3 Items' transformation

A number of variables pertaining to the different CAT categories were transformed in order to assist data analysis. Variable transformation was driven by a careful examination of the distribution of the original variables and guided by both the model used as a framework for the study (Figure 1) and the relevant literature on caregiving and service use. Transformations mainly consisted of recoding variables' response categories. In a number of circumstances this recoding was followed by a combination of two or more recoded variables to create new theoretically relevant third variables (e.g., summary measures). A summary of the transformed items is presented in Table 1.

Figure 1: Model used as guide for questionnaire item and instrument development



Adapted from Aneshensel et al. (1995)

Table 1: CAT transformed variables

Variable name	Categories/Levels	Values
Elder's marital status	Widowed, divorced/separated or single	1
	Married/cohabiting	0
Elder's usual place of residence	At home	1
	Care home/sheltered housing/other places	0
Elder's cognitive status	No cognitive disorder	0
	Behavioural problems without cognitive disorder	1
	Age associated memory impairment	2
	Suspected dementia	3
Elder's dependency	Cognitively able *and* no/slight physical disability	0
	Cognitively able *and* more severe physical disability	1
	Suspected cognitive disorder *and* no/slight physical disability	2
	Suspected cognitive disorder *and* more severe physical disability	3
Carer's marital status	Widowed, divorced/separated and single	1
	Married/cohabiting	0
Carer's relationship to elder	Partner	0
	Child	1
	Son/daughter in law	2
	Others	3
Number of children aged 14 or less in carer's household	None	0
	At least one	1
Carer's highest educational attainment	Low	1
	Intermediate	2
	High	3
Carer's employment status	Retired	0
	All other non-working (eg housewife/househusband)	1
	Working	2
Proximity of the respondent to Elder	Cohabitant	1
	Non-cohabitant	0
Number of nights of caregiving in typical week		0-7
Units of caregiving during week-end		0-10
Additional costs index		0-5
Number of services used by elder		0-15
Number of services used by carer		0-15

3.3.1 Elder’s demographic and background characteristics

Elder’s marital status was recoded by aggregating together the categories ‘widowed’, ‘divorced/separated’ and ‘single’ (1) of the original variable vs. ‘married/cohabiting’ (0), whilst elder’s usual place of residence was recoded so as to differentiate elders who lived ‘at home’ (1) from those living in a ‘care home’ or ‘sheltered housing’ or ‘other places’ (0).

3.3.2 Elder’s disability and need

A measure of elder’s cognitive status was constructed by combining the variables assessing elder’s memory and behavioural problems. The variable cognitive status consisted of the following categories: ‘no cognitive disorder’ (0), for elders without memory or behavioural problems; ‘behavioural problems without cognitive disorder’ (1), for elders reporting at least ‘rarely’ one of the behavioural problems listed in questionnaire, but not reporting memory problems; ‘age associated memory impairment’ (2), for elders with memory but no behavioural problems; and ‘suspected dementia’ (3), for elders showing both behavioural and memory problems.

A measure of elder’s dependency was derived taking into account both cognitive and functional disability. This variable was constructed by combining a dichotomous version of the cognitive status variable above, where elders without cognitive disorder were differentiated from those with cognitive disorder, and a dichotomous version of the overall functional disability variable (see 4.1 below), where the median (50th percentile) of the distribution was used to distinguish elders with no/slight functional disability from elders with more severe functional disability. Thus, the elder’s dependency variable was made up by the following categories (groups) of elders: ‘cognitively able and no/slight functional disability’ (0); ‘cognitively able and more severe functional disability’ (1); ‘cognitively impaired and no/slight functional disability’ (2) and ‘cognitively impaired and more severe functional disability’ (3). A three-category ordinal measure of elder’s dependency was also made available for more complicated – rather than merely descriptive – analyses, in which the ‘cognitively able and more severe functional disability’ category was merged with the ‘cognitively impaired and no/slight functional disability’ category of the original dependency variable.

3.3.3 Carer’s demographic and background characteristics

As with the recoding of the elder-related variable, carer’s marital status was recoded by aggregating together the categories ‘widowed’, ‘divorced/separated’ and ‘single’ (1) of the original variable vs. ‘married/cohabiting’ (0), while carer’s relationship to elder was recoded by differentiating ‘partner/spouse’ (0) from ‘child’ (1) from ‘son/daughter in law’ (2) from ‘others’ (3). The number of children aged 14 or less in carer’s household was dichotomised as ‘no children aged 14 or less’ (0) vs. ‘at least one children aged 14 or less’ (1). For the variable carer’s highest educational attainment, a synthesis was achieved at the European level by recoding the country-specific categories into three levels of educational attainment: ‘low’ (1) vs. ‘intermediate’ (2) vs. ‘high’ (3). Finally, a variable indicating carer’s employment status was created, which distinguished ‘retired’ (0) vs. ‘all other non working’ (e.g. housewife/househusband) (1) vs. ‘working’ (2) carers.

3.3.4 Carer's caregiving situation

The proximity of the respondent to Elder was recoded as 'cohabitant' (1) vs. 'non-cohabitant' (0).

From variables reporting on respondent's caregiving in a typical week, a measure indicating the number of nights of caregiving was derived. This was done by creating a new dichotomous variable for each day of the week, indicating whether caregiving activities were carried out during the night and early morning (from 10 p.m. to 9 a.m., see 2.5 above) (1) or not (0). By summing together all these seven variables representing each day of the week, an index reporting on the number of nights of caregiving in a typical week was produced, with values ranging from 0 to 7.

From the same typical week variable a further index was derived, which indicated the number of units of caregiving provided during the weekend. This was built by summing together the periods in which the carer provided care or support to elder on Saturday and Sunday. This measure could range from 0 to 10 (week-end entirely devoted to caregiving).

3.3.5 Financial Circumstances

An index was created, which reported on the number of additional costs (travel costs, special food, etc.) due to caring. The theoretical range for the additional costs index was 0 to 5 (maximum number of additional costs).

3.3.6 Service use

Two indexes reporting on the number of services used by elder and by carer were also created and used as measures of service use. These indexes were built by creating a new variable (1=service used vs. 0=service not used) for each service that could be potentially used by the elder and by the carer. Since in the questionnaire it was possible to report a maximum number of 30 services, of which 15 were used by the elder and 15 by the carer, both the new indexes of elder and carer service use had theoretical ranges of 0 to 15 (maximum number of services used).

3.4 Scale development

In this section, the psychometric procedure followed in order to construct scales from individual CAT items will be described. Descriptive statistics based on Italian data for Elder-related scales are presented in Table 2, while descriptive statistics for Carer-related scales are presented in Table 3.

3.4.1 Elder disability and need

The three items of the BISID (Keady and Nolan, 1996; see 2.3.3) were used to develop a measure of behavioural problems. Participants' responses to these three items had a satisfactory internal consistency (α=.78). Thus, responses to the three items were summed to produce a behavioural problems scale with a theoretical range of 0 to 9 (highest frequency of behavioural problems). The strong positive skew obtained on the scale implies that it is not optimally suited to discriminate individual differences at lower levels of behavioural problems in this sample.

Table 2: Elder-related scales

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Behavioural problems	990	0 (0.00)	2.19 (2.67)	1.00	1.03 (.08)	-.07 (.16)	0.00	9.00	.78
IADL	985	5 (.50)	4.61 (1.65)	5.00	-.96 (.08)	-.15 (.16)	0.00	6.00	.78
Barthel Index	978	12 (1.20)	63.04 (32.62)	75.00	-.65 (.08)	-.91 (.16)	0.00	100.00	.93
Functional disability index	972	18 (1.80)	6.47(5.66)	5.00	.53 (.08)	-1.06 (.16)	0.00	17.00	.94
Overall need for assistance	970	20 (2.00)	6.77(1.33)	7.00	-1.37 (.08)	1.72 (.16)	1.00	8.00	.62

Table 3: Carer-related scales

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Negative impact of caregiving	981	9 (0.9)	12.18 (4.27)	11.0	1.1(.08)	1.07(.16)	7.00	28.00	.83
Quality of support in caregiving	960	30(3.0)	10.20(2.73)	10.0	.05(.08)	-.42(.16)	4.00	16.00	.62
Positive value of caregiving	957	33(3.3)	13.27 (1.98)	13.0	-.52(.08)	-.21(.16)	6.00	16.00	.54
Well-being index	985	5(.5)	12.39 (5.89)	13.0	-.01(.08)	-.53(.16)	0	25.00	.87
Elder’s needs covered by carer	977	13(1.3)	6.06 (1.65)	7.00	-.87 (.08)	-.25(.16)	0	8	.64
Elder’s needs covered by informal support other than carer	977	13(1.3)	2.73 (2.61)	2.00	.52 (.08)	-1.05 (.16)	0	8	.86
Elder’s needs covered by formal support	976	14(1.4)	1.02 (1.75)	0.00	1.76 (.08)	2.18 (0.16)	0	8	.84
Carer perceived need for more support	895	95(9.6)	2.95 (2.79)	2.00	.47(.08)	-1.20 (.17)	0	8	.88

The six items of the Duke OARS assessment of IADLS (see section 2.3.4) were first recoded (1=not able vs. 0=able with or without help to carry out activity), before being analysed for their internal consistency (α=.78), and finally summed to produce an IADL scale with a theoretical range of 0 to 6 (highest number of activities for which elder needed help). The scale mean and median were quite high (M=4.61, SD=1.65; Median=5.00) indicating that the cared-for elders had, on average, a high degree of impairment on these kind of activities.

The individual items comprising the Barthel Index of ADLs (Mahoney & Barthel, 1965; see section 2.3.4) were then considered. The two Barthel items with four response categories had their two middle categories collapsed, prior to determining the internal consistency of the items, which was high (α=.93). The Index makes use of a weighting system for scale scoring, with each item response score multiplied by 5 prior to summing, producing a theoretical range of0 to 100 (totally independent on activities of daily living). Twelve participants (1.2%) had missing values on this scale. Mean and median values were moderately high (M=63.04, SD=32.62; Median=75.00), indicating that the majority of elders had a high level of independence on ADL activities.

To have available for analysis an overall functional disability index, which may be a more sensitive measure of functional impairment than ADL and IADL taken alone, a scale was built by using ADL items, IADL items and the additional mobility item (see section 2.3.4), all recoded as to separate elders with the highest degree of disability (1=not able or not continent, where appropriate) from the less disabled others (0=able with or without help or continent, where appropriate). These items had an excellent internal consistency (α=.94), and summed to produce a scale with a theoretical range of 0 to 17 (highest functional impairment). Eighteen participants (1.8%) had missing values on this scale. The mean and median (M=6.47, SD=5.66; Median=5.00) indicated a relatively low level of functional disability in the sample.

A further indicator of elder dependency was built through summing the items assessing need for help in different domains (see section 2.3.1). Items were recoded into dichotomous variables (partial need for help (1) vs. no need for help (0)). The newly created items had satisfactory internal consistency (α=.62), and were summed to produce a scale of overall need for assistance with a theoretical range of 0 to 8 (highest need for assistance). The scale mean and median were high (M=6.77, SD=1,33; Median=7.00) indicating a substantial need for help.

3.4.2 Carer-related scales

3.4.2.1 Well-being Index

The five items of the World Health Organisation-5 Well-being Index (WHO, 1998) demonstrated high internal consistency (α= .87) and were summed to produce the Well-being Index with a theoretical range of 0 to 25 (highest well-being). The mean and median (M=12.39, SD=5.89; Median= 13.00) were close to the scale mid-point.

3.4.2.2 Caregiving Indexes

Items assessing the Elder's need for support (see Section 2.3.1) were recoded into dichotomous items for use in four scales assessing the number of Elder's needs covered by the carer, by other informal supporters, and by formal supporters, and needs for which more help was required.

3.4.2.2.1 Elder's needs covered by carer

The items assessing elder's need for support were here recoded into 'need covered by carer' (1) vs. 'need not covered by carer' (0) and checked for internal consistency (α= .64) and were then summed to create a scale of elder's needs covered by carer, with a theoretical range of 0 to 8 (highest number of needs covered by interviewed carer).

3.4.2.2.2 Elder's needs covered by informal supporters

The items assessing elder's need for support were here recoded so as to indicate needs for which other informal carers provided help (1=need covered by other informal carers vs. 0=not covered by other informal carers). The items' internal consistency was good (α=.86) and they summed to produce a scale of elder's needs covered by informal support other than carer with a theoretical range of 0 to 8 (highest number of needs covered by other informal carer).

3.4.2.2.3 Elder's needs covered by formal services

The items assessing elder's need for support were here recoded so as to indicate needs for which help was received by services or other dedicated organizations (1=need covered by services or support organizations vs. 0=not covered by services or support organizations). The items' internal consistency was good (α=.83), and when summed produced a scale of elder's need's covered by formal support with a theoretical range of 0 to 8 (highest number of needs covered by services or support organizations). The scale mean and median (M=.85, SD=1.60; Median=0.00) clearly indicated that elder's needs covered by services or support organizations were on average very few.

3.4.2.2.4 Elder's needs for which more help is required

The items assessing elder's need for support were here recoded so as to indicate needs for which the carer would like to have more support (1=yes, 0=no/not applicable). Internal consistency for these items was very good (α=.88), and the items were summed to produce a scale of carer perceived need for support with a theoretical range of 0 to 8 (highest number of needs for which carer wanted more support for elder).

3.4.2.3 COPE Index

The Cope Index was developed to measure need in carers of older people. The instrument can be used in two main ways. First, the instrument can be used to facilitate a dialogue between a carer and a care practitioner about important aspects of the caregiving relationship. This is done through providing a profile of the caregiving relationship as indicated by the carer's responses to each of the fifteen COPE Index items. Important contextual information for understanding the caregiving relationship is also provided through the Carer Details section of the COPE Questionnaire. Second, the scores on some of the COPE Index items can be summed to give an indication of how well the carer is coping with the caregiving relationship. The COPE Index has been already validated (McKee et al, 2003), with findings showing the presence of two reliable factors (Negative Impact and Positive Value) with remaining items addressing domains of quality of support or financial difficulties. However, EUROFAMCARE offered the opportunity to assess the construct validity of the Index in a more substantial European sample, and the opportunity was taken to re-examine its internal structure (Beckmann, 2005).

Some response options were reverse-coded in order to maintain the correct direction of valence across all items ('never' =1, 'always'=4), and 'not applicable' responses were recoded as 'never'. A principal component analysis (PCA) with varimax rotation was run on the COPE items, first within countries to determine variability in the resultant solution, and then on the complete six-countries dataset once the variation across country-specific solutions was determined to be relatively minor. Here the results of the analysis carried out on the Italian dataset will be described.

The analysis (see Table 4) indicated the presence of three underlying components. The first component (22.72% of variance explained) was made by items 2–7 and 14 and tapped a dimension of caregiving burden (caregiving too demanding, caregiving causes financial difficulties, caregiving has a negative impact on physical health, etc.). In accordance with McKee et al. (2003), the component was named Negative Impact. The second component (13.57% of variance explained) was made by items 8, 10, 12, 13, 15 and tapped the perceived adequacy of social and professional support available (feeling supported by friends/neighbours, by family, by health and social services, etc.). The component was named Quality of Support. A third component (13.13% of variance explained) was made by the remaining three items: 1, 9 and 11, and tapped aspects of value related to the caregiving role (coping well as a caregiver, caregiving worthwile, having a good relationship with the cared for person). The component was thus named Positive Value.

In general terms this analysis was consistent with that conducted at the European level (see NASURE Chapter 3). However, item 13 (feeling appreciated as a caregiver) loaded on the Quality of Support component here, rather than on the Positive Value one, as found at the European level and in most of the other EUROFAMCARE countries. Nevertheless, since the item had also a sufficiently good (.45, see Table 4) load on the Positive Value component and since it was judged important to have homogeneity of scales composition in the different EUROFAMCARE countries, item 13 was included in the Positive Value subscale.

Table 4: The Cope Index: Items and factor loading

Cope Items	*Negative Impact*	*Quality of support*	*Positive Value*
1. ...cope well as a caregiver?			0.52
2. ...caregiving too demanding?	0.71		
3. ...caregiving cause difficulties in your relationships with friends?	0.75		
4. ...caregiving have a negative effect on your physical health?	0.76		
5. ...cause difficulties in your relationship with your family?	0.49		
6. ...caregiving cause you financial difficulties?	0.62		
7. ...feel trapped in your role as a caregiver?	0.74		
8. ...feel well supported by your friends and / or neighbours?		0.65	
9. ...find caregiving worthwhile?			0.67
10. ...feel well supported by your family?		0.46	
11. ...have a good relationship with the person you care for?			0.73
12. ...feel well supported by health and social services?		0.70	
13. ...feel that anyone appreciates you as a caregiver?		0.51	0.45
14. ...caregiving have a negative effect on your emotional well-being?	0.70		
15. ...feel well supported in your role of caregiver?		0.66	
Variance Explained	*22.72%*	*13.57%*	*13.13%*

After this preliminary exploratory work, the Cope Index subscales were developed. The Negative Impact items were analysed for their internal consistency, which was satisfactory (α = .83). Eventually, they were summed up and the Negative Impact subscale was thus created. Scores had a theoretical range of 7 to 28 (highest impact of caregiving).

The Quality of Support items were then considered and analysed for their internal consistency, which was not very satisfactory (α = .62), although Kline (1999) argues that for a psychological construct with relatively few items, an alpha of .6 to .7 is acceptable. The corresponding scale was thus derived, which had a theoretical range of 4 to 16 (highest quality of support).

The Positive Value items didn't show a sufficiently satisfactory internal consistency (α = .54). This was independent from the fact that item 13, which had a better loading on the Quality of Support component (see Table 4), was included in the Positive Value one – i.e., alpha of the latter scale with item 13 exluded was also very low (.47). Despite this low internal consistency, it was judged important to have a Positive Value scale available for analysis. Thus, items loading on this component were summed up and the corresponding scale derived, with a theoretical range of 4 to 16 (highest positive value). However, it should be noted that relationships/differences emerging from the use of this scale should be interpreted with care, given the low internal consistency of the items.

3.5 The Common Assessment Tool – Follow-Up Questionnaire (CAT-FUQ): Item and scale development and description.

3.5.1 Background

As part of the EUROFAMCARE project, a follow-up phase of data collection occurred one year after the initial survey (see Chapter 9). For this second wave of data collection, a follow-up questionnaire (CAT-FUQ) was developed that drew substantially on the CAT instrument used in the first wave, in order that comparison between the two waves of data would be most optimally effected. This section therefore describes the development of the instrument and its content.

3.5.2 The Common Assessment Tool – Follow-up Questionnaire: Development

The development of the Common Assessment Tool – Follow-up Questionnaire (CAT-FUQ) followed a similar trajectory to that of the original CAT. The first stage of development involved the selection of items and scales from the CAT that it was felt were essential for inclusion in the CAT-FUQ in order to understand the change in circumstances among our carer sample between the first and second wave of data collection. In this respect, most of the variable categories as obtained for the CAT also applied for the CAT-FUQ: *Elder's demographic and background characteristics; Elder's disability and need; Carer's demographic and background characteristics; Carer's caregiving situation; Carer quality of life (QoL); Financial circumstances* and *Service use*. To maximise comparability, items and scales selected from the CAT for inclusion in the CAT-FUQ were altered only if a) problems had been found in their original administration, and/or b) it was necessitated as a result of a change in mode of administration between the two waves.

In addition to the inclusion of variables in the CAT-FUQ that addressed issues related to the administration of the questionnaire, some new items were also included that the project group felt were justified on the basis of issues emerging from the first wave of data. For new items, development proceeded in the same way as for the original CAT items (see Section 1). Following the development of the CAT-FUQ, the draft questionnaire was tested in a pilot study carried out in each partner country. The final instrument described below therefore represents a second version, which incorporates minor changes to the original that followed evaluation of the pilot study results.

Each EUROFAMCARE partner was allowed to include a small number of country-specific items in their own version of the CAT-FUQ. The description of these items can be found in the partners' respective NASUREs.

The items and instruments in each of the above CAT-FUQ variable categories will be described below. Where items/instruments were drawn from CAT and remain unchanged, the reader will be directed to the item description given earlier in this Chapter. CAT items that were altered for the CAT-FUQ, and new items not included in the CAT, will be described in full in the Sections below. Where a new item was drawn from the research literature, the source will be referenced. Where no reference is provided, the item/instrument was developed by the partnership for the purpose of this study, or drawn from previous unpublished work of partnership members.

3.5.3 CAT-FUQ Items and Instruments

3.5.3.1 CAT-FUQ administration

A series of items were required to clarify the source of the data. The date of issue of the questionnaire was indicated (dd/mm/yyyy), and the questionnaire number, which was required in order to case match with the CAT questionnaire completed by the same participant. Country code was also included, as well as the name of the interviewer and the number of the interviewer (see section 2.1). The mode of administration was then indicated by the interviewer, with response options being 'postal' (1), 'phone' (2), 'postal supplemented with phone' (3), 'face to face' (4), other' (5). In case the latter mode of administration was used, the interviewer was required to specify (open response).

3.5.3.2 Items to determine current caregiving status

The first section of the CAT-FUQ contained items that had the dual purpose of determining whether the participant was still providing care for their care-receiver (and therefore eligible for inclusion in the follow-up study), and recording some basic data on the participant.

Question 1 asked 'Are you still providing more than 4 hours of care/support per week for the same Elder we spoke about in our original interview' (yes=1, no=0). Participants answering 'no' were directed to Questions 2 and 3 (see below) before proceeding to the following questions, while participants answering 'yes' were directed to Question 4, thereby omitting Questions 2 and 3.

Question 2 asked 'How many months ago did you stop/reduce caring for elder', with an open response where the number of months was required. Question 3 asked 'Why are you no longer providing more than 4 hours of care and support per week to Elder?' There were three response options. Option A was 'Elder still needs more than four hours of care and support, but somebody else is providing that amount of care and support', with alternative boxes for selecting to indicate who the 'somebody else' was: 'other family member' (1), 'professional carer' (2), 'nursing home' (3), and/or 'other' (4). Option B was 'Elder died', with alternative boxes for selecting to indicate the place of death as 'at home' (1), 'in a nursing home' (2), 'in hospital' (3), or 'elsewhere' (4). Finally, Option C was 'If there is another or additional reason, please specify' (open response).

After these two questions answered only by participants no longer providing more than 4 hours of care, all participants answered Question 4 (and subsequent questions). This question was the single item measure of carer health status drawn from the Short Form-36 (SF-36; Brazier et al., 1992). Following this question, a single item assessed overall carer quality of life for the preceding two weeks, also drawn from the SF-36, and information on carers' psychological well being was gathered using the World Health Organisation-5 Well-being Index (WHO, 1998) (see Section 2.6).

Finally, an item asked 'Generally speaking, who do you consider should be responsible for the care and support of older people'. Response options were 'the family should have full responsibility' (1), 'family should have main responsibility, state/society/public authority contribute' (2), 'state/society/public authority should have main responsibility, family contribute' (3), 'state/society/public authority should have full responsibility' (4), and 'it is difficult to say' (5).

Following this item, carers providing 4 hours of care per week or less were directed to the final section of the questionnaire, which offered the opportunity to provide additional comments (see Section 5.3.3.6) before returning the questionnaire to the researcher. Carers providing more than 4 hours of care per week were asked to continue to the main questionnaire.

3.5.3.3 CAT-FUQ Main Questionnaire

3.5.3.3.1 Elder's residence

An item determined Elder's usual place of residence (see Section 2.2.1)

3.5.3.3.2 Elder's disability and need

3.5.3.3.2.1 Mental health problems

As in the CAT, the respondent indicated whether his/her Elder had any memory problems (yes=1, no=0). Those indicating 'yes' were asked if a doctor had given a cause for the memory problems (yes=1, no=0). Those indicating 'yes' were asked if the cause was dementia (1) or other (2), and if 'other' to specify the cause.

3.5.3.3.2.2 Behavioural problems

The three items from the CAT assessing the frequency of specific behavioural problems (see Section 2.3.3) were again used here (Behavioural and Instrumental Stressors in Dementia, BISID; Keady & Nolan, 1996).

3.5.3.3.2.3 Dependency

As in the CAT, dependency was assessed through the 10-item Barthel scale (Mahoney & Barthel, 1965), a 6-item IADL scale derived from the Duke OARS assessment (Fillenbaum & Smyer, 1981), plus an additional item on mobility (see Section 2.3.4).

3.5.3.3.3 Carer's demographic and background characteristics

3.5.3.3.3.1 Carer employment status and impact of caregiving on employment

Whether the respondent was currently employed was established (yes=1, no=0).

For participants responding 'yes', the number of hours work in an average week was established (open response). The participant was then required to select one of three optional responses: 'all in all the number of your working hours per week is unchanged despite caring for Elder' (1), 'because of caring for elder you had to reduce your working hours' (2), or 'you had to reduce your working hours not because of caring for Elder, but for another reason' (3). Finally, participants who had to reduce their working hours were asked to indicate by how many hours per week reduced (open response in hour units), and to indicate the difference this had made to their net income per month (open response in national currency units, e.g. Euro, Pound Sterling, etc.).

For participants responding 'no', the participant was required to select one of three options: 'because of caring for elder you cannot work at all' (1), 'because of caring for elder you had to give up your job during the last 12 months' (2), or 'you stopped work not because of caring for elder but for another reason' (3). Non-working participants who had to give up their job/stop working (option 2 or option 3) were then required to indicate 'how many hours were you working each week before you had to give up/stop work' (open response in units of hours).

Finally, two items drawn from the CAT were asked of *all carers* regarding restrictions to working life or career (see Section 2.5.5): 'can/cannot develop professional career or studies'; 'can/could work only occasionally' (all response options yes=1; no=0)

3.5.3.3.3.2 Change in circumstances

A single item asked 'are there any significant changes in the last year that affected your life that we have not covered' (response options, yes, no). Participants indicating 'yes' were asked to specify (open response).

3.5.3.3.4 Carer's caregiving situation

As in the CAT, The number of hours support per week provided to Elder was established, as was the total number of hours of support/care per week provided to all people apart from Elder, both determined as open response items in units of hours per week. The proximity of the respondent to Elder was assessed using the same item as in the CAT (see Section 2.5)

3.5.3.3.4.1 Role inflexibility

One item drawn from the Social Restriction Scale (McKee et al., 2001) assessed this construct as in the CAT (see Section 2.5.1): The respondent was asked 'If you needed a break from your caring role is there someone who would look after Elder for you?' The response options were 'Yes, I could find someone quite easily' (1), 'Yes, I could find someone but with some difficulty' (2), and 'No there is no one' (3).

3.5.3.3.4.2 Positive and negative aspects of care

As in the CAT, The COPE Index (McKee et al., 2003) was used to assess the respondent's perception of their caring role (see Section 2.5.3).

3.5.3.3.4.3 Future care role

The CAT item assessing carers' willingness to continue caring (adapted from Gilhooly, 1986) was utilised in the CAT-FUQ (see Section 2.5.4).

3.5.3.3.5 Caregiving allowances

Four items (country specific) asked whether the carer or elder received financial support or allowances because of the care situation, with response options for each item being yes (1) vs. no (0). An additional item allowed the respondent to indicate whether they or their elder received any other form of financial support (specified; response options as above). The total amount of benefits received per month was then required (open response format). This group of items was a slightly modified version of those included in the CAT (see section 2.7.2).

3.5.3.3.6 Service Use

A comprehensive lists of services used by carers and elders was derived from the CAT dataset, and used to compile an assessment of service use in the CAT-FUQ.

From the list of services, respondents were asked to indicate, for first elder and then themselves, whether each service had been used in the last 6 months (check 'yes' if true). For those services checked 'yes', the number of units of service was required (open response, units variable by service), as was the frequency of service use, indicated as optionally 'per day' (1), 'per week' (2), 'per month' (3), or 'in 6 months' (4).

For services used by Elder, and for services used by carer (respondent), participants were asked to list the three services used in the last 6 months that had been most helpful and the three services used in the last 6 months that were not helpful (both open response).

3.5.3.3.7 Additional comments

Respondents were provided with an opportunity to express 'comments, suggestions, experiences or ideas' (open response).

4 Sampling, recruitment and representativeness

by Sabrina Quattrini and Maria Gabriella Melchiorre

4.1. Aims of chapter

This chapter describes the procedure that has been followed in Italy for obtaining a sample of caregivers that could be considered representative of the Italian population of carers, according to the common rules stated by the partnership in the EUROFAMCARE Standardised Evaluation Protocol for the National Surveys (STEP for NASUR). Therefore, in the following paragraphs both sampling and recruitment procedures will be illustrated in detail, in order to clarify the representativeness of the obtained sample in the light of other national surveys carried out in Italy on this topic.

4.2. Sampling and recruitment methodology

4.2.1 Sample strategy for the family carers survey

The sampling process of the subjects recruited for the Italian survey of the EUROFAMCARE project (EFC in the following) has been based on several assumptions and components, which can be synthetically described as follows:

- **sample units**: the sample units used for the survey has been represented by individuals living in Italy who usually care for an over 65 year old person, for at least 4 hours per week. This definition excludes those who provide only financial support or companionship. Since nation-wide statistics on the distribution of family carers of elderly people do not exist for Italy (cfr. below par. 4.3), the sampling of the 1.000 carers to be interviewed has been made on the basis of the distribution of disabled people aged 65 or over living at home (i.e. non institutionalised) on the 1st January 2001. This procedure is based on the assumption that in all chosen sampling sites:
  - each older person can count on average on one primary caregiver;
  - the great majority of caregivers live in the same community of the cared for older relative;
  - disabled older persons represent everywhere the same percentage of the over 65 year old population[1].
- **sample sub-areas**: the universe of the population to be sampled (older people living in Italy, and their primary family carers) has been subdivided into four sub-populations, according to Italy's four main geographical sub-areas: North West, North East, Centre and South & Islands (the latter including Sicily and Sardinia);
- **sample regions and municipalities**: for each sample sub-areas at least three municipalities have been chosen, one metropolitan, one urban and at least one rural, for a total of 14 municipalities (3 in the North West, 3 in the North East, 3 in the Centre and 5 in the South, so as to include also island municipalities), in order to ensure the greatest variability both with regard to the urban-rural context and to the availability of support services;

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[1] This assumption can be considered acceptable for the purpose of this study, although some recent research results show a tendency to a reduction in the disability rate of the older population in several countries, cfr. Manton & Gu (2001), Jacobzone et al. (1998), Jacobzone (1999) and ISTAT (2001a).

- **recruitment procedure**: in each municipality selected for recruitment, a “saturation zone” has been identified in terms of resident population and the resident carers have been recruited through the most relevant available channels: General Practitioner (GPs) or other care professionals, volunteer associations, private organisations, door-to-door census, integrated by snowballing through contacts reached by means of any of the previous methods, including interviewers’ personal contacts;
- **number of planned respondents**: 1.000;
- **number of respondents actually sampled:** 990;
- **type of sampling**: non-random sample, combination of judgmental and informed expert advice (Lonner and Berry, 1986, p. 87)[2].

4.2.1.1 Sampling parameters

The parameters used for the computation of the number of carers to be interviewed in each metropolitan, urban, rural municipality located in the four sub-areas can be synthesised as follows:

1) **territorial parameter**: a proportionate sampling has been carried out according to the size of the disabled population aged 65 and over living at home in the four sub-areas identified above (North West, North East, Centre and South);
2) **urban-rural parameter**: each of the four sub-samples has been subsequently subdivided according to the metropolitan, urban and rural population distribution, thus reaching a total of 12 sub-groups;
3) **availability of care services**: the regions and municipalities to be involved in the survey have been selected according to the criteria of the level of supply of support services for older people, in order to ensure that both regions with high and low availability of services were included.

The combined application of the territorial and urban-rural parameters described above, together with the multi-channel recruitment procedure applied to a limited saturation zone identified in each selected municipality, ensures that the final sample can be reasonably considered as representative of the socio-economic differences existing throughout the country in terms of income, level of education, kind of professional activities performed and social structure. In the following paragraphs a more in-depth description of the sampling process is provided.

4.2.1.2 Recruitment criteria

4.2.1.2.1 The identification of Italy’s macro sub-areas

As a first recruitment criterion, sampling has been carried out according to the **demographic size** of the main Italian geographical sub-areas. These four macro-territories, each including several of the twenty regions compounding Italy, have been traditionally identified, according to their territorial location and socio-economic characteristics, as follows:

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[2] In “judgmental samples” the researcher uses judgment in selecting individuals who will be instrumental in gathering certain kinds of data or in testing certain hypotheses; in “expert choice samples”, the key persons in selecting this kind of samples are the “expert”, who expresses an informed opinion about the composition of some sample, often without specifying the reasons underlying the selection. Expert choice and judgmental samples are very similar (Lonner and Berry 1986).

- **North West**: the economically most developed and urbanised part of Italy, including several metropolitan cities such as Milan, Genoa and Turin, and the Regions of Lombardy, Piedmont, Liguria and Val d'Aosta;
- **North East**: this area has in the last decades become the leading motor of the economic development in the country, and is characterised by smaller cities (Bologna, Trieste, Venice, Padua et.), widespread small industries and specialised agriculture. Regions are: Emilia-Romagna, Trentino Alto Adige, Friuli Venezia-Giulia and Veneto;
- **Centre**: smaller manufacturing industries, a less specialised agriculture and a widespread tourism industry are the main features of this sub-area, whose major cities are Rome (the capital city) and Florence, and the regions of Toscana, Umbria, Marche and Lazio;
- **South and Islands**: this area – which is sometimes also subdivided into two different ones, distinguishing the mainland South from the Islands of Sicily and Sardinia – represents the economically least developed and urbanised part of the country, but also the youngest one in terms of population structure. Major cities are Naples, Bari, Palermo and Cagliari, while relevant Regions are Abruzzo, Molise, Campania, Puglia, Basilicata and Calabria, besides the two already mentioned major Islands.

For the purposes of the EFC project, we have first subdivided the 1.000 hypothetical subjects to be reached by the survey according to the distribution of the dependent over 65 year old population living at home in the four Italian sub-areas[3]:

- North West **(NW): 275** subjects, corresponding to 27,5% of the total sample;
- North East **(NE): 198,** corresponding to 19,8%;
- Centre **(C): 211,** corresponding to 21,1%;
- South/Islands **(S): 316,** corresponding to 31,6%.

4.2.1.2.2 The inclusion of the "urban-rural" dimension

The four sub-samples identified above have been further subdivided according to the rural-urban-metropolitan dimension, in order to take into account the sometimes quite strong differences existing in the distribution of the population living in these three kinds of localities throughout the country. To this purpose, the following definitions have been used:

- ***"metropolitan":*** this definition includes 14 big Italian cities officially identified as such by the national and regional legislation, according to parameters which include population density, size as well as the economic and socio-political relevance of the city[4];
- ***"urban":*** for this study, urban municipalities have been considered those presenting both a population density higher than 100 inhabitants per squared Km (excluding those which are considered "metropolitan") and a resident population higher than 5.000 inhabitants. The latter cut-off has been taken from a classification of municipalities made in the last Italian population census based on the number of inhabitants (lower than 5.001, 5.001-20.000, 20.001-100.000, over 100.000) (Istat 2002);

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[3]: percentages based on the data available at that time, up-dated to the 1st January 2001 (ISTAT 2002).

[4] The national law n. 142 of the 8 June 1990 identified the municipalities of Torino, Milano, Venezia, Genova, Bologna, Firenze, Roma, Bari, Napoli and Cagliari, while the municipalities of Trieste, Palermo, Messina and Catania have been defined by the regional laws of their respective regions with special status.

- **"rural"**: this definition includes both municipalities with a population density lower than 100 inhabitants per squared Km [5], (independently from their size) and those with less than 5.001 inhabitants (independently from their population density).

The number of interviews to be made in each macro-area has been distributed between rural, urban and metropolitan municipalities using the proportion of people living in the respective type of locality, as above defined, included in each sub-area (Table 4.1).

Table 4.1: Percentage of residents in rural/urban/metropolitan communities in the Italian sub-areas

	Sub-areas			
Type of community	NW	NE	C	S
Rural	25,58	22,56	17,79	23,16
Urban	55,71	69,29	55,05	63,57
Metropolitan	18,71	8,15	27,16	13,27
Total	**100**	**100**	**100**	**100**

Source: own calculation on ISTAT data

4.2.1.2.3 Identification of regions and municipalities

Another assumption that has been taken into account is that the availability of support services in the four sub-areas differs very much, generally going from a higher availability in the North to a lower one in the South. Thus, selecting at least one region from each sub-area should ensure the inclusion of regions with different availability levels. More precisely, classifying Italian regions on the basis of the availability of services for elderly people, it emerges that Lombardy, Liguria (both located in the North West) and Emilia Romagna (located in the North East) are more equipped with support services, Calabria, Sicily and Campania (in the South) are less equipped, while Marche and Lazio (in the Centre) have an intermediate service supply. These are the regions that have been selected for recruitment of the Italian EFC sample, and in each macro-area at least three municipalities have been identified, one metropolitan, one urban and at least one rural, for a total of 14 municipalities (3 in the North West, 3 in the North East; 3 in the Centre, and 5 in the South, in order to include also island municipalities), as illustrated in Table 4.2. As a result of the illustrated method, the final Italian sample counts 990 caregivers, mostly living in urban localities (57%), the rest almost equally distributed between metropolitan and rural areas, thus reflecting the hypothesized distribution of family carers of disabled older people in the country.

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[5]: this is the definition of "rural" normally used by the European Union – for instance for the implementation of its structural funds policies (Esposti and Sotte 1999: 139) – by the Italian National Institute of Statistics (ISTAT 2001b) and by Eurostat (2001).

Table 4.2: Municipalities involved in the Italian survey and number of interviews by site

Macro Areas (% interviews)	**Regions**	**Municipalities**	**Type of Locality**	**N. of interviews made** (planned)
North East (19,9%)	Emilia Romagna	Bologna	Metropolitan	50 (50)
	Emilia Romagna	Ferrara	Urban	102 (103)
	Emilia Romagna	Bentivoglio	Rural	45 (45)
North West (27,8%)	Lombardia	Milano	Metropolitan	51 (51)
	Lombardia	Lecco	Urban	153 (153)
	Liguria	Varese Ligure	Rural	71 (71)
Centre (21,3%)	Lazio	Roma	Metropolitan	57 (57)
	Marche	Ancona	Urban	116 (116)
	Marche	Sassoferrato	Rural	38 (38)
South and Islands (31%)	Sicilia	Palermo	Metropolitan	50 (50)
	Calabria	Cosenza	Urban	193 (193)
	Campania	S. Stefano del Sole	Rural	11 (25)
	Campania	Volturara Irpina	Rural	32 (24)
	Campania	Salza Irpina	Rural	21 (24)

	Type of Locality	***Absolute value***	***%***
Italy	Metropolitan (4)	208	**21**
	Urban (4)	564	**57**
	Rural (6)	218	**22**
		990	**100**

4.2.2. Recruitment procedure

Family carers have been recruited in the period December 2003 – April 2004 in each chosen site by means of a local co-ordinator and a number of interviewers ranging between one and twelve (depending upon the size of the local sample). The recruitment procedure followed the agreed *saturation method*, which consists in contacting the universe of caregivers living in the "saturation zones" (see below) of each sample community by using as many of the following recruitment channels as possible[6]:

- contacts through volunteer, religious, and private organisations, etc.;
- contacts through GPs or other care professionals;
- door-to-door census;
- advertisement in newspaper, local TVs etc.;
- personal contacts of interviewers;
- snowball through contacts reached by means of any of the previous methods.

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[6] For an overview of possible methods to be used for survey purposes cfr. Neuman (2003), while a synthetic description of possible biases in caregiving research can be found in Dura and Kiecold-Glaser (1990).

In each chosen municipality a “saturation zone” has been identified, formed by one or more sub-areas representative of the municipality in term of socio-economic context and availability of some basic services. The necessary prerequisite to reach the universe of caregivers living in the selected communities is that the area of each chosen community is as small as possible. Therefore, the size of the saturation zones has been calculated in terms of the resident population, taking into account an average success rate of 1 out of 3 interviews for rural communities, 1 out of 6 for urban communities, and 1 out of 12 for metropolitan communities (Table 4.3).

Table 4.3: Computation of Italian saturation zones’ size

Macro area and urban/rural typology	Carers to be interviewed	Resident population	Population of saturation area to be considered for recruitment	% of saturation area population on total population of community	Number of inhabitants per interviewed carer
NW - metropolitan	51	1.256.211	16.885	1,3	331
NW – urban	153	45.501	25.327	55,7	166
NW – rural	71		5.877		83
NE – metropolitan	50	371.217	16.249	4,38	325
NE- urban	103	130.992	16.736	12,78	162
NE – rural	45	4.557	3.656	80,23	81
C – metropolitan	57	2.546.804	18.134	0,71	318
C – urban	116	100.507	18.452	18,36	159
C – rural	38	7.419	3.022	40,74	80
S+I - metropolitan	50	686.722	19.849	2,89	397
S+I – urban	193	72.998	38.308	52,48	198
S+I - rural	73		7.245		99
Total	**1.000**	**3.921.216**	**189.740**	**4,8**	**190**

Some differences were recorded in terms of efficiency and appropriateness of the potential channels in reaching caregivers in the identified communities. As a result of this variability, while at the national level the channels that have mostly contributed to recruit the carers are, in decreasing order, health and social care professionals (30,8%), religious organisations (21,4%) and interviewers' personal contacts (21,1%) (Table 4.4), considerable differences can be observed both within the sub-areas and within rural and urban communities. With regard to macro-areas, religious organisations have played a more substantial role in recruiting carers in the Centre (45,9%), while personal contacts of the interviewers (36%) and voluntary organisations (24,4%) have resulted more relevant in the North East. As for the urban-rural dimension, in metropolitan areas health and care professionals have allowed to reach half of the carers and have also played a considerable role in rural settings, while in urban settings the contribution of the different channels has resulted to be more balanced.

Table 4.4: Distribution of the Italian sample per recruitment channel, type of locality and region (%, absolute values; n=988)

	Health or social care professionals	Religious organisations	Personal contacts of interviewers	Voluntary organisations	Door to door	Other channel	%	Number of interviewed carers
North East- Metropolitan	22	0	16	60	0	2	100	50
North East - Urban	12,7	14,7	44,1	17,6	0	10,8	100	102
North East - Rural	31,1	0	40	0	0	28,9	100	45
North West - Metropolitan	74,5	25,5	0	0	0	0	100	51
North West - Urban	43,8	18,3	17,6	9,2	0	11,1	100	153
North West - Rural	28,2	12,7	45,1	0	7	7	100	71
Centre - Metropolitan	16,1	28,6	7,1	23,2	14,3	10,7	100	56
Centre - Urban	12,2	57,4	2,6	9,6	4,3	13,9	100	115
Centre - Rural	0	36,8	0	18,4	0	44,7	100	38
South - Metropolitan	94	0	2	0	4	0	100	50
South - Urban	10,4	25,4	33,2	2,6	23,8	4,7	100	193
South - Rural	79,7	1,6	9,4	0	9,4	0	100	64
ITALY: % North East	**19,3**	**7,6**	**36**	**24,4**	**0**	**12,7**	**100**	**197**
% North West	**45,5**	**18,2**	**21,5**	**5,1**	**1,8**	**8**	**100**	**275**
% Centre	**11**	**45,9**	**3,3**	**14,8**	**6,2**	**18,7**	**100**	**209**
% South	**38,4**	**16,3**	**23,1**	**1,6**	**17,6**	**2,9**	**100**	**307**
% metropolitan	**50,7**	**14**	**6,3**	**20,8**	**4,8**	**3,4**	**100**	**207**
% urban	**20,2**	**28,1**	**24,7**	**8,5**	**9,1**	**9,4**	**100**	**563**
% rural	**39**	**11**	**25,7**	**3,2**	**5**	**16,1**	**100**	**218**
% recruitment channel	**30,8**	**21,4**	**21,0**	**9,9**	**7,3**	**9,6**	**100**	**998**

Association between recruitment channels and macro-areas: Phi = 0.615 (p < .001)
Association between recruitment channels and types of locality: Phi = 0.41 (p < .001)

4.3 Representativeness of Italian survey

There is a lack of nation-wide data published on family carers of older people in Italy, the only exception until now being ISTAT data regarding only carers who do not cohabit with the cared for older people (Tomassini and Principi 2005). Since however it is well known that a considerable proportion of Italian primary caregivers live together with the cared for person (see also chapter 5.3.5 in this same report), these statistics do not provide a reliable option for testing the representativeness of the Italian sample of carers achieved in the EFC survey.

The only nation-wide survey regarding family carers that we could use for an at least approximate comparison with the EFC data in terms of demographic characteristics of both carers and older people, has been carried out by INRCA in the context of the European Study of Adult

Well-being (ESAW) Project[7]. Although this comparative procedure does not pretend to lead to conclusions about statistical representativeness, it still allows to verify possible analogies or discrepancies between the two samples, in order to indirect confirm – or invalidate – the quality of the EFC sample. Since the ESAW sample includes only adults aged 50 years and over, to be compared the EFC sample of carers has been restricted to people of this age group only. It should be also reminded that, differently from the EFC sample of carers, the ESAW sample is not made of primary carers and that the selection of carers has been made simply by asking the interviewed persons if they were caring for any elderly family member in need of care, without any mention to minimum number of hours of help provided per week. Table 4.5 illustrates the comparable data belonging to the two studies.

Comparing the socio-demographic variables collected in both surveys, we can notice that data about carers' age, carers' marital status and relationship to elder are quite similar in the two studies. As for discrepancies, in the EFC study female carers are over-represented, elders are slightly more dependent, graduated people are under-represented as well as working carers. EFC carers live more frequently in the same house or in the same building of the older people and provide care for a much higher number of hours per week: both these tendencies could reflect a higher dependency of elders. Nevertheless, on the whole the observed differences are not so high as to deny a sufficient level of comparability between the two samples, thus allowing to state that the EFC sample should quite reasonably reflect the universe of primary family carers of older people in Italy.

4.4. Summarising remarks

The EFC Italian sample of family carers reflects the varied cultural and socio economic characteristics of the family carers of people aged 65 and older living in the different Italian regions, as well as of the different caregiving situations which characterise the country, thanks to the combined action of the criteria that have been followed in order to achieve it, and which can be summarised as follows:

1. The regions that have been selected in each macro-area of the Italian territory for inclusion in the sampling procedure ensure a great variability with regard to territorial, socio-economic and cultural differences, as well as to the availability of support services.
2. In each group of regions belonging to the 4 sub-areas, one metropolitan, one urban and at least one rural community have been selected for inclusion in the sample.
3. The target of 1.000 interviews have been distributed among sub-areas proportionally to the size of the disabled population aged 65 and over living at home, and at the same time to the population living in metropolitan, urban and rural communities in each sub-area.
4. The multi-channel approach that has been adopted for reaching potentially all carers living in the selected saturation zones in each community, ensures that the different family caregiving situations are being considered by the reached sample.

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[7] The aim of the ESAW project was to develop a globally applicable model of Ageing Well, estimating the direct causal contribution of five key components, personal characteristics and culture to the outcome variable Ageing Well. The five components included in the study were: (1) physical health and functional status, (2) cognitive efficacy, (3) material security, (4) social support resources, and (5) life activity. A representative population of 2.000 adults aged 50-89 was selected by each of the country teams, including Italy, where a sub-study about carers of elderly people has been also carried out (for more in-depth details, please cfr http://www.bangor.ac.uk/esaw/index.htm).

5. Compared with the only previous national survey carried out in Italy on family carers of older people, the EFC sample shows high similarities as for socio-demographic variables such as carers' age, carers' marital status and relationship to elder. Although slight discrepancies have been recorded as for carers' gender, older people's level of dependency, carers' level of education, working status, living arrangements and number of hours of care provided per week, the EFC sample can still be considered sufficiently comparable to the ESAW sample, and suitable to reflect the variability of family caregiving situations characterising the Italian population.

Table 4.5: Comparison between EFC and ESAW samples

Variable	EFC (N = 624)	ESAW (N = 219)	Compared to ESAW, the EFC sample shows:
Elder characteristics:	M (SD) Median	M (SD) Median	a slightly higher level of dependency of elder
Elder total Barthel score	58.6 (1.34) 70	64.2 (1.96) 70	
Carer characteristics:			
	M (SD) range	M (SD) range	
Carer age	61.66 (0.36) 50-88	61 (0.59) 50-88	no difference
Carer gender	%	%	an higher proportion of female carers
- Male	23.8	35.2	
- Female	76.2	64.8	
Carer marital status	%	%	no difference
- Married/with partner	73.0	75.3	
- Other	27.0	24.7	
Carer educational status	%	%	a lower proportion of graduated people
- Illiterate / no school	5.4	0	
- Elementary school	26.0	26.0	
- Secondary school	24.5	21.5	
- High school	32.9	34.2	
- University and over	11.2	18.3	
Carer working status	%	%	a lower proportion of working carers
- Working	29.1	37.0	
- Retired	46.3	45.7	
- All other non-working	24.6	17.3	
Carer-elder relationship and residence:			
Carer-Elder relationship	%	%	no difference
- Partner/Spouse	17.0	15.6	
- Child	59.0	55.5	
- Son/Daughter in-law	9.6	13.8	
- Other	14.4	15.1	
Carer-Elder living place	%	%	an higher proportion of cohabitant carers
- within the same building	62.4	46.5	
- within walking distance	16.0	32.3	
- over walking distance	21.6	21.2	
Caregiving Characteristics	M, Median	M, Median	
Number of hours per week caring for the elder	63.0, 40	23.8, 15	an higher number of weekly hours of care provided

5 Main characteristics of the Italian family carers' and older people's sample

by Sabrina Quattrini

5.1 Aims of chapter

The aim of this chapter is to summarise the main features characterising the sample of older people and family carers recruited for the EUROFAMCARE baseline survey. To this purpose, the socio-demographic situation, the financial and working status of both groups of people as well as the elders' degree of disability and the burden level in the carers are presented in a descriptive way, so as to show the most relevant factors related to different and sometimes complex caregiving situations.

5.2 Profile of cared-for older people

It should be clarified that the data describing the cared-for people are a "proxy" in their nature, since all information collected during the interview were reported by the caregivers and not by the elders themselves.

5.2.1 Socio–demographic characteristics

Keeping in mind that the inclusion criteria for the survey was "being a family carer of an over 65 year old person", it shouldn't be a surprise that the average age of the Italian cared-for people is 82 years, with people aged 80 and over reaching 63.6% of the whole sample.

The great majority of older people, almost all of Italian nationality, are women (71.2%) and widowed (60.2%), married and single representing only a minority (32.6% and 6.4% respectively).

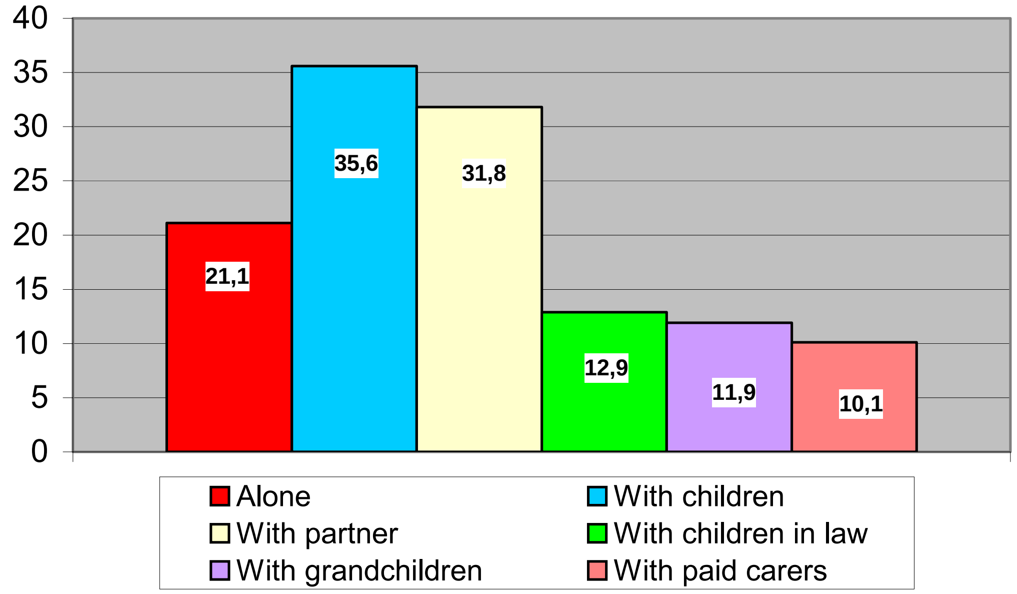
5.2.2 Place of living and household composition

Almost all older cared for Italians live at home (95.8%), those living in a care home representing only 3.7% of the sample, with some regional differences (the proportion reaching 7% of cases in the North East, 5,7% in Central Italy and 3% in the North West, no cases at all being reported in the South and Sicily). This result could be explained, on the one hand, with the low availability of institutional care for older people (Pesaresi and Gori 2003), particularly in Southern Italy – which is on turn a result of the families' low propensity to accept institutional care for their older members (Lazzarini 2004) – and, on the other hand, with the high costs related to this type of care (Cossentino and Innorta 2004; Azienda Usl di Cesena 2002).

In our sample, more than one out of five older people (21.1%) live alone (Figure 5.1), and this is usually correlated to higher levels of autonomy – compared to those living with other people – in performing both Activities of Daily Living (ADL: Person's Correlation for Barthel Index controlling for older person's age = 0.31, $p < 0.001$) and Instrumental Activities of Daily Living (IADL: the mean values of Barthel Index and IADL scores in the two subgroups being for those living alone BI = 81.96 and IADL= 1.49, versus BI = 58.06 and IADL= 3.55 recorded for older people living with others, $p < 0.001$ in U test).

Those who do not live alone mainly cohabit with children (35.6%), a partner (31.8%), children-in-law (12.9%) or grandchildren (11.9%), while the high percentage of those living with paid carers (10.1%) highlights one of the main features of the Italian care system: i.e., that the gap between demand and supply of public care services for highly dependent older people is very often covered by families by resorting to paid professional carers, mainly represented by foreign immigrants (who constitute 92% of all paid home carers). This is confirmed by statistically significant differences in the dependency levels of older people living or not with paid cares (older people living with paid carers reaching scores of BI = 41.31 and IADL= 4.69, compared to older people not living with paid carers, scoring BI = 60.76 and IADL= 3.38, p < 0.001 in U test).

Figure 5.1: Household composition of older people (%; N = 990)*



*: Percentage values do not sum up to 100 since multiple answer were possible.

5.2.3 Financial situation

The average personal monthly income of older people not living with their own family carer is 779.85 Euros (N=182; SD:+/- 360).

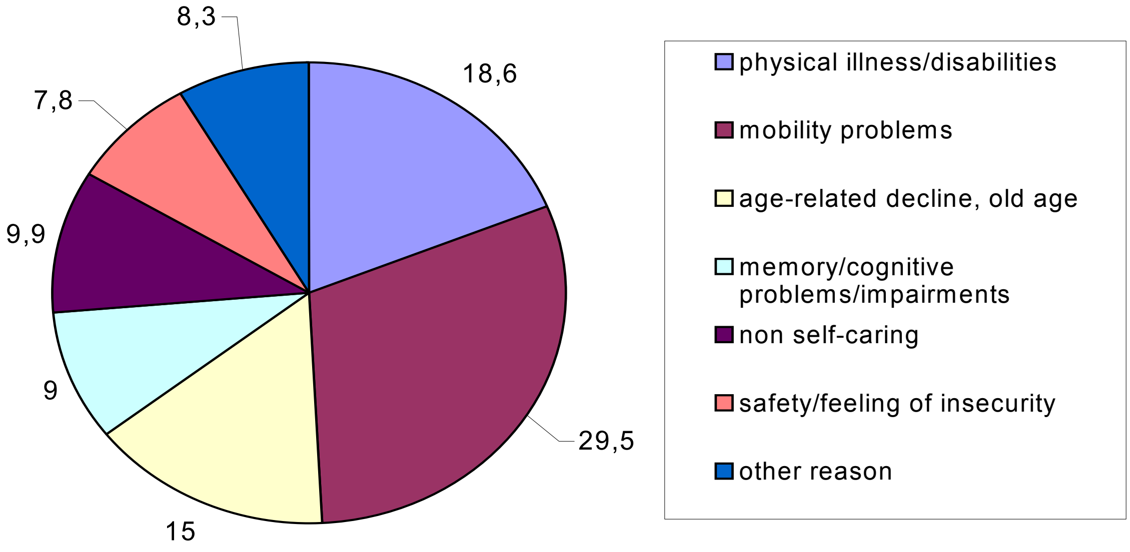
The collected data shows that the vast majority of all cared-for old people (92.9%) receive a pension or another kind of financial support from the State. Focusing on financial support or allowances related to the caring situation, only 35.7% of the cared-for people receive them and the average amount of financial help received by elder (excluding people who do not receive any benefits) is 453.10 Euros per month.

5.2.4 Elders’ health situation and need of support

Carers were asked to list the main reasons why older people need care and support. Answers collected through an open question and re-coded afterwards (Figure 5.2), show that mobility problems represent the most often declared main reason (29.5), while the second one is physical illness/disability (18.6%). Following reasons are more rarely indicated as the principal ones:

age-related decline (15%), difficulties in self-caring (9.9%), memory or cognitive problems (9%), lack of security or need for company (or loneliness) (7.8%).

Figure 5.2: The main reason of support/care to elder (% values)



It is well known that memory problems have a remarkable influence on caregiving relationships in many situations, and the EFC survey asked carers whether the cared-for person had this kind of problems, for example in form of difficulties in remembering what day it is or recognising friends or neighbours. Almost half of them (49.1%) answered affirmatively, and in 61% of these cases doctors had already provided an official diagnosis of this. A related, because of cognitive origin, but still distinguished source of stress for the caregiver is represented by possible behavioural problems of the older person – like for instance wandering, constantly repeating what has been said, shouting inappropriately etc. – which were present in 30.6% of the Italian sample.

As far as the perceived level of dependency[8] is concerned, 37,3% of carers evaluated the elderly people as severely dependent, 30% as moderately dependent and 23.8% as slightly dependent, those considered as independent being only a residual group (8.9%).

While the above aspects express the carers' perception of elder's functional status, more objective measures of the dependency of the elder can be derived from the BI and the 6-item IADL scale score (see chapter 3 for more details). The calculated means of these two detailed scales for each of the levels of elder dependency assessed by carers confirm the assessment of the

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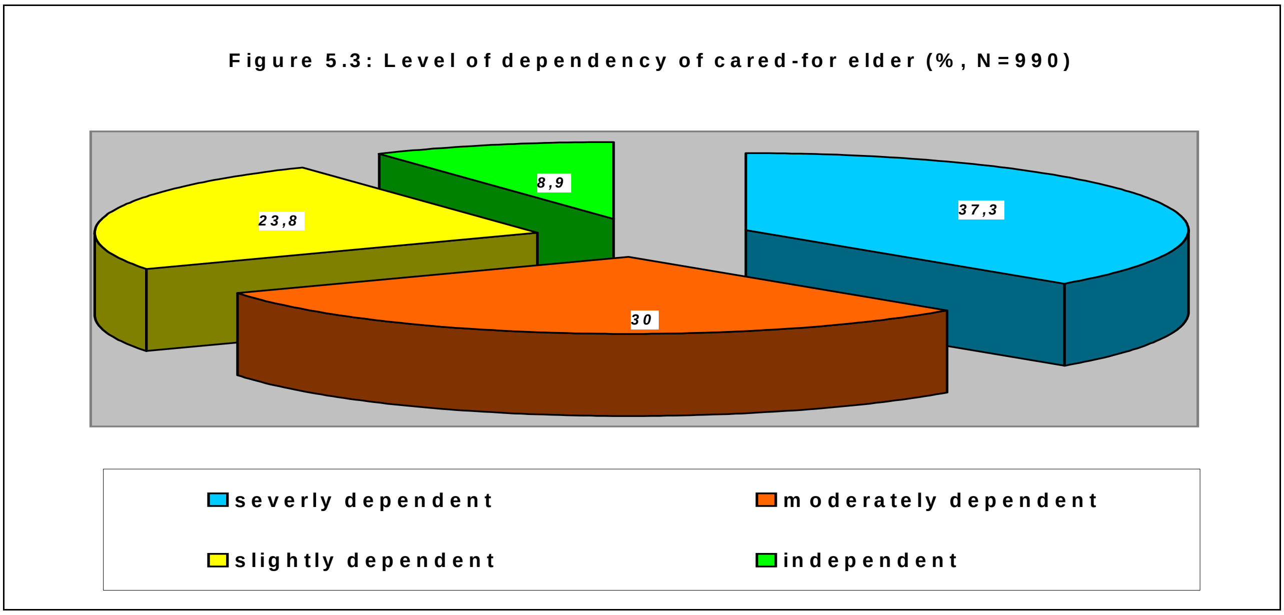
[8] The possible answers and the related description of the level of dependency that carers could chose where: independent (able to carry out most ADLs, but may need some help occasionally); slightly dependent (able to carry out most ADLs, but requires help with some IADL like shopping, cooking, housework, etc.); moderately dependent (able to carry out some basic ADLs like bathing, feeding or dressing, but unable without help to carry out most IADL like shopping, cooking, housework); severely dependent (unable to carry out most ADL without help, like eating or going to the toilet).

dependency of the older person provided in global terms by the carer, the BI scores decreasing significantly as the carer's assessment score rises from independency to severe dependency (p < .001 in K-W test).

Figure 5.3: Level of dependency of cared-for elder (%, N=990)



A more in-depth analysis of older people needs shows that, according to family carers (Figure 5.4), the cared-for persons depend completely from others in particular for organising support (71.1%), financial "management" (e.g. a third person paying the bills on behalf of the older person) (69.1%), domestic tasks (63.4%), emotional, psychological or social needs (e.g. companionship or reassurance) (61.9%) and, albeit to a lower extent, for mobility, health and physical/personal needs (like washing up or dressing) (32.3%), the lowest percentage being recorded for "financial support" (12.3%).

These figures show that a big group of Italian cared-for people cannot maintain an autonomous life at their homes, without the complete support of other people represented mainly by other family members, sometimes integrated by neighbours and locally available services.

Also the proportion of those who require partial help from others to satisfy their needs is considerable, particularly for mobility (46.8%), physical/personal needs (46%), health needs (40.3%) and emotional/psychological/social needs (43.6%).

The spheres of need for which instead older persons do not need any help at all are mainly financial support (58.4%), physical/personal care (21.8%) and health care (13,6%).

5.3 The profile of family carers

5.3.1 Socio–demographic characteristics of the family cares

The mean carers' age is 53.5 years, ranging from 18 to 88 years, with a predominant proportion of women (77.1%). The distribution of carers in age groups (Table 5.1) shows that over half of Italian family carers are concentrated in the age between 45 and 64, although both young carers (less than 35 year old) and very old ones (75 and over) are also well represented, each group reaching about 8-9% of the total sample. These two groups are also those where the sex ratio is less unbalanced, with female carers representing “only” 75% and 63% of the respective age group, for different reasons: among the younger carers, because of the relatively frequent presence of nephews and grandsons; among the older carers, for the presence of husbands.

Figure 5.4: Support needed by OP in each sphere of need (%, N = 990)

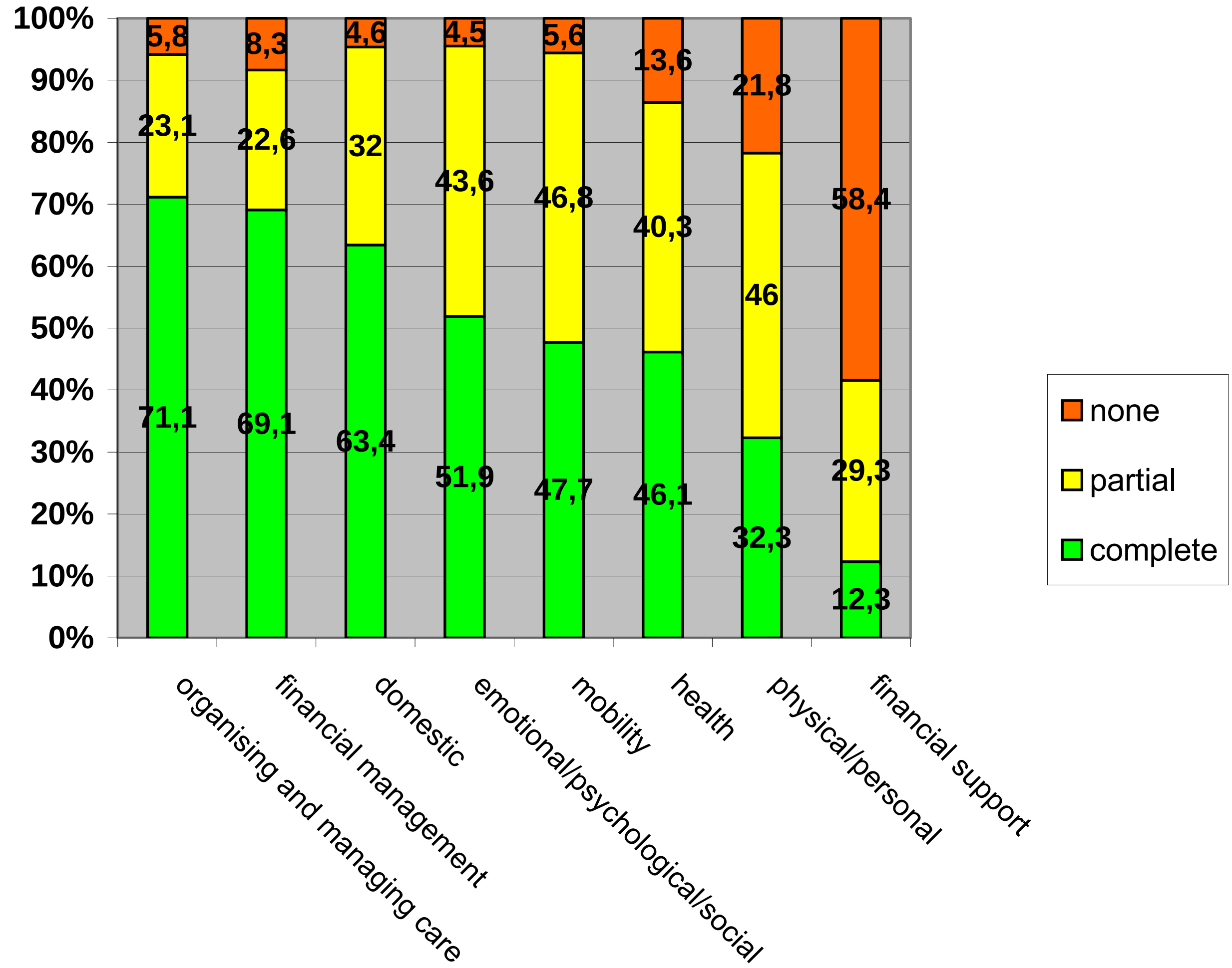


Table 5.1: Family carers by age group and gender (%, N = 989)		
	% on all carers	of whom female (% on same age group):
Less than 35 year old	8,8	74,7
35-44 year old	16,9	78,4
45-54 year old	27,9	76,8
55-64 year old	25,8	78,4
65-74 year old	13,0	82,9
Over 74 year old	7,7	63,2
Total	**100,0**	**77,1**

The analysis of the marital status on the whole sample (Table 5.4) shows that carers are mainly married or living with a partner (71%), while singles, widowed and divorced or separated individuals represent a much less relevant proportion of it.

Table 5.2: Marital status of carers (%, N = 989)	
Married / cohabiting with partner	71.0
Single	17.9
Widowed	7.2
Divorced/separated	3.9
Total	**100.0**

The level of education of Italian carers is on average relatively high (Table 5.5), as more than half of the sample has achieved at least the high school diploma (54,2%), while one out of five carers has attained only an elementary or lower degree of education, and one out of four carers has reached an intermediate level. It is worthwhile to mention that (non reported data) a certain number of carers (6.3%), mainly in the younger age group, is currently pursuing an educational degree by spending in education an average of 15 hours per week.

Table 5.3: The level of education of the family carers (%, N = 989)	
No School / Illiterate	3.6
Primary School	17.9
Intermediate Level of School (Left At Age 14-16)	24.3
High School (Left At Age 18)	39.1
College, University or Higher (PhD, etc.)	15.1
Total	**100.0**

Nearly all interviewed carers (99,5%) have the Italian nationality and belong to the same ethnic (Italian) group. They show also a high homogeneity from a religious point of view, a big proportion of them stating to belong to a religious denomination (87.8%), represented in almost all cases (96.8%) by the Roman catholic one (Table 5.4). As for the degree of religiosity, about two thirds of carers consider themselves as being “quite religious” and only one out of five as “very religious” (Table 5.5), while the percentage of those not religious at all (11.3%) confirms the data reported in previous table 5.4.

Table 5.4: Do caregivers belong to any religious denomination? (absolute and % values)

	%
No	12.2
Yes...	87.8
Total	**100.0**
... of which: Roman Catholic	*96.8*

Table 5.5: Do you consider yourself to be... (%, N = 972)

Very religious	20.8
Quite religious	67.9
Not at all religious	11.3
Total	**100.0**

5.3.2 Employment situation

One relevant factor affecting the condition of family carers is their employment situation (Table 5.6), which if on the one hand might give rise to possible tensions due to the overlapping of professional and caring responsibilities, on the other hand could also relief the carers by providing them useful breaks from the burdening experience of providing continuous care to the older relative. The proportion between employed (43.4%, mean age 46,1) and non-employed (56.6%, mean age 59,1) Italian carers reflects a slight majority of the latter. However, when we consider distinctly the sub populations of men and women, we observe that the percentage of employed men is significantly higher than the percentage of employed women ($p < .001$; Phi = -11.4).

Table 5.6: Employment situation of the family carers (%, N = 989)

Non-Employed:	56.6
Males	*46.3*
Females	*59.7*
Employed:	43.4
Males	*53.7*
Females	*40.3*
Total	**100.0**

Looking at the employed carers only (Table 5.7), it can be noticed that the predominant sector of carers' employment is the public one (46.8%), followed by the private sector (31.8%), although a still remarkable number of the carers are also self-employed (16.9%). It should be highlighted too that, although the legislation on paid and unpaid leaves to look after a dependent family member is the same for all employees, these benefits often represent a true opportunity for public employees only, because if one resorts to these measures in the private sector, the risk of negative repercussions on one's career is much higher than in the public sector (Tarabelli et al. 2001: 251).

Table 5.7: Sector of work of employed family carers (%, N = 421)

Private sector employee	31.8
Public sector employee	46.8
Self-employed	16.9
Other kinds of work (free lance, etc.)	**4.5**
Total	**100.0**

As far as the type of occupation[9] of the employed carers is concerned (Table 5.8), clerks and professionals represent the most numerous groups, together constituting over half of all employed carers. Technicians and associated professionals, similarly to service and shop/market sales workers, are instead occupations that involve each a bit more than one carer out of ten, all remaining ones concerning less than 10% of the respondents each.

Table 5.8: Type of work of the family carers (%, N = 425)*

Clerks (4)	27.8
Professionals (2)	26.1
Technicians and associated professionals (3)	12.0
Service workers and shop and market sales workers (5)	11.3
Legislator, senior officials and managers (1)	8.5
Elementary occupations (9)	5.6
Craft and related trade workers (7)	4.0
Plant and machine operators and assemblers (8)	4.0
Skilled agricultural and fishery workers (6)	0.5
Total	**100.0**

*: *the higher the number in brackets – which identify the different occupations according to the ISCO 88 classification - the higher the qualification usually required to carry it out.*

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[9] The coding of the occupations have been assigned according to the European Union variant of the International Standard Classification of Occupations (ISCO 88, as available in: http://www.warwick.ac.uk/ier/isco/isco88.html).

Working carers often experience restrictions to their working life or their career due to caring responsibilities. One of these restrictions is represented by the necessity to reduce the amount of performed working hours, a condition that affects 13,6% of employed Italian carers, with no significant differences between men and women (Table 5.9).

Table 5.9: Did you have to reduce your working hours due to caring for family elderly people? (%, N = 425)

No	86.4
Yes	13.6
men	*14.9 of all men*
women	*13.2 of all women*
Total	**100.0**

With regard to non-working carers (Table 5.10), more than half of them are retired, a condition which concerns however especially men, while professionally inactive women perceive themselves more often as housewives (a female only category). Although unemployed carers are much less numerous than the previous two groups, this condition affects men almost three times more often than women, thus showing a further clear connection between employment status and caregiving condition.

Table 5.10 Status of the non-working family carers, whole population, men and women sub-populations (%)

	All n-w carers (N=558)	All n-w male carers (N=105)	All n-w female carers (N=453)
Retired	52.0	82.9	44.8
Housewife/househusband	39.4	0	48.6
Unemployed and seeking work	7.2	14.3	5.5
Other	1.4	2.9	1.1
Total	**100.0 (N=558)**	**100.0 (N=105)**	**100.0 (N=453)**

Non-working family carers may also suffer from (current or past) professional restrictions, and feel excluded from a potential participation to the labour market due to their caring role. The most important reasons that in this respect have been referred to by carers are the impossibility to provide paid work (8.7%) and the necessity of giving it up (7.4%) (Table 5.11), with no statistically significant differences being recorded between men and women.

Table 5.11 Restrictions to the working life or career of the non-working family carers (%, N = 543)	
I can not work at all	8.7
I have had to give up work	7.4

While the above discussed restrictions to the working life or career have been asked separately either to working or to non-working family carers, those illustrated in table 5.12 have been asked to both groups and should be considered additionally to the previous ones. They reveal that, of all carers, 5.3% has declared that could not develop their professional career or studies due to caring responsibilities, while another 4,9% could not perform a regular work but had to opt for occasional jobs only.

Table 5.12 Additional restrictions to the working life or career of all family carers (%, N = 987)	
I can/could not develop my professional career or studies	5.3
I can/could work only occasionally	4.9
Other restrictions	3.2

Summing up the above described situations, we can state that, on the one hand, working carers can usually profit from a higher income that enables them to buy services but, on the other hand, might not seldom have to face difficulties in conciliating family care and professional responsibilities, because of the conflicting time, cognitive and emotional requirements deriving by this multiple role of theirs.

5.3.3 Financial situation

In the EUROFAMCARE survey, a question about income has been asked to all carers in parallel to a similar question asked to those elders not living with their own primary caregivers. The results show that the average personal income of carers is 1,118.96 Euros per month (SD: +/- 438.93; N = 327), a value that can be split by distinguishing carers living with the elder and carers who do not, as follows: 1,138,03 Euros per month (+/- 412.05; N = 146) for carers living with elder and 1,103,58 Euros per month (+/- 460.03; N = 181) for carers not living with elder.

5.3.4. Carers' family situation

The size of the carers' household in terms of average number of components, including the carer himself/herself, is 3.2. As a consequence of so many married carers, most of them have children (74.4%), and less than half of those having children (32.7%) have grandchildren, too (Table 5.13).

Table 5.13 Carers having children (%, N = 990) or grandchildren (%, N = 737)	
Carers with children	74.4
Carers with grandchildren	32.7

5.3.5 Characteristics of the caring situation

Discussing the general caring situation and the different possibilities to provide care, it is possible to recognise the presence of both objective and subjective factors. With regard to **objective factors**, a first dimension to be considered is the formal family relationship between the carer and the cared-for person. Table 5.14 summarises the variety of possible relations between the two, showing that, in the Italian sample, over three fifths of carers are the cared-for person's children, followed by spouses/partners (10.9%), children-in-law (9.7%) and nephews/nieces (8.3%).

Table 5.14 Family relationship between the carer and cared-for elderly (%, N = 990)	
Child	60.9
Spouse/partner	10.9
Daughter/son-in-law	9.7
Nephew/niece	8.3
Grandchild	3.3
Other (sibling, uncle/aunt, cousin, friend, neighbour, etc)	6.9
Total	**100.0**

An high proximity between the carer's and the cared-for person's place of living is observed in the Italian sample, considered that more than half of the sampled units live in the same house or in the same building (table 5.15). Another 20% of carers live within walking distance to the cared-for person, while only 8.2% live more distant and need more than 10 minutes by car, bus or train to get to him/her.

Table 5.15 Distance between the carer's and the cared-for person's place of living (%, N = 990)	
In the same household	45.3
In the different households, but in the same building	10.2
Within walking distance	20.0
Within 10 minutes drive/bus or train journey	16.3
Over 10 minutes drive/bus or train journey	8.2
Total	**100.0**

To describe the duration of the time spent in caring for the elderly, four categories of caring periods have been identified (table 5.16). The biggest group of carers have been providing care for 5 years or more (35.3%), the second biggest group is represented by those caring from 1 to 3 years (31.5%) and the third by those caring 3 to 5 years (24.5%), while only few carers are "newcomers" since less than one year (8.8%). The average period devoted to caring for the elderly is 57.2 months (SD:+/- 62.4) and the median 36 months (which in other words means that half of carers have been assisting elder for less than 3 years and half for over 3 years).

Table 5.16 Time period of caring (%, N = 981)

Less than one year	8.8
From one year to less than 3 years	31.5
From 3 years to less than 5 years	24.5
5 years or more	35.3
Total	**100.0**

The length of the caring period is correlated to several factors (table 5.17): the negative impact of caregiving (the higher the duration of care, the higher being the negative impact of it on the carer); the cared-for persons' ability to perform activities of daily living (the lower the ability, the higher the duration of care); the elder's age (the higher the age, the higher is the duration of care); the family relationship between carer and elder (partners care for longer periods of time – mean 79 months – compared to other family members – mean 54.5; p < .01 in Mann-Whitney U test). This simple associations hide sometimes more complex situations, which should always be kept in mind when interpreting the reported findings, such as for instance the fact that the length of the caring period might reflect the type of care/support needed by elder with respect to the available or accessible services (a lower number of residential care homes in the country possibly leading to longer caregiving periods in this kind of areas).

Table 5.17 Correlation between duration of caregiving and some other variables

	Pearson's Correlation	N
Negative impact of care	,142**	972
IADL Score	,131**	976
Elder' age	,129**	979
How dependent is elder? – Carers' subjective perception	,113**	981
BARTHEL INDEX	-,084**	969
Quality of life 5 items	-,075*	976
Positive value of care	,056	948
Has elder any memory problems?	,033	981
Number of elder's behavioral problems	-,027	981

**: p < 0,01; *: p < 0,05.

While the above are objective factors that may have an influence on the carer's situation, we can now focus on the impact of **subjective factors**.

Within the EFC survey, carers have been submitted a list of reasons that may have influenced their decision to care for an older family member, and asked to identify all reasons that they considered relevant in their situation, as well as the main one (table 5.18). The great part of carers link their caring commitment mostly to emotional bonds, indicated by almost all carers (96.3%) and considered the main reasons for caring for 71.2% of them. By contrast, the "sense of duty", indicated by 73.3% of carers as a relevant reason for caring, is the main one only for 11.2% of them, while all other items reflect a much lower importance.

Table 5.18 Reasons for caring: % of respondents on the total sample (multiple answers possible, N = 990) and main reasons (%, N = 986)

	% respondents	main reason
Emotional bonds	96.3	71.2
A sense of duty	73.3	11.2
A personal sense of obligation	57.4	6.5
Caring makes me feel good	56.4	3.3
Elder would not wish any one else to care for them	45.4	1.3
Religious beliefs	38.0	0.8
I found caring by chance	31.5	1.7
There was no alternative	30.3	1.7
The cost of professional care is too high	31.1	0.5
Economic benefits for both	4.3	0.1
Other reason	4.1	1.7
Total		**100.0**

In general, Italian carers show a high willingness to continue caring in the future, given that 70% of them would be even ready to increase the amount of care provided if necessary, while about 20% would continue caring in case the situation does not change (Table 5.19).

The consideration of the elder's placement in a care home is an even more evident sign of very burdening situation from the point of view of the main carer, and in general of the sustainability of elders been cared for in the community. In the Italian sample 67.1% of the interviewed carers would never take into consideration the event of moving their cared-for elder in a care home, irrespective of circumstances (Table 5.20), but a second big group of carers (31.6%) would consider the placement in a care home in case the senior's conditions get worse.

Table 5.19 In the next year, are you willing to continue caring for the elder? (%, N = 984)	
Yes, and I would even increase	70.0
Yes, if the situation remains the same	18.8
Yes, and I would increase for a limited time	6.2
Yes, but only with more support	4.2
No, no matter what extra support I receive	0.8
Total	**100.0**

Table 5.20 Would you be prepared to consider elder's placement in a care home? (%, N = 943)	
No	67.1
Yes, but only if elder's condition gets worse	31.6
Yes, even if elder's condition remains the same	1.3
Total	**100.0**

5.3.6 Carers' health status and their quality of life

The health status and the quality of life of caregivers have a high influence both on the possibilities of giving help to older family members and on the quality of the care provided. Carers' health status has been evaluated by asking the carers to self-assess whether their health was excellent, very good, good, fair or poor. The intermediate "*good*" health level has been mentioned most often (41.5%), followed by the "*fair*" category (37.4%) (table 5.21). A high percentage of carers reported therefore a non positive health status (42.8%, categories "fair" and "poor" merged together), while those presenting a very good or excellent subjective health status aggregate to 15.7%.

Table 5.21 Subjective health status of the carers (%, N = 988)	
Excellent	2.7
Very Good	13.0
Good	41.5
Fair	37.4
Poor	5.4
Total	**100.0**

A further important indicator is the subjective perception of one's quality of life (table 5.22). The biggest group of carers state their overall quality of life as "*good*" (45.5%) and the second one as "*neither good nor poor*" (40.4%). The lowest level (the "*very poor*" and the "*poor*" categories taken together) is not very relevant (8.2%), but neither is the "*very good*" level of quality of life (chosen by as few as 5.9% of carers).

Table 5.22 Subjective quality of life of the carers (%, N = 988)	
Very Good	5.9
Good	45.5
Neither Good Nor Poor	40.4
Poor	7.0
Very Poor	1.2
Total	**100.0**

5.4 Summarising remarks

The age of the Italian older people cared for by the family carers belonging to the Italian EFC sample is quite high (82 years on average). They mainly live at home, even alone when less dependent, while the more dependent ones live with others, in particular with their children and/or partners, in many cases also resorting to the help of cohabiting paid migrant carers (particularly for the most severely dependent elders).

The main reasons for which the elders need care are mobility problems and physical illness/disability; memory or cognitive problems are more seldom the main reason for care, but they are co-present in almost half of cases. Organising support, financial management, domestic tasks and responding to emotional, psychological or social needs are the activities for which more than half of older Italians need complete help from others.

Carers are mainly women and married, with a mean age of 53.5 years, in most cases represented by children, followed by spouses, children-in-law and nephews/niece. Their level of education is medium-high and the majority are not working. Those who are however active in the labour market are mostly employed in the public sector. Work restrictions due to caregiving, such as difficulties in developing one's career and to work with continuity are recorded both for those who are working (who also suffer from a reduction in working hours due to caring) and for those who are not employed (who not seldom experience the impossibility to work at all and have given up work, too).

As far the characteristics of the caring situation are concerned, the mean duration of caregiving is quite long (on average almost 5 years), while the motivation to care is ascribed in most cases to emotional bonds and, to a lower extent, to a sense of duty or obligation.

Despite the fact that near half of the carers present a fair or poor health status, most of them rate their quality of life rather positively, and show a high willingness to continue providing care to elderly people, and a low propensity for elder's placement in a care home.

6 Typology of caregiving situations in Italy: a cluster analysis approach[*]

by Cristian Balducci, Eva Mnich, Kevin McKee, Liz Mestheneos, Birgitta Öberg and Beata Wojszel

6.1 Introduction

In general terms, the caregiving literature is dominated by research aiming at describing the carer's situation by focusing particularly on health outcomes, with older person characteristics being usually used as explaining factors (i.e. independent variables). This is of course of importance, since caregiving may be a very demanding experience, leading the carer to clinically relevant psychophisical consequences and even to an increased risk of mortality (Schulz, Beach, 1998). Thus, understanding which factors contribute the most to carer's health, may give important insights as to which interventions should be put in place to improve carer's well-being.

However, this approach has also a number of limitations, the main of which is that the older person's characteristics are only included - particularly in dementia research - as more or less objective measures of carer's stress, rather than factors contributing to our uderstanding of the caregiving situation or relationship on its whole. It may well-be, for example, that older person's characteristics are dependent, rather than independent, variables, such as in a situation in which carer's dispositional affect influences the older person's mood and this in turn impacts on older person's physical disabilty. Indeed, research has already showed that the well-being of one spouse is significantly related to the well-being of the other spouse (Bookwala, Schulz, 1996) and that older person's mood significantly affects his/her functional disability (Penninx, Guralnik, Ferrucci, Simonsick, Deeg, Wallace, 1998).

Another limitation of the above mentioned approach is that focusing on only carer's health outcomes appears rather simplistic even to describe the carer's situation. For example, carers in bad health conditions may find themselves in substantially different situations and have different needs according to their background characteristics (gender, occupational status, age, etc.). Thus, it may be necessary to offer them completely different forms of support, according to these characteirstics.

In light of these considerations, in EUROFAMCARE it was decided to adopt a broader approach to describe caregiving situations, in which both carer's and older person's related characteristics were included. By using this approach it was aimed at obtaining general constellations of caregiving situations, which could then be used for further analysis including services.

While data analyses reported in this chapter were carried out at the European level (on the six countries' dataset), the results that will be discussed will only focus on the Italian data.

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[*] This chapter represents a partially revised and adapted version of the parallel description made at the European level for the Trans-European Survey Report (TEUSURE) Chapter 6.

6.2 Methodology

6.2.1 Preliminary considerations

Each interview conducted with the carer represents a specific relationship to the older person that is embedded in further relevant informal and formal social relationships. To abstract from each individual case and combine comparable cases to groups that in turn each represents different possible constellations, a listing of characteristics is required. Here, one has to be modest regarding the number of characteristics, their degree of differentiation or the dimension of time.

The characteristics used in this analysis were taken from the Eurofamcare questionnaire by using a number of key questions to lead variable choice. In particular, from the carer's perspective the following key-questions were used:

- What is the degree of strain and well-being experienced by the caregiver?
- Is there social support available for the carer in case of need (e.g., if ill)?
- Is the carer a working person?
- Is the carer of the same generation with elder?
- When did the carer take on the caring role?
- From the older person's perspective:
- What is the degree of impairment (both physical and cognitive) of the older person?
- Is the older person in financial need?
- Where does the older person live with respect to carer?

6.2.2 Variables included in the analysis

On the basis of these questions, the following carer's related variables were taken in consideration: carer's demographics as indicated by gender (1=male, 2=female), educational level (1=low–3=high), working status (0=not working, 1=working), generation with respect to elder (0=not same, 1=same) and the characteristics of carer's place of residence (0=rural, 1=urban). The perceived burden of caregiving as indicated by the Cope Index's negative impact subscale (McKee et al, 2003) was also included (range 7–28, with higher scores indicating higher impact) as well as the quality of subjective health (1=excellent–5=poor) and psychological weel-being (range 0–25, with higher scores indicating better quality of life) (World Health Organization, 1998). Finally, duration of caregiving in months, availability of help if ill (1=yes, I could find someone–3=No, there is no one) and availability of help if a break is needed (1=yes, I could find someone–3=No, there is no one) were also taken in consideration.

As for the older person's related variables, age in years and gender (1=male, 2=female) were included, as well as older person/carer cohabitation status (0=no, 1=yes) and whether the older person was in need of financial support (0=does not have this need–2=completely in need). A measure of IADL (independent activity of daily living) was also included (range 0–6, with higher scores indicating higher impairment) as well as an indication of the older person cognitive status. This last variable – derived from an initial variable described in detail in Chapter 3 – differentiated older persons with no cognitive problems or age associated memory impairment (0) from older persons with behavioural problems or suspected dementia (1).

Before deriving the caregiving situations, correlations between the chosen variables were examined (see Table 1). This was necessary since we had to ensure that variables with no/low level of correlation (i.e., with a consistent amount of information not shared with other variables) had to be taken as input of the following analyses. In other words, each chosen variable had to bring original information to be used for situations' derivation.

Correlations showed that variables reporting on caregiver's 'availability of help if ill' and 'availability of help if a break is needed' were strongly associated (r = .81). This suggested that these variables gave similar information (i.e. the level of social support available to the caregiver). As a consequence, it was decided to keep only the former of these two variables. High correlations were also found between the variables 'subjective health' and 'psychological well-being' (r= -.50) and 'psychological well-being' and 'negative impact' of caregiving (r= -.50). Here it was decided to drop the variable 'subjective health' reported by the caregiver and use the more general indicator of 'psychological well-being', while keeping also the 'negative impact' variable, since it was the only specific caregiving-related outcome available. Other correlations between the chosen variables were also found to be moderately high or high (e.g. between 'IADL' and 'cognitive status' of the older person); however, no further variables were dropped, since the remaining ones were all judged to tap important dimensions of caregiving to be taken into account for a typology of caregiving situations.

Altogether 15 characteristics remained after this selection, that, however, partly displayed metric and partly nominal scales. In these cases of “mixed" variables three strategies can be followed:

a) Perform separate analyses for metric and nominal scales;
b) Create a dummy variable for each category of a nominal variable and treat it as metric (Bacher, 1994: 186-191);
c) Separate each characteristic – both metric and nominal – in a corresponding dummy variable and thus scale to the smallest common denominator.

It was decided to use variant c) for this analysis, as it was chosen to consider all variables simoultaneosly, which excludes the first strategy from the outset. In variant b) the number of dummy variables would have quickly increased to two or three dozen, which would have made the later description of the clusters very intricate (and possibly difficult to explain). However, it is to note that variant c) leads to loss of information, as with the selection of the cutting points between 0 and 1 other possible differentiations are lost. In return it was gained a much simpler model, in terms of interpretability. Table 2 shows the variables included in the analysis.

6.3 Results

6.3.1 Number of clusters

It is to be considered that with 15 dummy variables (0 means: "characteristic does not apply"; 1 means: “characteristic applies”) more than 30.000 combinations are possible. It becomes apparent which high degree of data and thus information reduction can be reached with less than ten caregiving arrangements that are internally homogenous. To achieve this it was selected a cluster fusion procedure (Ward procedure) that gives information about the possible number of clusters.

Table 1. Non parametric correlations between selected variables to derive a typology of caregiving situations

Carer's variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	
1.Carer's gender	1.00																
2.Carer's education	-.07	1.00															
3.Working status	-.04	.31	1.00														
4.Generation	-.09	-.22	-.39	1.00													
5.Locality	-.06	.16	.04	.03	1.00												
6.Negative impact	.10	-.05	-.09	.11	.02	1.00											
7.Subjective health	.09	-.20	-.24	.18	-.04	.26	1.00										
8.Quality of life	-.14	.11	.12	-.07	.02	-.49	-.50	1.00									
9.Duration of caregiving	.01	-.05	-.10	.08	-.07	.08	.15	-.08	1.00								
10.Help if ill	.00	-.07	-.19	.27	.06	.32	.17	-.20	.07	1.00							
11.Help if break needed	.03	.06	-.16	.22	.06	.35	.20	-.25	.07	.81	1.00						
Older person's variables																	
12.Elder's age	.10	.00	-.07	-.31	-.02	.08	.07	-.05	.15	.01	.02	1.00					
13.Elder's gender	-.14	.11	.11	-.37	-.01	-.08	-.07	.07	.04	-.11	-.09	.15	1.00				
14.Chabitation with carer	-.03	-.14	-.22	.33	-.05	.18	.17	-.18	.14	.15	.16	-.09	-.14	1.00			
15.Financial support	-.04	-.06	-.04	.04	-.01	.27	.11	-.18	.05	.10	.12	-.01	.03	.15	1.00		
16.IADL	.06	-.10	-.17	.10	-.02	.42	.17	-.24	.08	.21	.22	.24	-.07	.20	.30	1.00	
17.Cognitive status	.06	-.01	-.04	.03	.04	.35	.11	-.18	.00	.11	.13	.09	-.06	.03	.18	.45	1.00

Table 2: Variables included in cluster analysis

Carer related variables (name in database)	***Variables coding (overall % of indicated responses)***
Gender (csexr)	0 = male 1 = female (77.1)
Education (c172_r)	0 = higher level 1 = lower level (21.5)
Working status (work_r)	0 = non working 1 = working (43.5)
Generation (generat)	0 = not the same generation 1 = same generation (15.4)
Place of residence (g4locar)	0 = rural 1 = urban (78)
Caregiving duration (c67_r)	0 = up to two years 1 = more than two years (63.1)
Help if ill (c68_r)	0 = Yes I could find someone 1 = I could find someone with difficulties or no (51.3)
Subjective burden (nneg_c_7)	0 = lower impact_7 to 10 1 = higher impact_11 to 28 (59.4)
Psychological weel-being (nquol_5)	0 = worse well-being_0 to 14 1 = better well-being_15 to 25 (37.2)
Elder related variables	
Age (e17age_r)	0 = 65-79 1 = 80 and over (63.6)
Gender (e16sexr)	0 = male 1 = female (71.2)
Cohabitation status (c21_rr)	0 = different houses 1 = same house (45.3)
Financial support (e33a_rr)	0 = no need 1 = need (41.6)
Cognitive status (cogn_rr)	0 = no cognitive disorder or slight memory impairment 1 = behavioural disorder or suspected dementia (53.3)
IADL abilities (iadl_t_r)	0 = low to moderate IADL dependency 1 = more severe IADL dependency (74.7)

Such agglomerative procedures first combine all same characteristic combinations to clusters. As soon as identical models cannot be combined anymore, those two clusters are fused with which the internal heterogeneity raises the least. This process is performed until the last fusion step with which the last two remaining clusters are merged into one. From this point, the individual fusion steps are followed backwards in order to determine with the inverse screen test in which step the heterogeneity increased erratically (Elbow criterion). This is the termination condition and the definition of number of clusters, because this increase in dissimilarity must not be tolerated.

The inspection of the fusion table (Table 3) shows that with the change from six to five clusters noticeably more heterogeneity is added than with previous fusion steps. Previously this value has increased steadily (220, 230, 240) and then "jumps" (elbow criterion) by 300 points. This increase means that from now on two clusters are fused and form a new – comparatively heterogeneous – cluster. Thus, a solution with 6 clusters is to be seen as the limit of simplification possibilities.

Table 3: Agglomeration schedule

Number of clusters	Heterogeneity in all clusters	Increase of heterogeneity in the next fusion step
…	…	…
…	…	…
12	12.910	…
11	13.080	170
10	13.250	170
9	13.460	210
8	13.680	220
7	13.910	230
6	14.150	240
5	14.450	300
4	14.800	360
3	15.280	470
2	16.640	1360
1	18.370	1730

6.3.2 Quality of cluster partition

In order to verify the selectivity between the clusters, a **discriminant-analysis** was used. With this analysis the 15 cluster variables were used to reproduce the individual group membership. The degree to which this is successful can be interpreted as a quality factor for the cluster solution. The six clusters solution resulted in a rate of 81% correctly classified cases in the discriminant analysis. This relatively low value can be traced to the fact that in two of the six clusters only two out of three cases were assigned to the “correct” (from the cluster solution) subgroup.

It was then decided to run a new cluster analysis, by using a **non-hierarchical cluster-approach** (K-means procedure: Quick cluster in SPSS), which may be a better approach with a high number of cases such as here. The optimizing algorithm of quick cluster checks for each case whether the previous assignment from the hierarchical analysis is really the best or whether with another assignment the homogeneity of the new target cluster is less affected than with the previous one.

The new cluster solution was then followed by a discriminant analysis, which now delivered 92% of correctly classified cases. This second 6-cluster solution was the one used for the following analyses.

6.3.3 Description of caregiving situations

As it can be seen from Table 4, the six caregiving situations obtained from the cluster analysis were each characterised by a number of significant dimensions.

Table 4: Prevalence of characteristics in clusters

	Caregiving situations					
	1 N=241	*2 N=208*	*3 N=87*	*4 N=50*	*5 N=185*	*6 N=178*
Carer's related variables						
Gender: % female	90.9	78.9	97.7	6.0	74.1	68.0
Education: % lower	34.9	5.3	64.4	36.0	9.7	6.2
Working status: % working	0.0	99.5	3.4	4.0	48.7	62.9
Generation: % same	4.6	1.9	89.7	68.0	3.2	4.5
Place of residence: % urban	75.1	82.7	77.0	86.0	76.8	74.7
Caregiving duration: % > 2 years	71.8	63.9	73. 6	64.0	62.2	44.9
Help if ill: only with difficulties or no	67.6	56.7	67.8	78.0	27.6	29.2
Subjective burden: % higher	90.9	97.1	80.5	64.0	4.3	16.3
Psychological well-being: % better	15.8	23.1	14.9	38.0	61.6	67.4
Elder's related variables						
Age: % 80+	87.1	54.8	44.8	28.0	75.7	49.4
Gender: % female	88.8	76.9	3.4	92.0	67.0	73.6
Cohabitation status: % same house	58.5	39.4	94.3	96.0	21.1	16.9
Financial support: % needed	58.1	54.3	36. 8	62.0	29.2	11.2
Cognitive status: % higher impairment	71.8	71.2	59.8	54.0	46.5	10.7
IADL abilities: % higher impairment	93.8	86.5	92.0	78.0	100.0	0.0

More particularly, the first two subgroups were dominated by female caregivers (90.9% and 78.9%, respectively), reporting a high subjective burden (90.9% and 97.1% of carers, respectively), with the well-being measure indicating that only a minority of carers (15.8% and 23.1%, respectively) had a better quality of life. Not surprisingly the older person, in most cases female gendered (88.8% and 76.9%, respectively), had both a higher cognitive (71.8% and 71.2% of elders, respectively) and physical (93.8% and 86.5% of elders, respectively) impairment. To note is also that cluster one was made by the highest proportion of older persons aged 80 or more (87.1%, 54.8% in cluster 2). Cluster one and two, which were also mainly formed by dyads of carer/older person of different generations (95.4% and 98.1%), mainly differed in that cluster two was predominantly formed by working caregivers (99.5% vs. 0.0% in cluster one) with, on average, a higher educational level (94.7% vs. 65.1%, respectively). Given these characteristics, it was decided to identify cluster one as a situation of a 'highly burdened female non-working carer, caring for a highly impaired female older person of a different generation', whiles cluster two as a situation of a 'highly burdened female working carer, with a higher educational level, caring for a highly impaired female older person of a different generation'.

Cluster three and four were made by cohabiting carer/older person dyads (94.3% and 96.0%, respectively) of the same generation (89.7% and 68.0%, respectively). The carers, in these two groups, were mainly no working carers (96.6% in cluster 1 and 96.0% in cluster 2), meaning that these caregiving situations were made by a majority of spouses/partners. Moreover, carers in cluster 3 showed a substantially high negative impact of caregiving (80.5%), whiles carers in cluster four reported in most of the cases a lack of social support in case of necessity, stating that they caould find a help if ill or could find it only with difficulty (78.0%). As for the older persons, they appeared to be mainly phisically dependent (92.0% in cluster 3 and 78.0% in cluster four), with those in cluster four having also a high prevalence of financial needs (62.0%). The main difference between the two groups was that female carers (97.7%) cared for a male older person (96.6%) in cluster three, while the situation was reversed in cluster four, with male carers (94.0%) caring in most of the cases for a female older person (92.0%).

Giving this, it was decided to identify cluster three as ‘highly burdened, non working, female carer, caring for a mainly physically dependent partner’, and cluster four as ‘male, retired carer, with a lack of social support, caring for a mainly physically disabled partner in financial needs’.

Cluster five and six were formed by carers reporting a lower subjective burden (95.7% and 83.7%, respectively), having a higher educational level (90.3% and 93.8%), not cohabiting with the older person (78.9% and 83.1%) and being substantially well supported in case of necessity (72.4% and 70.8%). The difference between these two groups was in the characteristics of the older person, who showed a substantially low physical and cognitive impairment (0.0% and 10.7%, respectively) in cluster six, whiles showing a higher impairment in cluster five, physical in nature (100%). This is also a consequence of the highest prevalence in cluster five of older persons aged 80 or more (75.7%, 49.4% in cluster 6). Cluster five was thus identified as ‘low subjectively burdened, not cohabiting and well supported carers, with a higher educational level, caring for an older person with a mainly physical impairment’. Cluster six was identified as ‘low subjectively burdened, not cohabiting and well supported carers, with a higher educational level, caring for an older person with a lower level of impairment, either physical or cognitive’.

A summary table of the main features of the caregiving situations identified by cluster analysis is provided in Table 5. From this table it can be seen that the physical impairment dimension is the most present one, characterising all the six situations and indicating that a higher physical impairment of the older person is a defining feature of the caregiving experience. To note is also that a higher subjective burden of the carer is present in three out of six situations, thus showing a high prevalence of negative feelings among caregivers. In two of these three situations (situation 1 and situation 2) the older person shows also a higher cognitive impairment. Thus, in line with the literature in this area of research, caregiving situations in which the carer reports a high impact from caregiving are in most of the cases those in which the older person has both a higher cognitive and physical impairment. It is probably to further underline that these situations are far from being rare, giving that in this study they represent almost half of the cases (see Table 4, situation 1 plus situation 2).

Moreover, the high negative impact of the carer appears to be related to female gender – interestingly, when the carer is predominantly male, i.e. situation 4, negative feelings do not show such a high prevalence. On the other hand, carer’s working status, as well as availability of social support and educational level, doesn’t seem to play a (strong) role. This suggests that the causes of the high impact of caregiving may be due to something unique and gender-specific in the relationship with the older person, perhaps depending upon the losses which the latter experiences as the impairment – especially if related to a degenerative disease such as dementia – progresses (Lyons et al., 2002; MacRae, 2002). These of course remain only hypotheses, the test of which is not among the objectives of this descriptive chapter.

Table 5: Main characteristics of clusters

	*Caregiving situations**					
	1	*2*	*3*	*4*	*5*	*6*
Carer's characteristics						
Subjective burden	high	high	high		low	low
Working status	non-working	working	non-working	non-working		
Gender	female	female	female	male		
Generation to elder	different	different	same	same		
Help available if ill				no help	help available	help available
Cohabitation status			cohabiting	cohabiting	no	no
Educational level		higher			higher	higher
Older person's characteristics						
Gender	female	female	male	female		
Cognitive impairment	high	high				low
Physical impairment	high	high	high	high	high	low
Financial needs				high		

*Situation 1: Highly burdened female non-working carer, caring for a highly impaired female older person of a different generation

Situation 2: Highly burdened female working carer, with a higher educational level, caring for a highly impaired female older person of a different generation

Situation 3: Highly burdened, female, non working carer, caring for a mainly physically dependent partner

Situation 4: Male retired carer, with a lack of social support, caring for a mainly physically disabled partner in financial needs

Situation 5: Low subjectively burdened, not cohabiting and well supported carer, with a higher educational level, caring for an older person with a mainly physical impairment

Situation 6: Low subjectively burdened, not cohabiting and well-supported carer, with a higher educational level, caring for an older person with a lower level of impairment, either physical or cognitive

6.3.4 Caregiving situations and motivations to care and future care

To provide a more thorough description of the six caregiving situations reported above, it was decided to characterise these situations in terms of carer's motivation to care and willingness to hold the caring role in the future. Table 6 reports a cross tabulation between caregiving situations and motivations to care.

The overall results show that 'emotional bonds' such as love and affection is the most reported reason for giving care (96.8%), followed by a 'sense of duty' (73.4%). Moreover, more than half of the participants report that a 'sense of obligation toward elder' and that caring 'make me feel good' are among their motivations for giving care (56.7% and 55.9%, respectively). Although all the other reasons are less frequently reported – with the least frequent reason being 'economic benefits for me and/or elder' (4.3%) – it is nonetheless to underline that approximately 1/3 of the participants state among their reasons for giving care that there was 'no alternative' (30.4%) and that 'the cost of professional care is too high' (31.6%).

When motivations to care are analysed according to the different caregiving situations, several interesting results emerge. While there appear to be no significant differences among caregiving situations as for the motivation ‘emotional bonds’, which remains the general underlying reason for giving care shared by the majority of caregivers, situations do differ on other several motivations. More particularly, there seems to emerge a pattern in motivations to care in which the first three caregiving situations are similar between them and significantly different from the last two caregiving situations, with situation 4 being often similar to the first group and sometimes standing alone (Table 6). Highly burdened female carers giving care to a highly impaired older person (situation 1-3) together with male carers caring for a partner physically impaired (situation 4) report more often a ‘sense of duty’ among their motivations for caring than carers with a lower subjective burden, a higher educational level, not cohabiting with the older person (situation 5 and situation 6). To note is also that carers in the first four situations report more often than the others that there was ‘no alternative’, that ‘the cost of professional care is too high’ and that ‘I found myself in these circumstances by chance’. This suggests that role captivity – a feeling of constraint and no choice in role responsibilities characterising the carer – may have a higher prevalence in situations 1-4 than in others.

If the motivation ‘caring makes me feel good’ is analysed, again a clear differentiation emerges between caregiving situations. In this case situations 1-3 report a lower prevalence of ‘feeling good’ than situations 5-6, with situation 4 being in between. This result appears consistent with the ‘captivity’ hypothesis outlined above.

Despite no statistically significant differences appear for the motivation ‘a sense of obligation toward elder’, a trend in the percentages of agreement is nonetheless clear, in which situation 1 and situation 2 report a higher prevalence of this motivation than (particularly) situation 6.

Table 6: Caregiving situations and carer’s motivation to care

	Caregiving situations						*Overall*	*Chi-square*
Motivation to care*	*1* *N=241*	*2* *N=208*	*3* *N=87*	*4* *N=50*	*5* *N=185*	*6* *N=178*		
A sense of duty	80.1	78.4	75.9	76.0	64.3	65.7	73.4	p<.05
There was no alternative	40.7	34.6	34.5	34.0	18.9	19.7	30.4	p<.05
Cost of professional care is too high	39.8	36.5	37.9	38.0	19.5	18.0	31.6	p<.05
Emotional bonds (love, affection)	94.2	96.2	98.9	98.0	96.2	97.2	96.8	n.s.
Caring makes me feel good	49.4	50.5	44.8	56.0	66.5	68.0	55.9	p<.05
Elder would not wish for anyone else	51.9	44.2	46.0	34.0	38.9	46.6	43.6	p=.07
Because of my religious beliefs	40.7	33.2	42.5	38.0	40.0	33.1	37.9	n.s.
I found myself in these circumstances by chance	43.6	34.1	37.9	40.0	17.8	19.7	32.2	p<.05
Economic benefits for me or ELDER	5.8	4.8	1.1	8.0	3.8	2.2	4.3	n.s.
A sense of obligation towards ELDER	63.5	60.6	56.3	56.0	55.7	48.3	56.7	p=.06

*more than one choice was possible

Finally, it is interesting to note that a trend for significance is also in place for the motivation ‘Elder would not wish for anyone else’. It should be underlined that this is the only motivation that takes directly on the point of view of the older person. The results here show that Situation 4, which is different from the others for being predominantly made by male caregivers, reports the lowest prevalence of the reason ‘Elder would not wish for anyone else’. This may suggest that caring for another person may require a particular sensitivity which is not, traditionally – at least in Italy –, a male one.

In general, the results of this analysis suggest that motivational aspects are greatly involved in the experience of informal caregiving. The pattern emerged highlighted a consistent association between particular motivational dispositions and caregiver subjective burden and older person impairment. A high prevalence of motivations such as ‘a sense of duty’, ‘no alternative’ ‘the cost of professional care too high’, ‘I found my self in these circumstances by chance’, which all communicate a sense of constraint by the carer, are associated with a higher carer’s subjective burden and a higher older person’s impairment.

However, it is not possible from these cross-sectional results to infer any kind of causality. Thus, it may be that motivational dispositions are shaped by the subjective burden experienced by the caregiver, which in turn is determined by the older person’s functional impairment. For example, in case of degenerative diseases such as dementia, the progression of the older person’s impairment can impact on the reciprocity of the caregiving relationship; as a consequence the carer may report a consistent subjective burden and this may change the motivational disposition that sustain caregiving. However, the other way round may also be possible, in which initial motivational dispositions impact on the longer run on carer’s subjective burden and affect and these, in turn, play an effect on the older person level of impairment, both physical and cognitive. Still another hypothesis may be that motivational dispositions interact with older person’s impairment in determining the carer’s subjective burden. Longitudinal data are necessary to shed further light on this issue.

The results of these analysis suggest that the psychological ingredients (motivations to care) taken in consideration should be more thoroughly investigated and paid attention to in future research, especially when thinking to interventions of any kind devised to the caregiver or the older person. For example, it is not possible to think to stress reduction interventions for caregivers without taking in consideration the motivations above and the related underlying beliefs. Even interventions aimed at reducing the older person’s (e.g.) anxiety or depressive symptoms might benefit from taking carer’s motivations into consideration.

Table 7 reports a cross-tabulation between caregiving situations and the two items in questionnaire investigating future care. As for the item ‘In the next year, are you willingly to continue to provide care to elder?’, the overall results show that a high proportion of carers respond ‘Yes’, and thus show availability to continue to care in the future, independently of a possible worsening of the caregiving situation. However, carers in different caregiving situations show statistically significant differences in their responses. Carers with a high subjective burden caring for a highly cognitively and physically impaired older person of a different generation (i.e. situations 1 and 2) report a lower frequency of unconditional ‘yes’ responses, especially when compared to carers with a low subjective burden, a higher educational level, caring for an older person with a frequently low level of impairment (situations 5 and 6). Non-working carers looking after a partner characterised by having a high level of physical impairment (situations 3 and 4) appear to be in between.

When asked ‘Would you be prepared to consider Elder’s placement in a care home?’, approximately one third of the carers respond ‘Yes’. However, there is again a statistically significant difference between situations on this percentage. Highly burdened, female, working carers, looking after a highly impaired older person of a different generation (situation 2) state that they would be prepared to consider elder's placement in a care home in more than half of the cases. This is the highest percentage of 'Yes' responses. On the other hand, carers with a low subjective burden, a higher educational level, not cohabiting with the older person, who in turn shows a low functional impairment (situation 6), report least frequently to be prepared to consider elder's placement in a care home. All the other caregiving situations are in between, with a percentage of 'Yes' responses around 30% of the cases.

Table 7: Caregiving situations and future care

	Caregiving situations						*Overall*	*Chi-square*
	1 N=241	*2 N=208*	*3 N=87*	*4 N=50*	*5 N=185*	*6 N=178*		
*In the next year, are you willingly to continue to provide care to ELDER?**								
- Yes (%)	70.1	68.4	75.9	77.6	82.1	88.6	76.5	
- Yes, but only if the situation remains stable	24.9	21.8	19.5	16.3	14.7	9.7	18.5	
- Yes, but only with more support / No	5.0	9.7	4.6	6.1	3.3	1.7	5.1	p<.05
*Would you be prepared to consider ELDER's placement in a care home? ***								
- Yes	31.6	55.3	28.2	28.6	34.7	21.7	32.7	p<.05

* The original item had five ordered response options: 'Yes, and I would even consider increasing the care I give if necessary' (1); 'Yes and I would consider increasing the care I give for a limited time' (2); 'Yes, I'm prepared to continue to provide care if the situation remains the same' (3); 'Yes, I'm prepared to continue to provide care to Elder but only if I have some more support (from services, family, friends etc.)' (4); 'No, I'm not prepared to continue to provide care to Elder, no matter what extra support I receive' (5). Given the frequency distribution and the meaning of these responses, options 1 and 2 were merged together and coded as 'Yes', and options 4 and 5 were merged together and coded as 'Yes, but only with more support / No'.

** The original item had three response options: 'No, under any circumstances' (1); 'Yes, but only if elder's condition gets worse' (2); 'Yes, even if Elder's condition remains the same as it is now' (3). After inspection of the frequency distribution, response options 2 and 3 were merged together and coded as 'Yes'.

6.4 Discussion

In this chapter a cluster analysis approach was adopted to obtain a typology of caregiving situations in Italy. This typology will be used for more advanced analysis taking in consideration older person's and carer's service use.

Six different situations were obtained and described in detail according to the distributions of variables used for cluster partition. These situations, which took in consideration both the characteristics of the carer and of the older person, represent different constellations of caregiving, sometimes overlapping for certain characteristics, but unique for others.

The situations were identified as follows:

- Situation 1: Highly burdened female non-working carer, caring for a highly impaired female older person of a different generation;
- Situation 2: Highly burdened female working carer, with a higher educational level, caring for a highly impaired female older person of a different generation;
- Situation 3: Highly burdened, female, non working carer, caring for a mainly physically dependent partner;
- Situation 4: Male retired carer, with a lack of social support, caring for a mainly physically disabled partner in financial needs;
- Situation 5: Low subjectively burdened, not cohabiting and well supported carer, with a higher educational level, caring for an older person with a mainly physical impairment;
- Situation 6: Low subjectively burdened, not cohabiting and well-supported carer, with a higher educational level, caring for an older person with a lower level of impairment, either physical or cognitive.

After this, the six caregiving situations have been differentiated in terms of caregiver's motivation to care, with results showing that whiles 'emotional bonds' remains the most reported motivation independently of caregiving situations, situations do present different motivational dispositions. In particular, it emerged that a certain degree of role captivity may be at work, especially in those situations (1-3) were the carer is most burdened and the older person substantially impaired. Of course it was not possible to infer causal relationships between situations and motivations to care, but the results do suffice to highlight the opportunity of routinely investigating and possibly addressing carer's motivations when devising caregiving interventions of any sort, especially if addressed to caregiver's burden.

Finally, the six caregiving situations have been examined in terms of carer's intention to hold the caring role in the future and propensity to place the older person in a care home. Whiles in general most of the carers state that they are willing to continue to care in the future, in situations 5 and especially 6 – which could be defined as 'low-threshold caregiving' in terms of both carer's involvement and older person's impairment –, the carers report more frequently this willingness. Paralleling this, 'low-threshold caregivers' report also less often to consider elder's placement in a care home, even though here the results appear somewhat less clear.

7. Experiences and preferences of family carers in service use

by Sabrina Quattrini, Cristian Balducci and Giovanni Lamura

7.1. Aims of chapter

This chapter aims at describing the experiences and preferences of Italian family carers of older people in the use of care services and supports. After presenting the main types of services available and allowances received, the opinions of carers in using them as sources of help and the obstacles experienced in accessing formal services are illustrated, together with some insight on their costs. A detailed picture of the reasons for not using or for stopping using formal services is also provided.

A specific paragraph will point out whether services are able to reach the persons – family carers or older people – most in need of support, identifying major typologies of care situations as well as synthetic indicators of dependency and care needs. The analysis of the main factors associated with service use will follow, including the territorial dimension. Due to the cross-sectional design of this part of the study, the effectiveness of service use on the well being of carers cannot be properly evaluated here, since this aspect can more suitably be analysed in the light of longitudinal data, as it will be attempted – in a preliminary form – in the last paragraph of this report.

7.2. Data analysis methodology

Each national EUROFAMCARE team has developed – and included in the national version of the survey questionnaire (Common Assessment Tool) - an exhaustive national list of health and social care services likely to be used by older people, as well as a list of services aimed at supporting family caregivers (such as for instance training courses for carers or self help groups).

The information collected on services used are illustrated in the present chapter by means of a detailed descriptive analysis concerning all services present in the Italian list. For analyses involving single services, data are presented only if used by at least 30/50 persons, i.e. a quantity necessary to allow more sophisticated statistical techniques, such as for instance comparisons between users and non-users or factors associated with service use.

Services used by carers have been collected separately from those used by elderly people, and carers were explicitly asked to indicate only those services which where relevant to them in their role as caregivers. Notwithstanding, the use of health care services was sometimes reported by carers in connection to their “health status” rather than to their role as carers, so that these data should be considered with caution.

All other parts of the questionnaire asking information about care services - such as experiences in accessing services, reasons for non using or stopping using some needed services, reasons for not accessing formal services, whether services reach the people in need of support or fit with the carers’ needs, types of support and characteristics of services preferred by family carers, factors associated with service use including regional and urban-rural differences, effectiveness of services – are illustrated in the present chapter through descriptive analyses.

Furthermore, in order to identify factors affecting service use, associations between “background” variables (including socio-demographic and care related issues etc.) and single services used have been analysed using either T or Chi-square tests for ordinal or nominal variables, and Phi test for measuring the strength of the associations. Correlations have been performed between the dependent variable "negative impact of care" on the carer and the most relevant dimensions investigated by the questionnaire, including the use/non-use of services. Finally, a multivariate regression model has been calibrated to examine the effects of service use on the negative impact of care.

7.3. Main findings

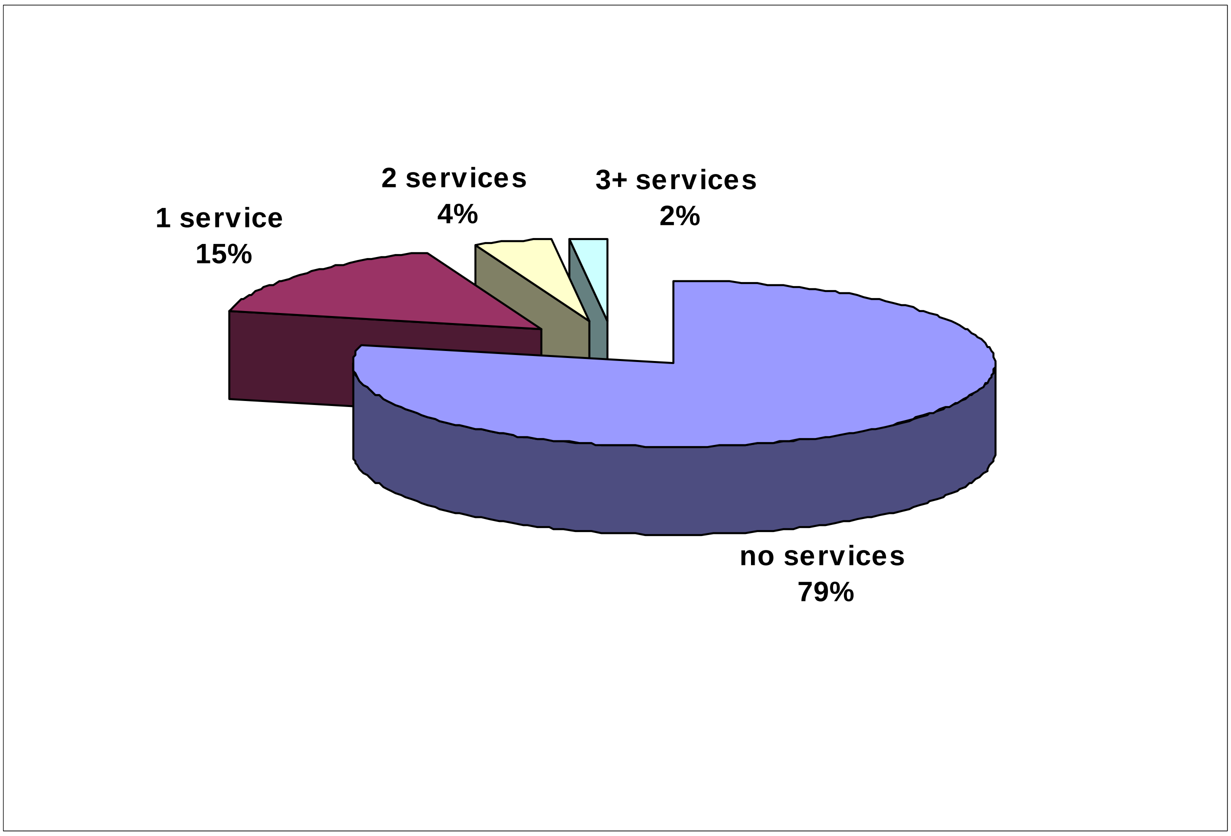
7.3.1 Which services and allowances are used by family carers and older people?

This paragraph examines the types of services used and the allowances received not only by family caregivers but also by the cared for older person, since the latter may also have a relieving effect on carers, although directly addressed to the older persons.

7.3.1.1 Services

The findings of the EUROFAMCARE survey show that the use of support services is very low among Italian carers, since almost four out of five of them have used no services at all in the six months prior to the EFC interview (Table 7.1, columns A and B). The mean number of services used by carers (excluding those not using any services at all) was 1,4 per person (SD ± 0,79), while only 3.9% of carers mentioned two services and 2% mentioned 3 or more services, the greatest part of them (15.5%) taking advantage of one service only (Figure 7.1).

Figure 1: Number of services used by family carers in connection with their care tasks (N=990)



TAB 7.1 Italian family carers by services and supports used, frequency of use, satisfaction and costs

	USE		Frequency (% values)				Mostly meets needs	Contribution of users to payment of services costs (% of users)			Amount paid in the last 6 months
	% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	% of users	Completely paid	Partially paid	Not paid	Euros/total sample
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**L**	**M**
Carers in total	**100,0**	**990**									
Carers using at least one service	**21,4**	**212**									
Types of services used by carers:											
General Practitioner (GP)	16,4	162	0	1,9	52,5	45,6	92,9	0,6	0	99,4	60
Specialist doctor	4,5	45	0	4,4	8,9	86,7	97,7	65,9	2,3	31,8	9.170
Specific services for carers, of which:	2,1	21									
- Self-help or relative support groups	0,9	9	0	44,5	33,3	22,2	100	66,7	0	33,3	90
- Training course in caring	0,5	5	0	20	0	80	80	0	0	100	0
- Support from voluntary organ.	0,4	4	0	100	0	0	100	0	0	100	0
- Counselling	0,3	3	0	0	33,3	66,7	100	0	0	100	0
- Help lines provided by charities	0,1	1	0	0	0	100	0	0	0	100	0
- Internet services	0,1	1	0	100	0	0	0	100	0	0	nr
- Regular respite service at home, supervision of the elder person at home for some hours per day	0,1	1	0	100	0	0	100	100	0	0	4.320
- Formal standardized assessment of the caring situation	0,1	1	0	0	0	100	100	0	0	100	0

TAB 7.1 Italian family carers by services and supports used, frequency of use, satisfaction and costs											
	USE		**Frequency (% values)**				**Mostly meets needs**	**Contribution of users to payment of services costs (% of users)**			**Amount paid in the last 6 months**
	% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	% of users	Completely paid	Partially paid	Not paid	Euros/total sample
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**L**	**M**
Other "generic" services used:	**5,1**	**50**									
General hospital	0,7	7	0	0	0	100	100	0	0	100	0
Laboratory tests	0,7	7	0	0	14,3	85,7	100	14,3	0	85,7	nr
Psychologist	0,6	6	0	60	20	20	80	20	0	80,0	420
Social worker	0,6	6	0	0	33,3	66,7	100	0	0	100	0
Diagnostic tests at home	0,4	4	0	0	0	100	100	50,0	0	50,0	40
Specialised diagnostic examinations	0,4	4	0	0	0	100	100	0	25,0	75,0	70
Day private care for cleaning home environment (housemaid)	0,4	4	0	75	25	0	100	100	0	0	4.090
Hairdresser at home	0,3	3	0	33,3	66,7	0	100	100	0	0	330
Day hospital	0,2	2	0	0	0	100	100	0	0	100	0
Medications	0,2	2	0	0	100	0	100	50,0	0	50,0	nr
Rehabilitation not at home	0,2	2	0	50	0	50	100	50,0	0	50,0	900
Home nursing services	0,1	1	0	0	0	100	100	100	0	0	nr
Laundry service	0,1	1	nr	nr	nr	nr	100	100	0	0	nr
Government provided home help for cleaning home environment	0,1	1	0	100	0	0	100	0	0	100	0
TOTALS							**91,6**	**8,8**	**15,7**	**75,5**	**19.490**

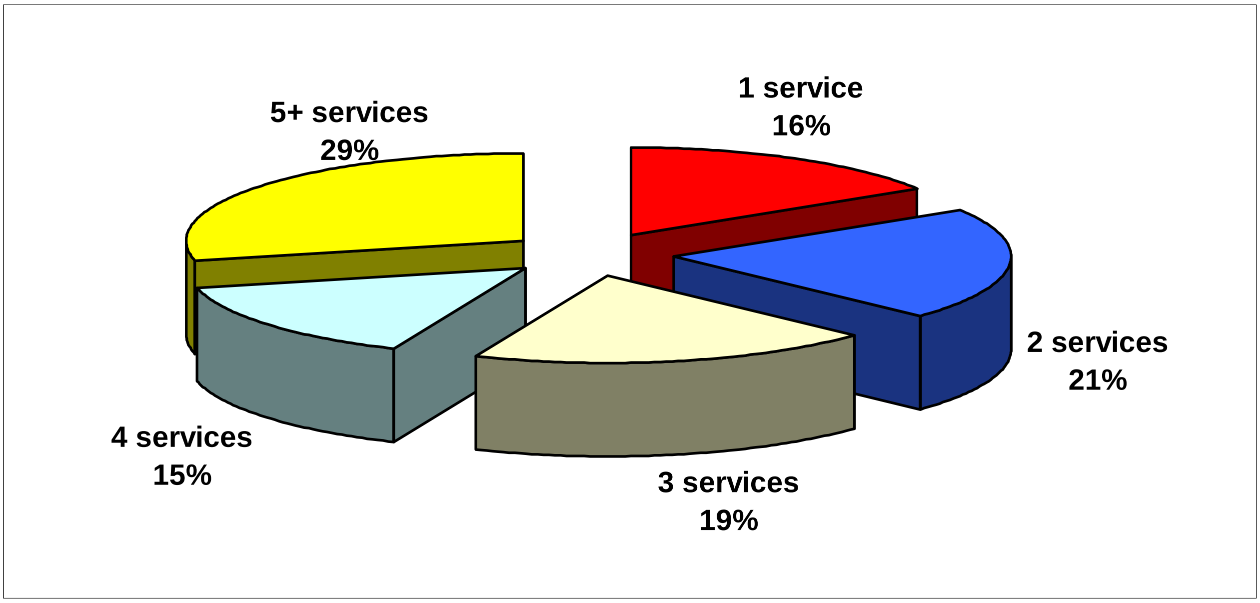
Only General Practitioners have been mentioned by a considerable number of carers (16,4%) as a service that has helped them in their role as caregivers, so that they could be partly viewed as playing a substituting role for almost absent carer-specific support services, such as counselling, training courses, support/self-help groups, respite service at home, that have been used in total by only 2.1% of carers.

Specialist doctors have been used by 4,5% of carers, but it should be underlined that most of them might have been consulted in order to find ways to improve the carer's health or to treat specific illnesses (orthopaedic, cardiologist, otolaryngologist etc.) not directly related to the caregiving situation. The same consideration applies to the "other services" mentioned by carers (5,1%), principally connected to their own illnesses or diseases.

Therefore, only one out of 50 Italian carers has used services specifically addressing caregivers' needs, while a much greater proportion of carers have used only generic services, which however have been evaluated as being of help also in their caregiving role.

The situation changes when it comes to services used by older people, who have practically all used at least one service (Table 7.2 columns A, B), with a mean number of 3,7 (SD ± 2,45) services per person. In particular, 16% older persons used only one service and around 20% used either 2 or 3 services, while about one elder out of three used more than 4 services (Figure 7.2).

Figure 2: Number of services used by OP (N=988)



As Table 7.2 clearly shows, the services mostly used by OP are health care services, in particular GPs (94,2%), specialist doctors (55,4%), general hospital (19,3%) and diagnostic tests (14,5% provided at home and 14,4% in laboratory). With regard to social services, it is interesting to observe the relatively high recourse to private services provided at home both for domestic duties (10,6%) and for personal care (6,4%; hairdresser, 7,9%). The peculiar feature of the Italian system, represented by the diffuse employment of cohabitant private helpers (the so called "badanti"), that in the last decade have become one of the most widespread source of help for older people, is confirmed by the EFC survey data, showing that 10% of the households constituting the Italian sample have made use of their support.

TABLE 7.2 Older people (OP) by services used, frequency of use, satisfaction and costs

	USE		Frequency				Mostly meets needs	Contribution of users to payment of services costs (% of users)			Amount paid in the last 6 months
	% total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	% of users	Completely paid	Partially paid	Not paid	Euros/total sample
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**L**	**M**
Older people (OP) in total	**100,0**	**990**									
OP using at least one care service	**99,8**	**988**									
Services used by OP:											
Health care services											
General Practitioner (GP)	94,2	933	0,2	20,2	59,0	20,6	90,8	0,6	0	99,4	470
Specialist doctor	55,4	548	0	1,0	18,4	80,6	94,3	36,7	10,1	53,2	61.687
General hospital	19,3	191	0	1,1	4,7	94,2	86,8	2,1	0,5	97,4	4.050
Diagnostic tests at home	14,5	144	0	2,8	26,7	71,5	99,3	21,5	0	78,5	1.604
Laboratory tests	14,4	143	0	2,9	28,8	68,3	98,6	11,9	0	88,1	1.073
Home nursing services	9,7	96	4,2	46,3	24,2	25,3	94,8	41,7	1	57,3	19.843
Day hospital	6,7	66	0	6,2	11,0	82,8	90,6	1,5	0	98,5	105
Home rehabilitation services	6,6	65	1,5	72,3	10,7	15,5	89,2	53,8	0	46,2	22.732
Rehabilitation not at home	3,2	32	0	37,5	18,1	34,4	90,6	43,8	0	56,3	11.351
Integrated planning of care for OP and families (hospital/home)	2,5	25	0	0	8	92	91,7	0	0	100	0
Psychologist	2,0	20	0	20	40	40	70	10	0	90	1.920
Specialised diagnostic examinations	1,8	18	0	11	11,2	77,8	88,9	5,6	0	94,4	100
Long term residential health care	1,3	13	41,7	16,6	0	41,7	92,3	16,7	0	83,3	16.920
Other health, nursing and rehabilitation service	1,0	10	10	40	10	40	100	50,0	0	50,0	3.000
Home care for terminally ill patients	0,3	3	33,3	66,7	0	0	100	0	0	100	0

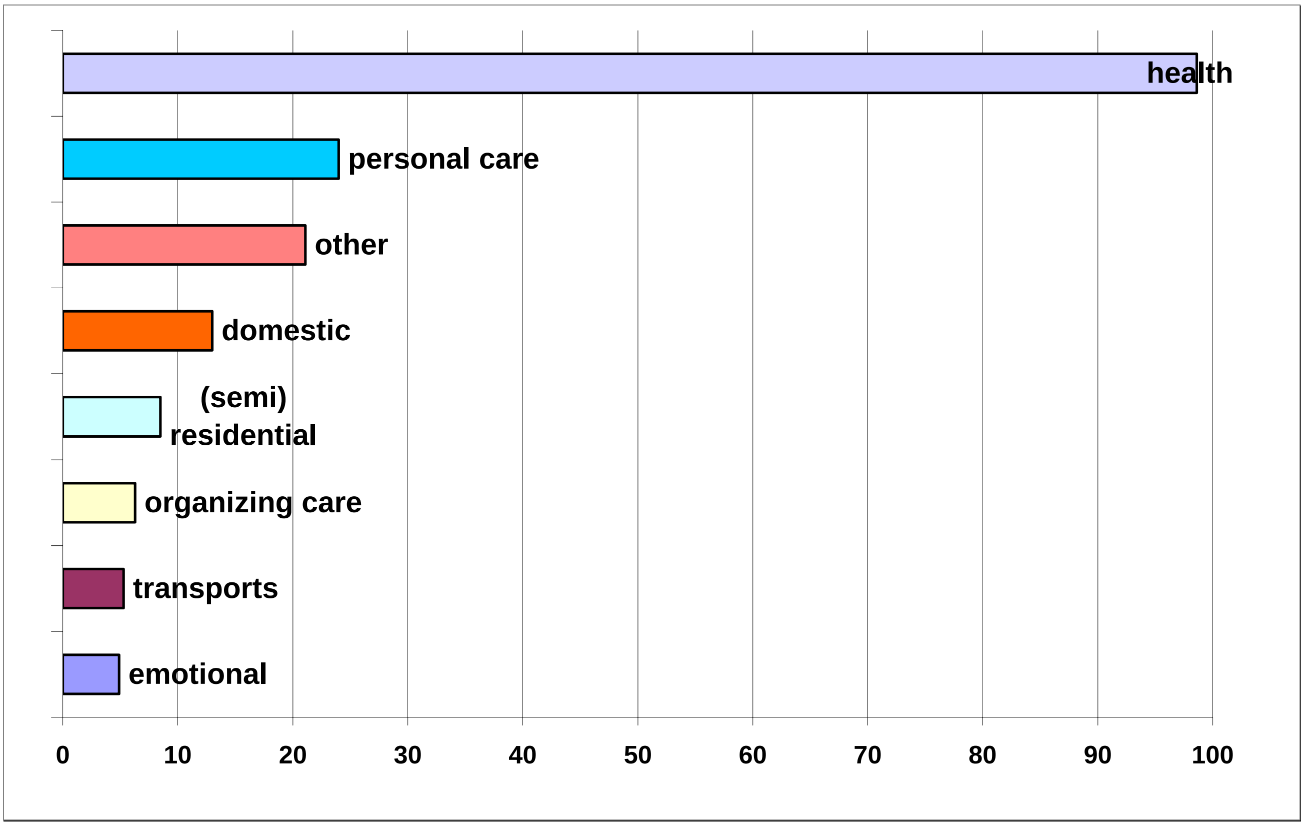
TABLE 7.2 Older people (OP) by services used, frequency of use, satisfaction and costs											
	USE		**Frequency**				**Mostly meets needs**	**Contribution of users to payment of services costs (% of users)**			**Amount paid in the last 6 months**
	% total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	% of users	Completely paid	Partially paid	Not paid	Euros/total sample
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**L**	**M**
Social services											
Technical aides	19,8	196	90,7	1,1	4,1	4,1	94,4	18,0	9,7	72,3	50.771
Day private care for cleaning home environment	10,6	105	22	71	5	2	100	100	0	0	89.834
Cohabitant private helper	10,0	99	100	0	0	0	97,7	99	0	1	385.643
Hairdresser at home	7,9	78	0	10,4	50,6	39	100	93,6	0	6,4	7.067
Social worker	6,4	63	0	3,2	29	67,8	82	0	0	100	0
Day private care for elder's personal care	6,4	63	41,3	53,9	3,2	1,6	98,3	98,4	0	1,6	90.254
Podiatrist	5,5	54	0	1,9	44,4	53,7	90,4	87	0	13	5.979
Transport	5,3	52	3,9	25,5	13,7	56,9	92	64,7	2	33,3	5.266
Government provided home help for elder's personal care	3,7	37	21,6	70,3	2,7	5,4	93,9	25	0	75	3.162
Permanent nursing home	3,2	32	96,9	0	0	3,1	90,6	96,4	0	3,6	202.898
Care attendant/sitter for the elder	2,2	22	13,6	68,2	4,6	13,6	95	63,6	0	36,4	12.592
Day care centre	2,0	20	20	55	5	20	85	60	0	40	20.719
Meals on wheels	1,8	18	50	27,8	11,1	11,1	100	72,2	0	27,8	4.129
Government provided home help for cleaning home environment	1,6	16	6,7	79,9	6,7	6,7	93,3	12,5	0	87,5	816
Respite care home/Temporary nursing home	1,1	11	9,1	9,1	0	81,8	81,8	90,9	0	9,1	15.765
Security alarm systems	1,0	10	30	20	10	40	100	50	0	50	62

TABLE 7.2 Older people (OP) by services used, frequency of use, satisfaction and costs

	USE		**Frequency**				**Mostly meets needs**	**Contribution of users to payment of services costs (% of users)**			**Amount paid in the last 6 months**
	% total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	% of users	Completely paid	Partially paid	Not paid	Euros/total sample
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**L**	**M**
Night private care in hospital or nursing home	0,8	8	25	12,5	0	62,5	100	100	0	0	7.734
Night private care at home	0,6	6	50	33,3	0	16,7	100	100	0	0	17.000
Recreational social centre	0,6	6	0	50	0	50	100	50	0	50	1.160
Counselling	0,5	5	0	0	20	80	80	20	0	80	36
Support from voluntary organ.	0,5	5	0	60	0	40	100	0	0	100	0
Laundry service	0,3	3	0	66,7	0	33,3	100	100	0	0	1.440
Removal of architectural barriers	0,2	2	0	0	0	100	50	100			nr
Day private care in hospital or nursing home	0,2	2	0	50	0	50	100	100	0	0	5.400
Sheltered housing	0,1	1	100	0	0	0	100	100	0	0	7.800
Help lines provided by charities	0,1	1	0	0	100	0	100	0	0	100	0
Other social services for elders	0,8	8	12,5	50	12,5	25	100	37,5	0	62,5	460
TOTALS							**82,9**	**1,7**	**55,7**	**42,6**	**1.080.842**

When looking at services used by older people classified in terms of spheres of needs they are supposed to cover (Figure 7.3), it becomes evident that almost the totality of elders used services belonging to the health area (like GP, medical specialists, hospital care, nursing care, rehabilitation etc). By contrast, personal care services (private or public home carers, hairdresser at home) are used by one out of four elder, those for fulfilling domestic needs (home cleaning service, meals on wheels, laundry service) by 13% of them, while services covering other areas of need reach less than 10% of elders each.

Figure 3: Older people by spheres of needs covered by used services (%, N=990)



The average number of services used by either the elderly and their carers as well as their cumulated number was computed for each of the 6 cross-nationally relevant caregiving situations[10] (as defined in Chapter 6), and results are presented in Table 7.3. The findings show that belonging to a peculiar caregiving situation (or cluster) influences the number of services used by the older person as well as by the carer. The average amount of services used by older people (mean 3.7) is

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[10] The first two situations are dominated by carers with high objective (elders show high levels of cognitive as well as physical impairment) and subjective burden and they differ in that carers in the first group are not working. Cluster three and four are characterised dyads of caregiver and cared for from the same generation, who live in the same house, who in the great majority are partners. The main difference is that in cluster three the carer is predominantly a women and in cluster four the carer is a men, while carer’s subjective and objective strain are high. Additionally we found two groups that both mentioned that they can find support if they need it. They differ in the fact that one group has objective strain but no subjective and the other has relatively less strain both subjectively and objectively. Carers included in cluster five have minor subjective strain and high objective strain, and they can easily find help if ill. Finally, group 6 includes those caregiving situations with less intense strains on all concerned.

highest (4.5) in case of elders with a serious physical and cognitive disability assisted by overburdened and working carers (cluster 2), and lowest (2.6) for older persons affected by light disability only and cared for by carers presenting low burden and high life satisfaction (cluster 6). Multiple comparisons (performed using the non parametric K-W test) reveal statistically significant differences in terms of mean number of services used by elder between the caregiving situation 6 and clusters 1, 2, 3 and 5, as well as between clusters 4 and 5.

Table 7.3 Average number of services used by elder, carers or both by type of caregiving situations

	Care situation (cluster number)						All
Services used by*:	1	2	3	4	5	6	
a) Carers	0.29	0.31	**0.49**	0.42	0.25	0.27	0.31
b) Older persons	3.63	**4.53**	4.08	3.72	3.80	2.61	3.72
c) Both	3.92	**4.84**	4.57	4.14	4.05	2.88	4.02

*: Kruskal-Wallis test: a) CHI^2 (5) = 57.35; P<.001; b) CHI^2 (5) = 55.83; P<.001; c) CHI^2 (5) = 13.25; P < .05

With regard to services for carers, the highest use is recorded in correspondence of overburdened carers living together with an older person of the same ages (clusters 3 and 4), such as for instance a spouse or a sibling. A significant different was also recorded in terms of mean number of services used by the carer between clusters 1 and 6.

When services used by carers are summed to those used by elders, the highest service use is observed in care situations characterised by overburdened working carers (cluster 2) and the lowest in case of less burdened carers, statistical differences being recorded between cluster 1 and 2 as well as between situation 6 and all other clusters.

The average number of services used by persons belonging to each care situation can also be considered with respect to the spheres of needs services are supposed to fulfil (table 7.4). Generally speaking, we can observe that the highest service use is recorded in cluster 2 (especially to respond to health, personal/physical, emotional residential care needs) and cluster 3 (more focused on services for carers, transports and organisational needs). Domestic care and generic services for carers are instead principally used by people belonging to cluster 4.

7.3.1.2 Allowances

The number of carers receiving allowances, benefits or financial support related with the caring situation is extremely low, accounting for only 6 carers in the whole Italian sample stating they are receiving a care-related allowances from local authorities (n = 3) or other kinds of allowances or fiscal benefits for elder care related expenses (n = 3).

This is because financial supports of caregiving situations are in Italy mainly addressed to the older person. EUROFAMCARE data confirm this, since over one third (35.7%) of all cared-for people receive some kind of financial support or allowances related to the caring situation. Allowances are

Table 7.4 Average number of services used for each sphere of need by care situations

	Care situation (cluster number)						All
CARERS:	1	2	3	4	5	6	
Specific services	0.02	0.05	**0.09**	0	0.02	0	0.03
Generic services	0.28	0.26	0.40	**0.42**	0.23	0.27	0.28
ELDERS:							
Health needs	2.42	**2.95**	2.89	2.56	2.59	2.38	2.61
Personal physical needs	0.29	**0.50**	0.26	0.34	0.36	0.03	0.30
Transports	0.04	0.08	**0.09**	0.04	0.06	0	0.45
Emotional needs	0.05	**0.09**	0.08	0.08	0.05	0	0.05
Organizing care	0.07	0.08	**0.13**	0.1	0.05	0.01	0.07
Domestic needs	0.12	0.17	0.10	**0.26**	0.17	0.08	0.14
(Semi) Residential care	0.11	**0.16**	0.09	0.06	0.10	0.01	0.10
Other	**0.51**	0.45	0.41	0.28	0.41	0.09	0.38

in Italy either disability-related or care-related, the latter being principally provided by the State and to a much lower (although growing) extent by local authorities. The EFC survey's findings show in fact (Table 7.5) significantly higher percentages of older people receiving care-related (29,5%) and/or disability-related (12,2%) allowances from the State, compared to those receiving other types of financial support (2,8%), the average amount of these allowances (excluding people not receiving any benefits) being 453,10 Euros per month.

Table 7.5 Older people by care allowances received*

	%	absolute value
Disability-related allowances from the State	12,2	121
Care-related allowances from the State	29,5	292
Care-related allowances from local authorities	1,6	16
Other allowances of fiscal benefits	1,2	12
Mean	453,10 (SD ± 152)	
Median	420	

*: the different kinds of allowances can be cumulated

7.3.2 Family carers' experience in using services

7.3.2.1 Cost of services

Most Italian carers using services do not pay anything for them (72,6%), and this is partly explained by the fact that the most used service is the GP, which is in Italy completely funded by the National Health System (Table 7.6). Only 10% of carers have paid on average less than 20 Euros per month, and 8,5% more than 20 Euros monthly.

TAB 7.6 Carers by cost of services used in the last 6 months

	Frequency	%	Valid %
No costs	154	15,6	72,6
From 1 to 120 € (less 20 € per month)	22	2,2	10,4
Over 120 € (more than 20 € per month)	18	1,8	8,5
Unknown amount	18	1,8	8,5
Total	**212**	**21,4**	**100**
Do not use services	778	78,6	
Total	**990**	**100**	

The overall expenses borne by Italian carers to cover the cost of services used in the last 6 months (see Table 7.1, column M) account to 19.490 Euros, mainly ascribing to costs for specialist doctors (47%), regular respite services at home (22%, born by one user only) and for private housekeepers (21%).

Almost half of the elders using services have not paid for them (42,6%) or have paid low sums (12,2%, less than 20 Euro per month). Not few are, however, those who have paid considerable amounts of money (11,3% from 100 to 500 Euro on average per month and 12,8% even more) (table 7.7).

Table 7.7 Older people by cost of services used in the last 6 months (absolute value and %, N = 988)

	Absolute value	%
No costs	421	42,6
From 1 to 120 € (less than 20 € per month)	121	12,2
121 - 300 € (21-50 € per month)	86	8,7
301 - 600 € (51-100 € per month)	54	5,5
601 - 3.000 € (101-500 € per month)	112	11,3
Over 3.000 € (more than 500 € per month)	126	12,8
Unknown amount	68	6,9
Total	**988**	**100**
Mean value of costs born by older people in the last six months: 2.166 Euros (SD ± 3.393)		

Considering the services used by older people in the last 6 months, the overall expenses borne either by elders or by carers account to 1.080.842 Euro in total, of which more than a third covers the costs for cohabitant private helpers (35,7%) and almost a fifth cover the cost for nursing homes (18,8%). Other services used by older people that have required remarkable financial effort are (Table 7.2, column M): private housekeepers (8,7%), day private care for elder's personal care (8,4%), specialist doctors (5,7%) and technical aids (4,7%). It should be noticed that these services, which account for the highest quota of the total care expenses, are also less financially covered (neither partially nor totally) by the Italian care system (Table 7.2, columns H, I and L).

Table 7.8 illustrates the additional financial costs borne in relation to the elder's care needs, apart from those already mentioned for accessing care services. Almost every second household bears additional costs due to buying the necessary medicines for elder, while a second significant source of expenses is represented by transportation costs (26.6%), followed by the costs to adapt the older person's home or furniture (17.3%) and to buy him/her special food (9.5%).

Table 7.8 Carers by type of additional financial costs born as the result of the caring situation (%, N = 989)

Medicines	47,4
Travel costs	26,6
Adaptation of the home environment and/or furniture	17,3
Special food	9,5
Other	14,3
Total	**100**

7.3.2.2 Experiences in accessing services

Carers have been also asked to list the three most important sources of help in accessing services or support for caring for elderly people. Their answers have been collected in free text and then post-coded on the basis of the most frequent typology of answers.

Both when only the first answer listed is taken into account and when all the three most relevant categories are considered, the two most important sources of help for Italian carers result to be medical/nursing professionals, on the one hand, and the family, friends and neighbours, on the other hand (Table 7.9). This confirms the importance, in Italy, of both GPs (the main gate-keepers in accessing other health care services) and the informal care network in supporting individuals to find solutions for caring for themselves or their relatives in case of need. Social services seem to play a much less relevant role in the opinion of carers, while it is worth mentioning that 6% of carers have received (or needed) no help for accessing services.

Carers have been also asked to list the three most important barriers or difficulties in accessing services or support for caring, and their full answers have been post-coded on the basis of the most frequent typology of answers. Interestingly, for a considerable group of carers (26,1%) there

Table 7.9 In your experiences as caregiver, who or what do you consider to have been the greatest help to you in accessing services/support? (absolute values and %, N=899)

	First listed		On the whole	
	%	Abs. V.	%	Abs. V.
medical/nursing professionals	43,7	393	50,5	454
family, friends and neighbours	21,6	194	31,3	281
social services	7,0	63	9,6	86
carer's personal experience and knowledge	6,0	54	8,0	72
no one, nothing	5,9	53	6,0	54
NGOs, voluntary organisations, support groups	2,6	23	5,0	45
information/advertisement in mass media, leaflets	2,4	22	4,0	36
financial resources/savings	1,4	13	2,0	18
local authorities	1,0	9	3,2	29
trade unions, workers organisations	1,0	9	1,4	13
religious organisations	0,7	6	1,2	12
don't know, never tried to access services	0,7	6	0,7	6
counselling agencies, centre of information	0,4	4	0,7	6
availability of services nearby	0,2	2	0,3	3
good transports	0,1	1	0,2	2
health and social insurance	-	-	0,1	1
other	5,2	47	8,1	73
Total	**100**	**899**	**100**	**899**

are no barriers or difficulties in accessing services. Bureaucratic or complicated procedures (23,4% - first answer; 28,0% – three answers), lack of information concerning the existence or how to access to service (11,4% - first answer; 14,6% – three answers) and long waiting lists (8,1% - first answer; 10,6% – three answers), have been mentioned by Italian carers as the most important difficulties in accessing services, followed by financial reasons or high costs of services (4,4% - first answer; 7,6% – three answers) and poor quality of services (4,7% - first answer; 6,5% – three answers), to a lower extent (table 7.10).

7.3.2.3 Reasons for stopping using needed services

A little but worth mentioning percentage of carers (8.5%) declared that some services that themselves or the older persons still needed have been stopped using (table 7.11).

Table 7.10 In your experiences as a caregiver, who or what do you consider to have caused the greatest difficulties to you in accessing services/support?
(absolute values and %, N=790)

	First listed		On the whole	
	%	Abs. V.	%	Abs. V.
No one, nothing	26,1	206	26,1	206
Bureaucratic/complicated procedures	23,4	185	28,0	221
Lack of information on existence/access to service	11,4	90	14,6	115
Long waiting lists	8,1	64	10,6	84
Poor quality of services	4,7	37	6,5	51
Financial/economic reasons, high costs	4,4	35	7,6	60
Not accepted by the elderly	3,2	25	3,4	27
Distance	2,9	23	4,8	38
Don't know, never tried to access services	1,8	14	1,9	15
Restricted acceptance criteria	1,6	13	2,0	16
Fixed/inflexible time schedules from the service side	1,0	8	1,9	15
Few available services	0,9	7	2,7	21
Other	10,5	83	14,9	118
Total	**100**	**790**	**100**	**790**

Table 7.11 Are there any services that you or elder still need that you have stopped using? (%; N = 990)

Yes	8,5
No	91,5
Total	**990**

In this respect, the only service that has totalled a significant number of answers was “home rehabilitation” (37,8% of respondents), the main reasons for stopping using it being the high costs and the low quality (Table 7.12). Taking into account the ratio between the number of people who have stopped using each service and the number of the people who have used that service in the 6 months prior to the interview plus those who have ceased using them, it can be also observed that about one third of all people receiving home rehabilitation service have stopped using it. In general, the main reasons for stopping using services still needed are the high costs (29,3% of respondents), the fact that the services were not available any longer (26,8%) and their low quality (19,5%).

Table 7.12 Carers by types of services stopped using and reasons for this

(%, absolute value, multiple answers possible; N = 82)

Service	%	Abs. V.	Service users ratio* (%)	Reasons for stopping using services				
				Expensive	Distant	Low quality	No more available	No longer entitled
Home rehabilitation services	37,8	31	32,3	32.3	9.7	19.4	9.7	9.7
Specialist doctor	8,5	7	1,3	42.8	14.3	14.3		14.3
Home nursing services	8,5	7	6,8	28.6	-	14.3	28.6	28.6
Other health, nursing and rehabilitation service	6,1	5	33,3	20	-	-	40	20
Government provided home help for elder's personal care	6,1	5	11,9		-	40	40	-
Day care centre	6,1	5	20	40		20	20	
Recreational social centre	6,1	5	45,5	20	20		40	20
Diagnostic tests at home	4,9	4	2,7	25		25	25	25
Integrated planning of care for elderly and families (in hospital or at home)	3,7	3	10,7	-	-	-	66.7	-
Respite care home/Temporary nursing home	4,9	3	21,4	33.3	-	33.3	-	-
Technical aides	3,7	3	1,5	33.3	-	33.3	33.3	-
Government provided home help for cleaning home environment	3,7	3	15,8	-	-	33.3	66.7	-
General hospital	2,4	2	1	-	50	-	-	50
Long term residential health care	2,4	2	13,3	-	-	50	-	-
Meals on wheals	2,4	2	10	-	-	-	-	50
Transport	1,2	1	1,9	-	-	-	-	-
Hairdresser at home	1,2	1	1,3	-	-	-	100	-
Care attendant/sitter for the elder	1,2	1	4,3	-	-	-	-	-
Social worker	1,2	1	1,6	-	-	-	100	-
Day private care in hospital or nursing home	1,2	1	33,3	-	-	-	100	100
Cohabitant private helper	1,2	1	1	100	-	-	-	-
Day private care for elder's personal care	1,2	1	1,6	100	-	-	-	-
Training course in caring	1,2	1	16,7	-	-	-	100	-
N=	**100**	**82**		**24**	**6**	**16**	**22**	**12**
%				**29,3**	**7,3**	**19,5**	**26,8**	**14,6**

*: ratio computed, for each service, as follows: n° of people who stopped using a service / (n° of people who stopped using that service + current users of that service).

7.3.2.4 Reasons for not using some needed services

One carer out of three has stated that he/she or the cared for elder have never used some services, although these would have been needed (Table 7.13).

Table 7.13 Are their any services that you or elder need but have not used so far? (%; N = 989)	
Yes	31,9
No	68,1
Total	**100**

The most frequently mentioned service among those never used (but felt they would be "needed") is "care attendant for elder" (23%), that is not used principally because the carer did not know that it existed and secondly due to financial reasons (Table 7.14). The publicly paid "housekeeper" (i.e. home help for cleaning the home environment) or "personal care for elder" have not been used by about 12% of the respondents each, mainly due to the lack of knowledge about their existence (31,6% and 41,7% respectively) and to the fact that the elder was not entitled to receive them (36,8% and 22,2% respectively). "Home nursing services" and "home rehabilitation services" were both not used by about one out of ten respondents, mainly for financial reasons, thus indicating that people may be sometimes forced to resort to private providers of this kind of services, which are provided by the public sector under restricted admission criteria. Other services report by lower percentages of respondents.

Table 7.14 Services never used and reasons (%; N = 314; multiple answers)

Service	**%**	Abs. value	Reasons for never use services				
			Expen-sive	Distant	Low quality	Don't know it exists	Not entitled
Care attendant/sitter for the elder	22,9	72	19,4	2,8	6,9	37,5	11,1
Publicly paid housekeeper	12,1	38	15,8	2,6	2,6	31,6	36,8
Publicly paid personal care for elder	11,5	36	8,3	0	2,8	41,7	22,2
Home nursing services	9,6	30	56,7	0	0	20,0	16,7
Home rehabilitation services	9,2	29	34,5	6,9	10,3	27,6	10,3
Recreational social centre	8,3	26	7,7	26,9	11,5	30,8	11,5
Technical aides	8,0	25	20,0	0	0	52,0	12,0
Day private housemaid	7,6	24	45,8	4,2	4,2	8,3	16,7
Diagnostic tests at home	7,3	23	47,8	0	4,3	21,7	13,0
Transport	7,0	22	36,4	4,5	0	27,3	13,6
Private personal care for older person	6,4	20	55,0	0	0	20,0	10,0
Podiatrist	6,1	19	5,3	5,3	0	52,6	10,5
Cohabitant private helper	5,7	18	61,1	5,6	5,6	11,1	11,1

Hairdresser at home	5,4	17	29,4	5,9	0	41,2	5,9
Integrated planning of care for elderly and families (in hospital or at home)	5,1	16	0	0	0	87,5	12,5
Day care centre	4,5	14	14,3	7,1	7,1	14,3	28,6
Security alarm systems	4,1	13	23,1	0	0	61,5	0
Respite care home/Temporary nursing home	3,8	12	33,3	0	8,3	8,3	25,0
Social worker	3,8	12	0	0	0	33,3	16,7
Regular respite service at home, supervision of the elder person at home for some hours per day, each week	3,5	11	18,2	0	0	54,5	9,1
Psychologist	3,2	10	60,0	10,0	0	30,0	20,0
Meals on wheals	3,2	10	0	0	0	40,0	10,0
Removal of architectural barriers	3,2	10	30,0	0	10,0	0	30,0
Laundry service	2,9	9	33,3	0	0	44,4	11,1
Night private care at home	2,5	8	87,5	0	0	0	0
Counselling	2,2	7	28,6	14,3	0	85,7	0
Temporary respite service at home, supervision of the elder person at home for limited periods (ex. For one week)	2,2	7	14,3	0	0	71,4	0
Specialist doctor	1,3	4	25,0	0	0	0	25,0
Day hospital	1,3	4	0,0	50,0	25,0	0	0
Permanent nursing home	1,3	4	75,0	25,0	0	0	25,0
Help lines provided by charities addressed to elderly people	1,3	4	0	0	0	100	25,0
Relative support or self-help groups	1,3	4	0	0	0	100	0
Tele-medicine	0,6	2	0	0	0	100	0
Sheltered housing	0,6	2	50,0	0	0	0	0
Help lines provided by charities addressed to family carers	0,6	2	50,0	0	0	50,0	0
Management of crises	0,6	2	0	0	0	50,0	50,0
Home care for terminally ill patients	0,3	1	0	0	0	100	0
Medications	0,3	1	0	0	0	0	100
Private care in hospital or nursing home	0,3	1	0	0	0	0	0
Training course in caring	0,3	1	0	0	0	100	0
Formal standardised assessment of the caring situation	0,3	1	0	0	0	100	0
Other social services for elders	2,2	7	0	14,3	14,3	28,6	28,6
Total	**100**	**314**	**49,0**	**7,6**	**6,7**	**63,4**	**27,7**

7.3.2.5 Reasons for not accessing formal services

In order to explore the reasons for non-usage of services (Table 7.15), carers have been asked to list the three currently most important reasons for not accessing services[11]. Both when only the first answer listed is taken into account and when all answers are considered, the most frequent reasons for not accessing services are the lack of need, the lack of knowledge/information, the personal attitude by the elder or the carer and the high costs of support services.

Table 7.15 For which reasons do you and/or elder not access services?
(%, absolute values; N = 177)

Reasons	First answer		All answers	
	%	Abs. V.	%	Abs. V.
Not needed/necessary	47,5	84	49,7	88
Lack of knowledge/information	10,2	18	12,4	22
Social/attitudinal reasons by elderly or carer	8,5	15	12,4	22
Financial reasons, high costs	7,3	13	10,2	18
Difficult access, mobility problems, barriers	2,8	5	3,4	6
Lack of trust to service workers/providers	2,8	5	5,1	9
No right to use	2,8	5	2,8	5
Not available	1,1	2	4,5	8
Distance	1,1	2	1,7	3
Poor quality of services	0,6	1	2,8	5
Complicated bureaucratic procedures	0,6	1	3,4	6
Long waiting lists			0,6	1
Other	14,7	26	16,9	30
Total	**100**	**177**	**100**	**177**

7.3.3 Do these services reach the carers and the older people in need of support?

Older person's needs have been synthesised in 8 spheres: health needs (e.g. help in taking medicine, medical treatment, rehabilitation, therapy, etc.); physical/personal needs (e.g. washing, dressing, eating, using the toilet); mobility/locomotion (e.g. help in moving around the house and outside, transports, etc.); emotional/psychological/social needs (e.g. company, comforting); domestic needs

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[11] There is no direct correspondence between the answers to this question and the number of services used in the 6 months prior to interview, since it may happen that no services were used at the moment of the interview and that some services had been used either by the elder or by the carer during the 6 months before the interview, so at least one service has been listed among those used. Moreover, several carers have referred to social services in answering to this question and have excluded health services and this can be derived both by the free answers given and by the fact that several GP users have answered to this question. Considering this interpretation, this question may be considered as the perception of the carer of not receiving support services for caring.

(housekeeping); financial management (e.g. paying bills with the older person's money); financial support (e.g. providing the older person with money); organizing and managing care and support (e.g. selecting services, keeping contacts with services providers).

The interviewed carer was asked to indicate whether the older person needed help within the above mentioned areas and, in this case, who of the following categories of subjects helped him/her to meet these needs: the interviewed carer him-/herself; other informal carers; formal services (voluntary, private or public organizations providing help); none of the above. Finally, carers were asked to express their opinion whether they would like the older person to receive more help in each area of needs. Table 7.16 shows the results of this analysis, which indicate that the main spheres of needs are in the fields of emotional care, domestic care, mobility and organizational and financial management. The lowest percentage of people in need of help is scored by financial support (41.6%), while health (86.4%) and personal care (78.4%) are at an intermediate-high level.

Table 7.16 Spheres of needs of care recipient and informal/formal support network

Area of need	Elderly requiring help in this area		Help is provided by:								Elderly needing more help	
			Nobody		Carer		Other informal carers		Service/Support orga-			
	N	%	n	%	n	%	n	%	n	%	n	%
Emotional needs	944	95.5	2	0.2	927	98.2	515	54.6	134	14.2	443	46.9
Domestic	941	95.4	4	0.4	725	77.0	363	38.6	223	23.7	405	43.0
Mobility	935	94.4	2	0.2	874	93.5	432	46.2	162	17.3	410	43.8
Organizational management	930	94.2	7	0.8	899	96.7	297	31.9	46	4.9	339	36.5
Financial management	905	91.7	2	0.2	839	92.7	331	36.6	17	1.9	204	22.5
Health needs	855	86.4	12	1.4	728	85.1	308	36.0	213	24.9	394	46.1
Personal care	773	78.4	12	1.6	663	85.8	335	43.3	188	24.3	330	42.7
Financial support	409	41.6	48	11.7	322	78.7	92	22.5	27	6.6	252	61.6

Most older persons can rely on somebody to satisfy their needs, except for financial support, since almost 12% of people needing this kind of help have no one who provides it to them. This data, when considered in combination with the highest percentage of carers that would require more help for financial support to the OP (61,6%), identifies financial support as one of the most critical sphere of need for Italian elders, despite it totalised the lowest percentage of older persons needing help in this respect.

Overall, the support provided by the **main carer** for each sphere of need exceeds the support provided by other informal carers and by formal services. The carers are particularly involved in helping the older person with emotional needs, organizational management, mobility and financial management (more than 90%), while they are relatively less involved in domestic tasks and financial support (less than 80%). **Other informal carers** give their help in particular for fulfilling the elder's emotional (54.6%), mobility (46,2%) and personal care needs (43,3%). To a lower extent, **professional services** are mostly used in case the older person needs assistance with health, personal and domestic care (around 24%), all spheres for which the support provided by the main carers is lower than that provided for other spheres, so that the need for extra support is quite high (around 43-46%).

With regard to the additional support that the main carers consider to be necessary to better meet the older persons' needs, the most often mentioned sphere is financial support, followed by emotional and health needs, mobility and domestic care; these could therefore be regarded as the areas in which the care network is currently less efficient in providing help.

Combining the opinion of carers regarding the need of additional support for each area of older people's needs and the service use by the older person in that area (Table 7.17), we can observe that over 10% need more help in the health and personal care spheres, although they already receive services in that area and decreasing percentages are observed for domestic, emotional and mobility needs. On the other hand, about 13-14% of OP receiving services in the spheres of personal, domestic or health care do not need any additional support. Turning to uncovered needs by services, it emerges that almost 60% of elderly people needing additional financial support do not receive any service in this sphere, followed by emotional needs (42%). For all other spheres of need, except for financial management, about one out of three elders requiring additional help does not receive any service addressing it.

Table 7.17 Distribution of older people for each area of needs respect the combination of additional help needed in the opinion of carers and receipt of service (%; N = 850)

	Additional help needed		**Additional help not needed**		**N**
Area of needs	**services received**	**services not received**	**service received**	**services not received**	
Health needs	11.9	36.2	13.1	38.9	818
Personal care	10.3	34.5	14.0	41.2	737
Domestic	9.6	35.6	13.8	41.0	899
Emotional needs	7.1	42.0	7.2	43.6	899
Mobility	6.0	39.9	11.0	43.1	893
Financial support	4.5	59.6	2.2	33.7	403
Organizational management	2.6	36.4	2.4	58.5	870
Financial management	0.7	23.2	1.3	74.8	850

The use of services may be combined with 6 different care situations, which have been developed by a cluster analysis (as described in detail in chapter 6). Considering the percentage of service users in the different care situations and only services mentioned by at least 50 persons (Table 7.18), we can observe that GPs and Specialist doctors have been used by all groups, the latter comparatively less used by older persons cared for by non working burdened family members (cluster 1). Cohabitant private helpers are more often used by working and burdened carers (cluster 2), whereas technical aids are more asked by elders cared by non working burdened carers (cluster 1) and less asked by those belonging to caregiving situations characterized by less intense strain (cluster 6). Carers using specific services are so few that the only possible comment that can be formulated in this respect is that they are mostly concentrated among female burdened spouses (cluster 3).

Table 7.18 Utilisation of services by elders and carers differentiated by care situation
(%; only services mentioned by at least 50 cases)

	Care situations						All
	1	2	3	4	5	6	
Health nursing services used by older persons							
GP	94.2	93.8	93.1	90.0	96.2	94.4	94.2
Specialist doctor	47.7	60.1	50.6	60.0	57.3	59.6	55.4*
General hospital	17.4	22.6	28.7	20.0	20.0	12.9	19.4
Diagnostic tests at home	19.9	17.8	17.2	16.0	13.5	3.9	14.8*
Laboratory tests	9.1	16.3	16.1	10.0	16.2	17.4	14.3
Home nursing services	10.4	13.0	14.9	12.0	10.8	0.6°	9.7*
Home rehabilitation services	4.1	9.1	11.5	6.0°	4.9	3.4	6.0*
Social services used by older persons							
Technical aides	28.2	22.1	23.0	10.0	22.2	5.1	19.9**
Cohabitant private helper	6.6	22.1	4.6°	12.0	11.9	1.1°	10.1**
Hairdresser at home	9.1	11.1	6.9	8.0	10.8	1.1°	8.1*
Day private care for personal care	5.8	10.6	8.0	6.0°	7.0	0°	6.2
Social worker	8.3	7.7	10.3	10.0	4.9	1.1°	6.4*
Podiatrist	5.8	9.1	3.4°	8.0°	5.4	1.7°	5.6*
Transport	4.1	7.7	8.0	4.0°	5.9	0°	4.8*
Services used by carers							
GP	16.2	13.0	21.8	22.0	15.1	18.5	16.5
Specific services for carers	1.2°	3.8	5.7	0°	1.1°	0°	1.9*
N =	**241**	**208**	**87**	**50**	**185**	**178**	**949**

* p < .05; PHI < .20; ** p < .05; PHI > .20; ° cells with less than 5 users

It can be supposed that the use of services by older people is linked, among other variables, both to their functional and behavioural status, as it can be also inferred by comparing the mean values of the Barthel Index (BI), the IADL scale and the behavioural problems scored by users and non users of certain services (Table 7.19).

The findings reveal that the use of almost all services considered is associated to lower Barthel Index scores, and higher values in IADL, both indicating more severe functional impairment. An exception is represented by services that are provided outside the home environment, such as specialist doctors and laboratory tests, for which users are less impaired than non-users. This is probably linked to the fact that being in fine fettle facilitates the movements that are necessary to reach those services provided outside the home environment. As for medical/nursing services, older people using “Home nursing services” are the most impaired in IADL, followed by “diagnostic test at home” and “home rehabilitation service” users. As for social services, the most impaired in IADL are, in decreasing order, those using “day private carer for personal care”, “cohabitant private helpers” and “technical aids”.

Considering the indicator of behavioural problems the general trend shows that older persons using services, either medical/nursing or social ones, score higher number of problems than non-users. This reveals that the higher number of behavioural problems may be considered as a predictor of services demand. Older people scoring the highest number of behavioural problems are those using “social workers”, “cohabitant private helpers”, “day private carers for personal care” and “podiatrists”. No statistical differences are instead recorded in the mean values of both older people’s functional status and behavioural problems between GP users and non-users, neither older people nor carers.

Table 7.19 Mean values of dependency and behavioural problems of elders using and not using certain services.

	BARTHEL INDEX° mean = 63		IADL° mean = 3,1		Behavioural Problems° mean = 2,2	
Health nursing services	users	non-users	users	non-users	users	non-users
Home nursing services	34.4**	66.2**	4.8**	2.9**	2.8*	2.1*
Rehabilitation at home	43.9**	64.4**	3.9*	3.1*	n.a.	n.a.
Diagnostic tests at home	48.4**	65.6**	4.3**	2.9**	2.8*	2.1*
GP	55.4	63.5	3.1	3.4	2.2	2.1
General hospital	55.7**	64.9**	3.5*	3*	n.a.	n.a.
Specialist doctor	67.3**	57.8**	2.9**	3.4**	n.a.	n.a.
Laboratory tests	68.9*	62.1*	2.7*	3.2*	n.a.	n.a.
Social services						
Day private care for personal care	35.1**	65**	4.7**	3**	3.3**	2.1**
Technical aides	41.2**	68.5**	4.4**	2.8**	2.9**	2**
Hairdresser at home	43.1**	64.7**	4.3**	3**	3.1*	2.1*
Cohabitant private helper	41.8**	65.4**	4.6**	2.9**	3.4**	2.1**
Transport	46.5**	64**	4.2**	3.1**	3.1*	2.1*
Social worker	48.7**	64**	4.1**	3**	4.3**	2**
Podiatrist	53.2*	63.6*	n.a.	n.a.	3.3*	2.1*
GP used by carers	62.4	62.2	3.3	3.1	2.1	2.2

°: BI ranges from 0 (complete dependency) to 100 (independence); IADL scale ranges from 0 (independence) to 6 (complete dependency); Behavioural problems ranges from 0 (no problems) to 9 (maximum degree of problems)

*: p < .05; **: p < .001; n.a.: less than 50 users in at least one sub-group

7.3.4 Do services fit with the needs and demands of caregivers?

In general, carers are quite satisfied with services they used, which meet carers' needs in the great majority of cases (91,6%), while those used by the older persons meet the needs in lower percentage of cases (82,9%) (Tables 7.1, 7.2, column G, last row).

Among carers, "Psychologist" and "Training course in caring" have scored the lowest percentages of appreciation, as did "Social worker", "Respite care home/Temporary nursing home", "Counselling", "Psychologist", "Removal of architectural barriers" among older people.

7.3.5 Supports and characteristics of services considered important by caregivers

7.3.5.1 Family carers' view on importance and attainment of different types of support

Within the EFC survey, an exhaustive list of types of supports has been submitted to carers, who have been asked to state whether they considered each of them as "very important", "quite important" or "not important". A further question asked whether each type of support was received. A large part of carers highlights the importance of receiving information, in particular about the type of help and support available and how to access it (81%) as well as on the older person's diseases (72%), but only one third and half of carers respectively assert to receive these types of support (Table 7.20).

Table 7.20 Carers by importance attributed to different types of support and whether they are currently received (%; N= 990)

	Very important	Quite important	Currently receiving this support
Information/advice about available and accessible supports	81.0	14.6	33.3
Information about the disease that the older person has	71.7	22.5	52.4
Opportunities to have a holiday or take a break from caring	48.6	30.5	27.8
More money to provide things needed to give good care	48.6	29.4	11.4
Opportunities for elder to undertake activities they enjoy	47.6	29.1	14.8
Help with planning future care	46.0	33.2	15.6
The possibility to combine care giving with paid employment	44.8	18.4	22.0
Help to make elder's environment more suitable for caring	40.9	30.6	18.4
Training to help family carers develop skills needed to care	40.0	32.9	16.5
Opportunities to spend more time with their family	39.0	32.5	37.1
Opportunities to enjoy activities outside of caring	34.2	30.2	19.7
The opportunity to talk over their problems as a carer	30.6	43.3	27.7
Opportunities to attend a carer support group	20.7	35.1	7.7
Help to deal with family disagreements	19.6	30.9	16.4

Other supports, stated as very important by carers, are "more money for care", "holiday break from caring", "activities for elder", "help with planning future care", "help to combine employment with caring", with a percentage ranging from 49% to 45%. It should be highlighted that only the 43% of caregivers consider quite important the “opportunity to talk over their problems as a carer”, and that a lower 35% of them think the same about “opportunities to attend a carer support group”. To notice also that few carers receive the supports we have mentioned above, in particular "more money to help provide things they need to give good care", which is stated as very important by about the half of the carers interviewed, but received only by 11% of them.

When the first most important type of support (among those considered as "very important" by carers) is taken into account (Table 7.21), we observe that "information and advice about the type of help and support that is available and how to access it" receives the appreciation of the largest percentage of carers (38%), followed by "information on elder's disease" (12%) and by "more money" (10%). Lower percentages of carers give the highest importance to “holiday breaks from caring” (8%) and to “opportunities for the older persons to undertake activities they enjoy” (8%).

Table 7.21 Carers by type of support considered most important (%; N= 990)

Information/advice about available and accessible types of supports	37.8
Information about the disease that the older person has	12.0
More money to help provide things they need to give good care	10.1
Opportunities to have a holiday or take a break from caring	7.9
Opportunities for the older persons to undertake activities they enjoy	7.7
Help to make the older person's environment more suitable for caring	4.6
Help with planning future care	4.0
Training to help family carers develop the skills they need to care	3.7
The possibility to combine care giving with paid employment	3.5
Opportunities to enjoy activities outside of caring	2.2
Opportunities to spend more time with their family	1.5
The opportunity to talk over their problems as a carer	1.2
Help to deal with family disagreements	0.9
Opportunities to attend a carer support group	0.7
Missing	2.0

Territorial differences are quite evident, as for instance with regard to "Information about support available" (Table 7.22), i.e. the most important type of support by carers, which is considered as such especially in the North West Italy (47.4%) and in the Centre (42.6%), while “information about the disease that the older person has” (13.9%) and “more money for care” (14.2%) are more appreciated in the South and Islands.

Looking the types of support mentioned by carers in the different locality types (Table 7.23), it is worth mentioning that “more money for care” is considered particularly important in the rural settings (15.5%), while "Information about available supports" remains the mostly mentioned option in all locality types.

Table 7.22 Carers by types of support considered most important and macro-region
(first three options only, % by columns)

	North East	North West	Centre	South & Islands	Italy
Information/advice about available types of help and support and how to access them	37.8	47.4	42.6	28.4	38.6
Information about the disease of older person	8.8	12.6	12.7	13.9	12.3
More money for care	10.4	7.0	8.8	14.2	10.3
Totals (100%)	**193**	**270**	**204**	**303**	**970**

Table 7.23 Carers by types of support considered most important and locality type
(first three options only, % by columns)

	Metropolitan	Urban	Rural	Italy
Information and advice about the type of help and support that is available and how to access it	36.0	38.8	40.4	38.6
Information about the disease of older person	12.8	12.5	11.3	12.3
More money for care	11.3	7.9	15.5	10.3
Total (=100%)	**203**	**554**	**213**	**970**

7.3.5.2 Family carers' view on the importance and attainment of characteristics of services

Similarly to the above, a list of “service characteristics” has been prepared and the opinion of carers about their level of importance collected. The characteristics stated as “very important” by more than 90% of the sample are that "care workers treat older person with dignity and respect", that "help is available at the time it is need most", that "care workers have the skills and training they require" and that "help provided improves the quality of life of the older person" (Table 7.24). Carers assess as very important also the opportunity that “help arrives at the time it is promised” (87%) and that “help is not too expensive” (76%).

Table 7.24 Carers by service characteristics considered important and met (%; N = 990)

	Very important	Quite important	Currently being met
Care workers treat older person with dignity and respect	96.2	3.6	65.3
Help is available at the time they need it most	93.2	6.6	52.7
Care workers have the skills and training they require	92.8	7.0	62.4
The help provided improves the quality of life of the older person	92.6	7.0	59.6
Help arrives at the time it is promised	87.1	11.8	55.6
The help provided is not too expensive	76.3	21.4	38.9
Care workers treat carers with dignity and respect	73.9	22.3	66.5
Help focuses on both carer’s and older person’s needs	67.1	29.7	51.2
The help provided improves the carers’ quality of life	59.3	33.9	48.8

Carers views and opinions are listened to	59.0	37.9	61.7
The help provided fits in with carers own routines	55.5	36.0	43.6
Help is provided by the same care worker each time	48.6	35.9	39.5

In carers' opinion, services used mostly meet the following characteristics: "care workers treat older person or carer with dignity and respect" (66%), "care workers have the skills and training they require" and “carers opinions are listened to” (62%). On the contrary, the cost of services is considered as not too expensive by only 39% of carers.

“Help availability at the time the family carer need it most” is rated as the first most important characteristic of a service by carers (38%), followed by “respect for elder”, “training for care workers”, and that” help provided improves elder's quality of life” (17%, 16%, 8%) (Table 7.25).

Table 7.25 Carers by service characteristics considered most important (%; N = 990)

Help is available at the time they need it most	38.8
Care workers treat older person with dignity and respect	17.2
Care workers have the skills and training they require	16.6
The help provided improves the quality of life of the older person	8.4
Help arrives at the time it is promised	7.9
The help provided is not too expensive	3.5
Care workers treat carers with dignity and respect	1.7
Help focuses on the carers’ needs as well as those of the older person	2.2
The help provided fits in with carers own routines	1.3
Help is provided by the same care worker each time	1.1
Carers views and opinions are listened to	0.5
The help provided improves the carers’ quality of life	0.3
Missing	0.5

Furthermore, “Help availability at the time the family carer need it most” is considered the most important service characteristic in particular by carers living in the North West of Italy (43.4%) and in rural areas (40.4%), followed by “respect towards elder” – mostly appreciated by carers living in the North East (25.4%) and in urban sites (19%) – and by the fact that care workers are “skilled”, this prevailing in Central regions (22.9%) and metropolitan areas (19.5%) (Tables 7.26 and 7.27).

Table 7.26 Carers by services characteristics considered most important and by region
(first three options only, % by column)

	North East	**North West**	**Centre**	**South & Islands**	**Italy**
Help is available at the time the carers need it most	36.5	43.4	39.5	36.3	39.0
Care workers treat the elder with respect	25.4	18.4	12.9	14.1	17.3

Care workers are skilled	15.7	14.3	22.9	15.0	16.6
Totals (100%)	**197**	**272**	**210**	**306**	**985**

Table 7.27 Carers by service characteristics considered most important and by locality type (first three options only, % by column)

	Metropolitan	Urban	Rural	Italy
Help is available at the time the carers need it most	35.6	39.7	40.4	39.0
Care workers treat the elder with respect	17.6	19.0	12.4	17.3
Care workers are skilled	19.5	17.1	12.8	16.6
Totals (100%)	**205**	**562**	**218**	**985**

7.3.6 Where can support services be found?

The assumption of different patterns of service use and/or availability in the regions and locality that have been selected for carrying out the survey (see chapter 4), is confirmed by the analysis of the average number of services used in each Italian macro-area both by the family carer and by the cared-for elder. Data show that the use of services by older persons is more intensive in the Northern regions (the average number of services used being 4.92 in the North East and 3.76 in the North West) and less intensive in the Southern ones (average number = 2.98). Focusing on services used by carers, their use is highest in the Central regions (0.54 against 0.30 on average) (table 7.28).

Multiple comparisons performed after non parametric K-W test showed that the mean number of services used by carers as well as those used by older persons is significantly higher in Northern East regions and lower in Southern ones ($p < 0.05$). Moreover, the mean number of services used by carers is statistically higher in Central regions compared to Southern and Northern East ones, and in the Northern West regions compared to the Southern ones. As for older persons, those who live in the Northern East regions use, on average, more services than those living in other regions.

Table 7.28 Average number of services used by elder, carers or both by sub-areas

	Italian sub-areas				Italy
Services used by:	North East	North West	Centre	South-Islands	
a) Carers	0.23	0.32	**0.54**	0.17	0.30
b) Older persons	**4.92**	3.76	3.59	2.98	3.71
c) Both	**5.15**	4.08	4.13	3.15	4.02

Kruskal-Wallis test: a) CHI^2 (3) = 32.83; P<.001; b) CHI^2 (3) = 70.43; P<.001; c) CHI^2 (3) = 74.49; P<.001

As for the type of locality where carers live (metropolitan/urban/rural), the average number of services used by the carers is highest in rural areas (where the help provided by GPs is almost the only support carers can rely on), while a reverse picture is found for services used by elders, mostly used in metropolitan areas (Table 7.29). Statistical significant differences are recorded in the mean number of services used either by carers or by elders in all three types of locality while, when considering the sum of the services used by the dyad carer-elder, no differences are found between rural and urban areas.

Table 7.29 Average number of services used by elder, carers or both by type of locality

	Type of locality			Italy
Services used by:	Metropolitan	Urban	Rural	
a) carers	0,37	0,16	**0,60**	0,30
b) elders	**4,56**	3,76	2,78	3,71
c) both	**4,93**	3,93	3,37	4,02
Kruskal-Wallis test: a) CHI^2 (2) = 157. 35; P< .001; b) CHI^2 (2) = 65.92; P< .001; c) CHI^2 (2) = 38.61; P< .001				

7.3.7 Which factors are associated with service use?

Bivariate analyses were used to identify those variables likely to have an influence on the use of services and hence those population subgroups more likely to use certain supports. Variables have been classified according to the causal model proposed by the consortium for the overall European data (see chapter 3, Figure 1). Within this model, the characteristics of the care situation – including socio-demographics of older persons and their carers, older persons' needs and their support networks, as well as financial resources and availability and quality of services – are considered as potentially influencing determinants of the use of formal services, this improving the well-being or reducing the "burden" of the carer.

The major limitation of the Italian data is the extremely low use of services addressed to carers, which does not allow to correctly test the above-mentioned causal model. In fact, the recourse to services in Italy seems mostly to be symptomatic of severe health status, functional or social problems of the older person, which of course produce evident repercussions also on the carer's life, although they do not seem to have a direct impact in the caregivers outcomes.

Table 7.30 provides a synthesis of the factors significantly associated with the use of most common health and social care services (i.e. accessed by at least 50 users, excluding GP for older people, since almost all of them use it). Care services used by older people have been divided into two groups: "health" and "social". As for services used by carers, only GP satisfied the minimum number of users and therefore is the only one considered in this analysis.

Services provided at home, such as laboratory tests, nursing care, rehabilitation, cohabitant private helper, private helper for personal care and hairdresser, show several similarities in factors influencing their use. First of all, the elder using them are generally very old (except for those using rehabilitation at home, who are younger), have an higher number of needs, are more dependent in ADLs, present a higher number of behavioural problems, and a smaller carer's household size. Secondly, cohabitant private helpers and privately paid carers for personal care provide help for almost all the spheres of needs, thus potentially representing strong sources of help not only for older persons but also for family carers. Moreover, the use of the former service is associated with a lower involvement of the carer in providing help for health care, personal care and housework. Nevertheless, the relief for carers in terms of less weekly hours spent caring is visible only for those who can rely on a cohabitant private helper, while the carers of people using the other services provided at home enjoy of less time free from caring activities. In particular, carers of older persons benefiting from nursing care at home devote a minor amount of hours to paid work. Thirdly, the additional costs due to caring expenses are higher in particular for the use of nursing care, private helper for personal care and cohabitant private helper. As for the latter service, it is worth mentioning that the carer's personal income is higher in case it is used, which could be considered as a confirmation of a restricted access to this expensive service only to richest people.

Table 7.30 Factors associated with service use in Italy^

	Health care services used by elder							Social care used by elder							GP
	Specialist	Hospital	Tests at home	Laboratory test	Home nursing	Rehabilitation at home	Technical aids	Colf	Cohabitant private helper	Hairdresser at home	Social worker	Private personal care	Podiatrist	Transport	used by carers
Elder Demo-graphics															
Higher age	-	-	+	-		-	+		+	+		+			
People in household					+		+		+					+	
Carer Demo-graphics															
Region							NE, NW		NE, C		NE, NW			NE	NW, C
Locality			metr	urban							metr				rural*
Higher age	-		+	-	+		+	+			+	+	+	+	+
People in household			-		-			-		-	-	-	-		-
Elder care needs															
Completely relies on others for following needs: - Health care									+						
- Personal care					+		+		+			+			
- Mobility							+								
- Housework							+								
- Organizing care							+								
Number of needs		+	+		+		+		+	+	+	+		+	
Behavioural problems			+		+		+		+	+	+	+	+	+	
Disability (ADL/IADL)	-	+	+	-	+	+	+		+	+	+	+	+	+	
Informal network															
Carer provides help for following needs: - Health care									-						
- Personal care									-						
- Housework									-*						
% needs covered by the carer						-	-	-	-	-	-		-	-	+
% needs covered by other informal carers	+		-	+			+		-						-
Formal network															
Services provides help for following needs: - Health care					+	+	+		+*			+		+	
- Personal care					+		+		+*			+			
- Mobility								+	+*			+		+	
- Emotional support							+		+*			+			
- Housework								+*	+*			+			
- Financial management												+			
% needs covered by services		+	+		+	+	+	+	+	+	+	+	+	+	-
Situation of the carer															
Weekly hours of care for elder	-		+	-	+		+		-			+			+
Number of other elders cared for		+					+								-
Number of non elders cared for			-								-				
Weekly hours of care for other people			-												
Duration of care			+	-			+	-							
Working hours					-										
Financial resources															
Additional costs	+				+		+		+		+	+		+*	
Carer's personal income							+		+						-

^: All reported associations are significant at p< 0.05 level for Chi-Square tests in ordinal variables or T-test in continuous variables, and Phi >= 0.20 (if Phi >= 0.30 they are also asterisked with "*"). Following variables have shown either levels of association with service use lower than 0.20 or p values higher than 0.50: family kinship, elder's gender, elder's marital status, cohabitation, elder living at home or not, elder living alone, memory problems, reasons for caring, reasons for not using services, difficulties in accessing services, types of support required by carers, service characteristics preferred by carers, carer's gender, carer's marital status, religion, household composition, educational level and work condition, restrictions to working life of the carer, elder's personal income.

With regard to services usually provided outside the home environment, specialist doctors (considered as an undifferentiated group) and laboratory tests are generally used by less aged older people, affected by lower disability levels, cared for by younger carers who care for them less hours per week, and who can count on a wider informal network to meet elder's needs. The additional costs borne by carers or by elders (for example, for adaptation of the home environment, furniture, travel costs, special food, medicines), besides those for accessing services, are higher in case specialist doctors are accessed; furthermore, laboratory tests are more used in urban settings.

In case of the only service used by at least 50 carers, i.e. the GP, it was more frequently used in rural areas and in North Western and Central regions, by more aged carers, living in less numerous households and with a lower income, covering an higher percentage of needs of the older persons and involved in caring activities for more hours per week. The support network older persons cared for by carers using GP can rely on is more restricted, being the percentage of older people's needs covered either by the informal support network and by formal services lower.

A transversal interpretation of some significant determinants of service use shows that living in metropolitan localities is associated with a more intensive use of health tests at home and of social workers by the older person, while living in Northern East regions is associated with the use of technical aids and social workers (also in Northern West regions), cohabitant private helpers (also in Central regions) and transport services.

Focusing on the percentage of needs covered by the carer, the association with the use of some services (rehabilitation at home, technical aids, hairdresser at home social worker, podiatrist and transport, private housemaid, and cohabitant private helper) is generally negative, except for the already mentioned positive association of this determinant with the use of GP by the carer. On the contrary, the percentage of needs covered by the informal network is lower in case tests at home, cohabitant private helper or GP by carers are used, and higher in case specialist doctors, laboratory tests or technical aids are used.

7.3.8 Which services are "effective"? Does service use make a difference?

In this paragraph a first approach is presented on the topic of effectiveness of service use for the carer's well-being on the basis of the Negative Impact (NI) factor, although a full and satisfactory analysis of this subject will be possible only using longitudinal data (which have also been collected within the EUROFAMCARE survey, but not yet made available for more in-depth analysis besides the preliminary one reported in chapter 9). The aim of this attempt is to verify if the use of certain services reduces the negative impact produced by caring for an older person on the caregiver's life.

The analysis starts from the selection of variables to be included in a multivariate regression model, belonging to different categories, describing older person's needs, situation of the carer, financial issues, characteristics of service use and accessed services. The selection was performed by using both theoretical and empirical criteria. In the first place, the most relevant theoretical variables were identified in their respective category. Following this, variables with the highest correlation with the Negative Impact (NI) were included. Furthermore, in case two variables measuring similar constructs were highly inter-correlated (Sperman's Rho correlations coefficient > 0.40), the one most correlated with NI was selected for inclusion in the model. The list of the variables satisfying these criteria and their description is presented in table 7.31, where model 2 differs from model 1 only for the variables indicating the use/non use of services. From this table, it can be seen that only three services resulted to be relevant for inclusion in the analysis.

Table 7.31 Variables included in the multivariate regression model to analyse the Negative Impact factor	
MODEL 1	
Variable label	**Variable name**
Elder care needs	
BEHAV_PR	elder behavioural problems (0 = absence of behavioural problems; 9 = maximum level of behavioural problems)
NEEDS_OI	% of needs covered by informal carers other than the main one
Situation of the carer	
C12HOUR	average number of hours of care for the elder in a week
C69BREAK	„If you needed a break there would be anybody looking after elder?“ (1= yes, easily; 2= yes but with some difficulties; 3 = no, nobody)
C77FAC8	I found myself caring by chance without making a decision (1 = yes; 0 =no)
Financial issues	
E33F	Financial support - more help needed? (1 = yes; 0 = no)
C72FAC3	Motivation to caring: cost of professional care too high (1 = yes; 0 = no)
C87COP6	Does caregiving cause financial difficulties? (1 = never; 2 = sometimes; 3 = often; 4 = always)
S135IMPA	Type of support: more money for care (0 = not important; 1 = quite important; 2= very important)
Characteristics of service use	
S120NOUS	Are there any services that you/ Elder need but you have not used so far? (1 = yes; 0 = no)
S151CHAB	help provided is not to expensive- currently met (1 = yes; 0 = no)
TOT_SE	total number of services used by elder
MODEL 2 – variables as above and:	
seit9ar	service 9 - nurse at home (0 = not used; 1 = used)
seit10ar	service 10 - diagnostic tests at home (0 = not used; 1 = used)
seit37ar	service 37 - day private care at home for elder’s personal care (0 = not used; 1 = used)

The analysis of the Sperman’s Rho Correlations between the dependent variable Negative Impact (NI) and the most relevant independent variables is presented in Table 7.32. All variables, except for those measuring the “percentage of needs covered by informal carers other than the main one” (NEEDS_OI) and that “help provided is not to expensive: currently met” (S151CHAB), were positively correlated with the NI outcome scores, the highest correlations being recorded for variables measuring the following dimensions: “Does caregiving cause financial difficulties?” (C87COP6), “average number of hours of care for the elder in a week” (C12HOUR), “elder behavioural problems” (BEHAV_PR) and availability of someone looking after elder if the main carer should need a break (C69BREAK). This means that people who more often encounter financial difficulties due to caring for the older person, or who usually devote more time to caring or who care for older persons presenting behavioural problems, score an higher negative impact due to caring. Variables NEEDS_OI and S151CHAB were negatively correlated with NI, meaning that the presence of a wider informal network supporting the older persons to meet their needs or the fact that the help received is not to expensive is associated with a lower NI score. The use of services was generally positively associated with NI scores, showing that those who care for older persons using the selected services also experience a higher burden due to providing care. Nevertheless, the strength of the association remains low.

Table 7.32 Correlations (Spearman's Rho) between Negative impact of care with the most relevant independent variables (Sig. 2-tailed < 0.001)

VARIABLE	Correlation coefficient	N
BEHAV_PR	0,426549	981
NEEDS_OI	-0,16202	958
C12HOUR	0,435295	980
C69BREAK	0,345217	981
C77FAC8	0,255916	981
E33F	0,1808	401
C72FAC3	0,245533	981
C87COP6	0,533641	981
S135IMPA	0,171289	977
S120NOUS	0,226162	980
S151CHAB	-0,12467	808
TOT_SE	0,193245	981
seit9ar	0,132107	981
seit10ar	0,143885	981
seit37ar	0,122221	981

The analysis continues with a hierarchical multiple regression, whose results should be interpreted carefully, given that the Negative Impact and a number of independent variables were not optimally distributed. However, it should be said that in this analyses rather substantial departures from a multivariate-normal distribution are likely to be tolerable (Howell 1997: 520). In the first stage of the analysis, the dependent variable NI was regressed on the independent variables belonging to model 1, which on the whole explained 49,8% of the variance in NI (Table 7.33).

In the next stage, the variables concerning the use of services being significantly correlated with NI have been entered in the equation (Model 2): service 9 (nurse at home), service 10 (diagnostic tests at home) and service 37 (day private care at home for elder's personal care) (Table 7.34). The introduction of the service use variable in the model increased by 0.9% the NI variance accounted for. This increase was statistically significant [F(3, 319) = 2.957; p < .05]. Only service 37 has a statistically significant impact on the dependent variable (Beta = 0.107; p < .05).

The results suggest that the most important predictor of NI is "Does caregiving cause financial difficulties?" (C87COP6) (Beta = 0.443; p < .001), followed by "elder behavioural problems" (BEHAV_PR) (Beta = 0.242; p < .001). The use of service 37 is only the sixth predictor of NI. This means that carers who more often encounter financial difficulties due to caring and those looking after older persons presenting higher number of behavioural problems are more likely to score higher values in NI scale.

In other words, in order to reduce the negative impact of care it would be useful to provide appropriate support to face the financial costs connected to caring and to improve and/or increase respite services addressed to carers with elders presenting behavioural problems. No indication can be formulated with respect to service policies at this stage of the analysis.

Table 7.33 Recapitulation of the regression analysis for Model 1

Summary of the regression of the dependent variable NI
Adjusted R^2= .498; F(12,322)=28.585; $p < 0.001$

	Beta (Standardized Coefficients)	t	Sig.
Constant		8,107	,000
BEHAV_PR	0,242	5,786	,000
C69BREAK	0,114	2,558	0,011
E33F	0,012	0,284	0,776
NEEDS_OI	0,018	0,425	0,671
C72FAC3	0,006	0,138	0,890
C87COP6	0,448	9,303	,000
S135IMPA	-0,079	-1,871	0,062
S151CHAB	0,028	0,661	0,509
C12HOUR	0,138	3,320	0,001
C77FAC8	0,173	3,979	,000
S120NOUS	0,057	1,412	0,159
TOT_SE	0,039	0,961	0,337

Table 7.34 Recapitulation of the regression analysis for Model 2

Summary of the regression of the dependent variable: NI
Adjusted R^2= .507; F(15,319)=28.585; $p < 0.001$

	Beta (Standardized Coefficients)	t	Sig.
Constant		8,374	,000
BEHAV_PR	0,242	5,839	,000
C69BREAK	0,108	2,448	0,015
E33F	0,021	0,485	0,628
NEEDS_OI	0,023	0,537	0,592
C72FAC3	0,015	0,355	0,723
C87COP6	0,443	9,210	,000
S135IMPA	-0,076	-1,801	0,073
S151CHAB	0,034	0,808	0,420
C12HOUR	0,120	2,881	0,004
C77FAC8	0,167	3,811	,000
S120NOUS	0,057	1,404	0,161
TOT_SE	-0,030	-0,613	0,540
SEIT9AR	0,024	0,555	0,579
SEIT10AR	0,073	1,600	0,111
SEIT37AR	0,107	2,597	0,010

Surprisingly, even though service use could potentially relieve in part the carer from the load connected with caring, in this case it does not improve but seems to worsen the negative impact of caregiving. This result could be due to the limit connected with the cross sectional design of this part of the survey, which only allows to state whether associations between variables exist but cannot state the direction of the causal interaction between them. Therefore, a more appropriate answer to the question “do service use make a difference?” to the carer can be given only using longitudinal data, as will be partly attempted with provisional data in chapter 9.

Running the preliminary regression model allowed to choose the significant predictors of NI, with a p value lower than 0.05 in model 2, which were entered in a final regression equation. By including only the significant variables, an R^2 adjusted value was achieved equal 0.486 (Table 7.35) and, after adding the variable use/non use of service 37 (day private care at home for elder’s personal care), an increase of 0.001 is achieved in the adjusted R^2 (Table 7.36), but it was not statistically significant [F(1, 973) = 1.519; p = 0.218)].

Table 7.35 Regression of the Negative Impact dependent variable for model 1: significant variables only

Summary of the regression of the dependent variable: NI
Adjusted R^2= .486; F(5, 974)=186.336; $p < 0.001$

	Beta (Standardized Coefficients)	t	Sig.
Constant		21,447	,000
BEHAV_PR	0,250	10,327	,000
C69BREAK	0,110	4,428	,000
C87COP6	0,446	17,716	,000
C12HOUR	0,137	5,552	,000
C77FAC8	0,109	4,599	,000

Table 7.36 Regression of the Negative Impact dependent variable for model 2: significant variables and using service 37

Summary of the regression of the dependent variable: NI
Adjusted R^2= .487; F (6, 973)=155.616; $p < 0.001$

	Beta (Standardized Coefficients)	t	Sig.
Constant		21,448	,000
BEHAV_PR	0,247	10,181	,000
C69BREAK	0,110	4,436	,000
C87COP6	0,444	17,594	,000
C12HOUR	0,135	5,444	,000
C77FAC8	0,110	4,641	,000
SEIT37AR	0,029	1,232	,218

All variables entered in the last model, excluding the use of service 37, achieved significant positive association with NI scores ($p < 0.001$). As far as the order of importance of predictors is concerned, the results achieved through the previous regression model are confirmed, with “Does caregiving cause financial difficulties?” (C87COP6), being the most strongly related predictor of NI (Beta = 0.444), followed by “elder behavioural problems” (BEHAV_PR) (Beta: 0.247).

7.4 Final remarks

Based on the above research findings, we can state that in Italy the use of services by caregivers of older people in need of help is very limited, in particular for what concerns those services specifically addressing carers such as self-help or relative support groups, training course in caring, support from voluntary organisations, counselling, help lines, Internet services, regular respite service at home and formal standardised assessment of the caring situation. The highest use of services is recorded in correspondence of overburdened carers living together with the older, of similar ages. A remarkable percentage of caregivers (16,4%) mentioned the GP as a service that has helped them in their role as caregivers, so that this could be partly viewed as playing a substituting role for almost absent carer-specific support services. Nevertheless GP’s activities are likely to mostly concentrate on the medical aspects of care, so this anomalous situation should be considered as a palliative and temporary solution that should be replaced by a wider diffusion and/or information about specific services supporting caregivers.

The use of care services is more frequent among Italian older people, almost the totality of them having used services belonging to the health area (GP, specialists, hospital, nurse, rehabilitation, etc). Services addressed to give support for personal care are used by one elder out of four, and those to fulfil domestic needs by 13% of elders. It should be highlighted the popularity of private services provided at home both for domestic duties (10,6%) and for personal care (6,4%; hairdresser, 7,9%) as well as the high recourse to cohabitant private helpers (10%), the so called “badanti”, that represents one of the emerging features of the Italian elder care system, that is likely to be related, on the one hand, to the substantial gap existing between the demand for home care for older people and the supply of such type of service by the Italian Welfare State, which has pushed a lot of families to find alternative and “self-made” solutions and, to the other hand, to the abundant availability of migrant care workers, who have chosen Italy as destination country because of its relatively “generous entry policy”.

The average amount of services used by older people is highest in case of persons severely disabled (both physically and cognitively) assisted by overburdened and working carers, while it declines in care situations where the older person is affected by lighter disability and the carer presents low burden and high life satisfaction levels.

With regard to the financial support related to the caring situation, in Italy it is mainly addressed to the older persons, as it is confirmed by the survey findings, showing that over one third of older people, but only less than 1% of carers in the whole sample receive it.

The services used by respondents were mostly free of charge, this being true for 72,6% of carers and 42,6% of elders. Care costs however occurred, and the greatest part of them was borne to cover the expenses for paying cohabitant private helpers (35,7%) and temporary residential care (18,8%).

While, on the whole, carers are quite homogeneously satisfied with the services they use (but a bit less with those used by the older persons), a certain territorial variability is present with regard to service use and/or availability, being it more intensive in Northern regions and metropolitan areas as for those used by the older persons, and in Central regions and rural areas as for services used by the caregivers.

The experiences in accessing services reported by Italian carers reveal that the most important sources of help are medical/nursing professionals and family, friends and neighbours, while the most important barriers or difficulties encountered in accessing services are bureaucratic or complicated procedures, lack of information concerning the existence or how to access to service and long waiting lists.

On the other hand, almost one third of carers stated that themselves or the older people had never used some services although these were needed, such as in particular “supervision of the older person”, “public home help for cleaning home environment” or “public personal care”, mainly due to the lack of knowledge about their existence, while “home nursing services” and “home rehabilitation services” were not used mainly because of their cost.

High costs, no longer availability and low quality of services were also the most frequently indicated reasons for stopping using services which were still needed, situation which occurred in particular for “home rehabilitation service”, the main reasons for stopping using it being again its high costs.

The most important reasons for not accessing services at all are the lack of need and, but to a much lesser extent, the lack of knowledge/information, social/attitudinal reasons by elder or carer and the high costs.

Formal services are mostly used in case the older person needing assistance with health, personal and domestic care, all spheres for which the support provided by the main carers is lower than for other spheres and the need for extra support is quite high. The use of almost all services by the older person is associated to their more severe functional impairment, except for services provided outside the home environment, such as specialist doctors and laboratory tests, for which users are less impaired than non-users and thus more facilitated in moving to use ambulatory services. As for medical/nursing services, the most IADL impaired older persons are those using “Home nursing services”, “diagnostic test at home” and “home rehabilitation services”, while for social services, the most impaired in IADL are those using “day private carer for personal care”, “cohabitant private helpers” and “technical aids”.

The use of services has been analysed also with regard to 6 different care situations. GPs and specialist doctors predominantly have been used by all groups, specialist doctors being comparatively less used by older persons cared for by non working burdened family members. Cohabitant private helpers are more often used by working and burdened carers, whereas technical aids are more frequently taken advantage of by elders cared by non working burdened carers and less by those belonging to “light” caregiving situations. Specific services for carers are mostly accessed by female and burdened spouses.

Furthermore older persons using services, either medical/nursing or social ones, present a higher number of behavioural problems than non-users, and this is true in particular for those using “social workers”, “cohabitant private helpers” and “day private carers for personal care”. This shows that also the higher number of behavioural problems may be considered as a predictor of services demand.

The types of supports that are considered very important by caregivers are “information about the type of help and support that is available and how to access it” and “information about the older person’s diseases”, "more money for care", "holiday break from caring", "activities for elder", "help with planning future care". The service characteristics stated as “very important” are that "care workers treat older person with dignity and respect", that "help is available at the time it is need most", that "care workers have the skills and training they require" and that "help provided improves the quality of life of the older person", “arrives at the time it is promised”, and “is not too expensive”.

Looking at the factors that influence the use of the various service and hence those population subgroups who were more likely to use certain services, services provided at home are mostly used by more aged elderly persons, more ADL dependent, presenting a higher number of behavioural problems and a lower number of people living in the carer's households.

Carers who can rely on a private helpers living with the older person enjoy more time free from caring duties, but this service seems to be accessible to more wealthy carers due to its high costs. Furthermore, the use of private carers for elder's personal care is associated with a lower involvement of the carer in providing help for health care, personal care and house works. On the other hand, services that are usually provided outside the home environment, like specialist doctors and laboratory tests, are generally used by less aged elderly people, affected by lower disability levels, who are cared for by younger carers who care for them less hours a week, and who can count on a wider informal network to meet elder's needs.

In case of the only service used by at least 50 carers, i.e. the GP, this was more frequently used in rural localities and in North West and Central regions, by more aged carers, living in less numerous households and with a lower income, covering an higher percentage of needs of the older persons and involved in caring activities for more hours. The support network older persons cared for by carers using GP can rely on seems more restricted, being the percentage of OP's needs covered either by the informal support network and by formal services lower.

The analyses performed on cross-sectional data in order to test if the use of certain services reduces the negative impact produced by caring for an older person on the caregiver's life, have not resulted in any remarkable indication. On the contrary, the use of services was generally positively associated with NI scores, showing that those who care for older persons using services also experience a higher burden in providing care. This result could be due to the limit connected with the cross sectional design of this part of the survey, which only allows to state whether associations between variables exist, but cannot state the direction of the causal interaction between them. Therefore, a more appropriate answer to the question "does service use make a difference to the carer" can be given only using longitudinal data, as partially attempted in chapter 9.

An important result that come out from these analyses is that carers who more often encounter financial difficulties due to caring, as well as those looking after older persons presenting behavioural problems, are more likely to score higher values in NI scale. In other words, in order to reduce the negative impact of care, it would be useful to reduce the care costs borne and to improve and/or increase respite services addressed to carers with elders presenting behavioural problems.

In Italy, where the ageing process is particularly remarkable, caring for elderly people is becoming an increasingly important social issue. Notwithstanding, specific services aimed to help carers to continue performing their informal support role in spite of its growing difficulties - also due to multiple spheres of life they are involved in – are almost absent or their use is in any case very low. Public authorities should therefore consider developing policies aimed at widening the range of community services helping family carers struggling between caregiving tasks and other working and family obligations, in order for them to maintain a healthy balance between caregiving and other spheres of life. As for the preference of carers regarding the types of support needed and the characteristics that services should have, the indications coming out from this survey should been taken into consideration while developing these new services.

8 Services providers’ and family view on services for family caregivers and older people

by Maria Gabriella Melchiorre

8.1. Aims of chapter

The purpose of this chapter is to gather information about services provided for carers and elder, overall aims of these services, main benefits for family carers, problems for family carers in accessing, charge for services, areas of family carers’ need not covered, assessment and monitoring needs, example of good practice, service providers’ perspective on current and future challenges concerning service provided for family caregivers of older people, service providers’ strategies on current and future developments. A further aims is also to compare service providers' and family carers' view on importance and attainment of different types of support and of quality characteristics of services.

8.2. Method and sample

8.2.1. Sample

The interviewees (in 35 cases the highest responsible person, and in 10 cases a manager) are representatives of the most relevant care service organisations operating in the Italian sites/regions where the Eurofamcare survey on family carers has been carried out, including therefore rural (12 units), urban (20) and metropolitan (21) areas. The distribution of the services providers reached by region, shows 11 units in North East, 12 in North West, 16 in Centre and 14 in South & Islands; the distribution by type of organisation highlights 24 public care units (12 social and 12 health), and 19 voluntary units.

The interviewees belong above all to locally based organisations (36 units, of which 20 in North Italy), and of medium size (i.e. with a number of employee between 11 and 50) or large size (more than 50); 24 of the 53 contacted services providers are characterized by 100% (o nearly) of their activity concerned with older people, and 31 provide services specifically aimed at supporting family carers. In 21 of these 31 institutions, the services for carers represent less than 50% of the overall activities carried out by the organisations, and the average number of carers using the organisations' services is lower than 100 in 10 out of the 23 cases, but exceeds 500 in further 7 cases.

8.2.2. Recruitment

The data has been collected by using a short questionnaire concerning background information about the interviewed person and their organisation, with questions about their experiences and views on services for family caregivers. The questionnaire contained both structured questions with response alternatives and some open questions.

In the period July-December 2004, 53 questionnaires have been collected, using face-to-face interviews or postal questionnaires. Some interviewees have been contacted per telephone and have received the SPQ in advance before they have been interviewed.

8.2.3. Method of analysis

Content analysis has been used to handle the answers of open questions, and frequency description has been used for quantitative data. Open questions of sections B (filled in by 31 service providers for carer) and C (filled in by 49 service providers for elder) have been analysed at a national level, with some reference to single sites. An overview of provided services, and specific issues connected to them, presents these data in a synthetic-quantitative form.

8.3. Main findings

In section 8.3.1 findings are presented in a way to show how widespread – and where – specific support and care services are delivered by different Italian care organisations (reporting in brackets data taken from Tables 1 and 2, indicating how many providers are involved on the total, cfr. also the asterisked notes in both tables). The sites reported in brackets show where the mentioned topic is more evident analysing the answers given to the open questions. Finally, it should be underlined that the contents reported in the following paragraphs reflects faithfully the answers given by the interviewees, so that these do not necessarily reflect the opinion of the authors of this present chapter.

8.3.1. Service providers' view on services for family caregivers' concerning their goals, benefits, quality, attitude and future developments

8.3.1.1. Analyses of services for family carers

Goals and benefits

The objectives declared by the service providers are:

- to relieve the family from the burden of the job of care giving, acknowledging its role, supporting and making the most of its resources, accompanying it in mourning;
- to support the family in avoiding the permanent institutionalisation of the older person, especially in moments of crisis or in emergency situations, such as the older person’s return home following hospitalisation, the care of the terminally ill, the management of an Alzheimer patient;
- to make the family aware of the problems of senility in precautionary terms, to help understand what behaviour to adopt before its numerous and variable symptoms. To this end, the care services themselves aim to being an orienteering and reference point for finding the best relief and care solution, to increase knowledge and preparation (for example, a basic health care education), to provide information and training on the issues faced in various pathologies, thereby a better ability to cope with the situations encountered while feeling involved by the care services themselves in assessing and managing care;
- to provide relief to the family in its daily care of the older person, for the older person’s well-being, to facilitate maintaining and healing their residual abilities and physical well-being, to avoid making the older person feel like “a sick person”, but rather a person who is to be treated with dignity and respect, to promote home care and support in the familiar settings of a family life for as long as possible;
- to offer, both to the older person and their family, tangible psychological support, a better quality of life, and to share the weighty burden of daily emotional involvement, to favour the exchange of the older person’s experiences through self-help groups and to supply relevant support aimed at strengthening the relationship between carer and cared for.

According to the interviewed providers, the increased benefits family carers derive from care services are:

- to be relieved by the support provided, even momentarily, to enjoy a few moments of relief for oneself, thereby reducing stress levels and physical fatigue, enabling the conduct of a normal life, knowing one can count on people who support them both materially and psychologically;
- to have continuity in their assistance and, therefore, in relationships with the operators, who offer the carer humane contact that is both responsible and professional, for an improved quality in caring and assistance. One must bear in mind the fact that the family members do not often speak to the older person, and vice versa, but open up to the care service providers and give vent to their thoughts and emotions with often endless confessions;
- to be able to make comparisons with other family members, or with other people undergoing the same experiences and worries, to alleviate and share the burden of care, and realizing that one is not alone in facing the problems of the older person.

Coverage

In Italy, as a whole, the following care services are provided for family carers of older people:

- *training courses on caring* (61%) (Bologna, Rome): esp., caretaker training**,** meetings and seminars on existing opportunities and available services, evening talks by experts on themes requested by the families, publications;
- *regular relief home services*, with supervision of the older person for several hours a day during the week (55%) (Lecco, Bologna, Rome, Palermo);
- *consulting services for families* (51%) (Rome, Lecco) and, esp., all matters concerning Alzheimer's disease (Ancona);
- *support or self-help groups for families* (51%) (Rome, Bologna, Bentivoglio);
- *integrated care plans* for older persons and family members, at home or in the hospital (45%) (Rome, Avellino);
- *support for families provided by associations via telephone* (42%) or *internet* (39%) (Rome, Avellino): esp., telephone call-in service for psychological support, (Ferrara), toll-free call centre for food and medicines (Palermo);
- *assessment of carers' needs through instruments such as questionnaires, charts, etc., (35%)* (Rome, Bologna, Avellino), esp. research on sections most sensitive to inequity or disadvantage, analysis of the older person's situation, of the existing local services and of the carers' perception as to the care service situation, projects aiming to measure consumer satisfaction for the services provided;
- *crisis management* (35% (Rome, Licks, Bologna);
- *monetary transfers* (32% (Avellino, Bentivoglio, Bologna): esp. welfare vouchers and contributions for expenses incurred (Lecco), focused economic aid (Milan), checks for care and taxi vouchers (Bologna);
- *welfare secretariat* (13%), to facilitate administrative practices for families unable to leave the older person, provide judicial and legal assistance (Bologna, Ferrara) and special agreements with a notary and a lawyer (Ancona);
- *temporary home care services*, with family carer being replaced for brief periods (6%) (Rome, Bologna);
- *services devoted to family assistants of different ethnic groups* (a single case in Bologna). Concerning this last point, it must be noted that it has been proposed but disregarded by families in

Lecco; in Avellino, it is in the planning stages, while in Bentivoglio, there is, for the moment, only an information/orientation office for foreign carers, through a listening point (Ferrara).

Assessment Tools

These service providers carry out periodic assessments and monitoring of the family carer's needs by considering, in each case, the state of abandonment, the economic conditions, the physical, psychological and emotional conditions through interviews and meetings with GPs (General Practitioners), with the experts and social welfare assistants, with home visits conducted by the operators (Lecco), through listening posts. Useful to such ends is also the information supplied by carers based on their own personal experience, especially as regards older persons suffering from Alzheimer's (Ancona).

Furthermore, there are panel or group meetings and thematic seminars; occasionally, influential individuals from the neighbourhood or district are asked to become involved as focal points for the older persons and family members, people such as the local priest or pastor. For a more precise contextual analysis, participatory projects are used by technicians (Bentivoglio), surveys and registry data (Avellino), statistical analysis of requests and applications for support obtained through qualitative and quantitative surveys based on periodic questionnaires (Bologna, Ferrara), the assessment of customer satisfaction for services provided, as well as carers' psychological stress levels through special graph charts and tests (Rome, Palermo).

It is precisely through such assessment processes and monitoring that information is gathered concerning areas of family carers' needs, where services are uncovered or covered and in which areas.

Observed gaps - uncovered services

The first gap, signalled by care service providers, is due to the insufficient distribution of the home care services; hence, companionship and temporary carer substitution are in short supply. To this regard, help and support interventions provided by local municipalities are generally limited to people with low income; insufficient are both regular home care services (48%) (Rome, Avellino, Bologna, Cosenza) and temporary services (35%) (Avellino, Lecco), esp., home care services spanning the entire day, and during nights and holidays (Rome, Palermo, Milan). It would be useful to be able to assign a maid/caretaker for several hours a day during the week, someone who could supervise the older person and give further support to the carers (Bologna). The home care relief services is insufficient and inadequate in cases dealing with older persons with mobility and psychological difficulties as well as older persons confined to their beds, who require 24 hour support (Palermo, Cosenza).

As for integrated public health care and social welfare support, the approach is, in several centres, new, and is sources for complaints regarding some gaps or uncovered services. (Bentivoglio). Uncovered services are, esp., dealing with the family's social needs through support or self-help groups (39%) (Rome, Bologna, Ferrara), counselling (32%) (Rome, Avellino) and individual psychological support (Bologna). Also lacking is family support and training (19%) (Rome), esp. in the first phases of Alzheimer patients (Ferrara), and terminally ill patients, behavioural troubles and crises management (16%) (Rome), and telephone call-in services provided to families by care service associations (16%). Furthermore, venues and opportunities for the needy are few (Avellino) as are the number of agencies providing a sufficient number of qualified personnel dedicated to care (Lecco).

Usage and Access

Access to services generally occurs through personal initiative, and therefore upon request by the families correlated by medical certification and completed by a social welfare report. Another experimented method is word-of-mouth among people living in the same district, or from acquaintances that have already had access to the services themselves. Entrance is also gained through referrals by a General Practitioner (MMG), or social welfare services, upon referrals by the local health care agency, ASL, the geriatric ward, the Geriatrics Evaluation Units (UVG) (Varese Ligure, Rome), or the Alzheimer Assessment Units, (UVA), on direct application from the “Filo d'Argento” (Rome), through special agreements with public hospitals and local agencies, such as local municipalities, districts. Not lacking are openings wherein promotional initiatives undertaken by districts and parishes are followed up.

Yet beyond such formalities, the family carers may have problems in using the support and care services at times. Generally speaking, care cost at a private firm can represent a hindrance to access (Milan), while in voluntary organizations there may, in part, be problems due to the territory’s lack of available positions and due, also, to limited care service continuity because, not infrequently, the volunteers are volunteers as they are related to the older person (and once the family member passes away, the volunteer retires). Furthermore, problems are due to the small number of personnel available for home care services in general (47%) (Rome), to the few available resources, and to the restrictive access parameters for monetary transfers (40%), such as health care checks (Lecco, Ancona). There are, then, difficulties in accessing telephone assistance services (38%), crisis management (36%) (Rome), Internet services (33%), evening training courses (26%) (Rome, Bologna), self-help groups (25%) and counselling (25%). Obstacles to access, therefore, seem to be due to the lack of awareness concerning available services, the lack of information and coordination between the services, and the limited amount of promotion dedicated to services in that they are already saturated.

The difficulties if gaining access to services for the family carers seems, at times, to be conducible to the lack of personnel capable of replacing the family in providing assistance. Nevertheless, despite obstacles to a more complete usage, what has been successful are training courses (58%) (Rome, Bologna), self-help groups (57%) (esp. Northern East Italy and Rome), call-in telephone support (54%) and regular home care (53%) (Varese Ligure, Rome, Palermo). Furthermore, of quite common use are monetary transfers (50%) (Avellino) and counselling for carers (50%) (Rome), while the voluntary work is very much appreciated, it is considered insufficient (Ancona).

Costs

The social welfare and public health care services to families (as, for example, local home care relief, counselling, integrated care plans), are generally free (Lecco, Varese Ligure), except for regular and temporary home care relief, the cost due depending on income levels; at times, disputed for the maximum income levels allowed for gaining access to services (Bologna, Rome, Avellino) (26%).

A cost-sharing policy, based on income, is also in place wherein Service Checks are granted (Varese Ligure), new procedures consisting of support to the families through purchase vouchers for care and relief services (ex., family and home-based help in housekeeping, personal hygiene, feeding, mobility, etc.), carried out by specialized carers from social welfare cooperatives, family carers or caretakers regularly hired by the family.

Telephone support is also paid for (15%) (Avellino), as are tele-alarm system (Lecco) and internet services. A small fee is paid to voluntary organizations for meals provided during the day, without causing any particular problems (Palermo); the remaining voluntary care services are free as the local municipality makes a contribution to cover costs (Cosenza).

Private care services are all by payment; this not only constitutes a problem for gaining access to the services, as already mentioned, but especially for service continuity and the regularity of payments (Milan).

Attitude towards Family Carers

Generally speaking, family carers of older people are treated as partners, that is, they are involved, in various manners, in the process of assessment, monitoring and providing care services, but this may depend on the situations.

On the whole, the families as direct consumers of the support dedicated to them; forward requests for services, they illustrate the situation and negotiate matters regarding the availability of said services; as indirect consumers of care services for older people, they make themselves available to collaborating in the care and support of the family member, in laying out and monitoring Plans of Individual Assistance (PAI), (Varese). In essence, the family member is a constant presence in the various phases involving the elder's management and reception, and shares the relief project with the carer through interviews and visits at home, through dialogue with the social welfare assistant, and through family and individual meetings.

In different services - public or those operating within the realm of the public health service - the carers are involved in managing help and support and in making choices regarding therapy (therapy agreement program) through enquiries into consumer satisfaction, or also through training and information talks (Bologna). Carers are educated on how to live with the older person, an Alzheimer-afflicted patient, for example, and they participate in training courses to improve their professional care skills (Palermo). They are involved, of course, in that it concerns their loved one who is suffering, but also and above all, in the suffering of finding oneself having an ailing older person at home.

For health care checks, the families sign a contract; the tutor listens to the needs and the carer must adhere to the contract itself (Bentivoglio). With respect to the Italian Association of Alzheimer Patients, i.e., Associazione Italiana Malati Alzheimer (AIMA), the carers participate directly in the association's activities (Ancona).

The effort to involve the carers in the care and support process, however, has not yet been completely assimilated by all the carers and operators and by all the care service organizations. Collaboration occurs, above all, if the family of reference is, in fact and with dignity, helping and supporting its own relation, and its involvement depending, therefore, on its own conscience. Another fact to consider is that some families submit themselves to the care services with complete confidence, while others are thoroughly distrustful and are, consequently, absent, thereby making it difficult to establish a constructive dialogue, and provide the requested care and support in a positive manner.

Quality

To assess the quality of the services provided, hence the carer's satisfaction levels, the suppliers or distributors use both statistical analysis of requests for help and support, and assessments of the satisfaction levels of the provided services, through qualitative and quantitative surveys. Survey results reveal that appreciation levels of the services provided is certainly positive; that said, increased support would be much appreciated. Regarding integrated care plans, there is some dissatisfaction for the unequal distribution of services (14%), but not for the quality of the services provided (Lecco).Similar problems are, in part, also true for counselling services (19%) (Cosenza), and, above all, for money transfer services (30%) (Varese Ligure, Avellino); the dissatisfied one are, of course, those still awaiting for health care checks (Bentivoglio). AIMA's voluntary service is deemed insufficient and there is definitely a need for more volunteer work (Ancona). Concerning private cooperatives, much depends on how long and how steadily care service operators remain in the service, this to ensure a certain continuity of presence (Milan).

Examples of good practice

In any case, there are aspects in care services that are well run and many examples of good practice. Overall, services can be considered as operating effectively, but can be variable; much depends on the carer's character and his/her stress levels (Palermo); certainly positive signs are the operator's meticulousness and attention to specific requests, their flexibility in intervening, contexts wherein the carer is made to feel part of the services themselves, (Rome).

More specifically, counselling services for families work well (94%) (Rome, Lecco), with social welfare assistants as tutors catering to all the carer's needs (Bentivoglio), as do the self-help groups (87% (Rome, Bologna), wherein participants recuperate opportunities to socialize and share common problems (Ancona, Avellino, Rome), telephone call-in service (77%) (Rome, Avellino, Palermo), especially for psychological comfort and companionship.

Positive aspects are the training courses on caring provided to families (68%) (Rome, Bologna), esp., actions aimed at families of older people affected by dementia (Bologna), regular home care services (65%) (Lecco, Varese Ligure, Rome, Palermo), and crisis management (63%) (Rome); more specifically, families can rely on the services provided by the social welfare cooperative even in emergencies or moments of dejection, thereby offering a possibility to diminish the stress levels involved in caring for the older person and the loneliness involved in facing to such problems (Ferrara).

Valid work has been done by volunteers in easing the burden from family carers for several hours a week (Cosenza), the periodic training courses between the two (Ferrara, Bologna), and the judicial-legal counselling offered by purposely-trained volunteers (Ancona). To bear in mind, the care services provided by the volunteer often become the focal point compared to the provisions of other supports (Rome).

Aspects to be improved

What first emerges among the aspects that require improvement is the necessity of a broader, and better, distribution of services, esp., between mutual and self-help groups (87%) (Rome and Bologna), regular home care services (82%) (Rome, Palermo), and counselling services (81%) (Rome, Lecco), substituting relatives in carrying out the various bureaucratic practices and administrative paperwork, which, it must be said, need to be processed in less time (Varese Ligure). Also requiring improvement, telephone service (69%) (Rome, Avellino, Palermo), and crisis management (63%).

To be further developed, increased training courses on caring for volunteers, increased availability of specialized personnel, with heightened awareness of the aforesaid in the involvement of the carers in all the services provided; it is also necessary to extend cultural attentiveness in support of the carer in terms of direct assistance and through training courses (58%) (Rome, Palermo, Avellino), avoiding categorizing needs in favour of a more general assessment of the situation involved. Finally, increased integrated care plans (57%) (Lecco, Rome), health care checks (50%) (Ancona, Bologna), and increased promotion of available services with General Practitioners, who are sometimes poorly informed in this regard (Ferrara).

Future developments

Considering the increasingly exponential growth of needy older people and the presence of a consumer that is increasingly informed and aware, what is also required is that the approach adopted in the sector is updated on a timely basis. It would be advisable to expand the network of interventions on the territory by involving, in a systematic fashion, the various resources already present available, but which are, at times, disconnected and uncoordinated, granting space to all the resources in the territory in terms of a network of care services and people caring for the elder or those supporting them. The important thing in this sense is the promotion of a more participatory relationship among service providers and institutions, that the tasks are not left entirely to volunteer workers, but become institutionalised in order to guarantee continuity and a greater reach of the care services themselves.

To such end, it would be of strategic importance to involve the entire community, the ASLs, public health care, hospitals and MMGs in sharing information and management of older people, in general, and particularly those suffering from Alzheimer’s. The experiments taking place within districts and parishes should rise to the dignity of systematic and widespread action, a harmonious collaboration between local municipalities, ASLs, voluntary organizations, and other sectors (Bologna). A truly winning strategy is having the collaboration of all those that, indeed, want to do something for their neighbour and not simply leaving the task to the labours of a few “martyrs.”

This implies the creation of an integrated network of public health care and support with the local municipalities, according to and as foreseen by Law 328 dated 8 November 2000, a law for the creation of an integrated service system which aims to coordinate and render the help and support services homogeneous throughout Italy, and the guaranteeing a adequate public services with the support of the private sector.

The opinions gathered express, in particular, the necessity to broaden the offer of home care relief, with a truly concrete integration of territorial public health care and social welfare organizations, as well as integration between the public and private sectors (Rome), creating, ad hoc, new projects such as the same home-based care services (Ferrara). In essence, what should be increased are the number of services, operators and hours available in order to extend the fruition of the various initiatives undertaken to an ever-greater number of families; examples are providing help during the holidays without a decrease in available service (Palermo), or at critical times during the day, such as lunch (Lecco). For the older person, being with others during meals becomes a moment of sharing and socializing, an aspect that can, simultaneously, become a moment of relief for the family carers. A challenge in this regard is to be able to standardize and professionally qualify the submerged assistance carried out by the caretakers (Bentivoglio).

To develop, increased involvement of family carers who, to a greater degree, should be part of the process of programming and managing the services provided and, likewise, in the relief project (Milan); to such ends, it would be useful to designate a time and place for discussions between staff and family members in order to plan and, together, assess the general quality of the services provided (Lecco), and to develop and produce projects together, projects aimed at preventing problems of relief through personalized action.

Numerous complaints are conducible to the resources; despite difficulties, many initiatives are directed at looking for funds necessary to finance the development of new help and support strategies, and to increase the number of available volunteers and operators (Varese Ligure, Rome).

An important contribution would, however, be an increase in offers from the Public Service (Lecco), and also a study on the possibilities of developing support services enabling local Municipalities to act with the public health system in an coordinated fashion, and by employing young graduates, for example, who are specially trained, or by creating care service cooperatives with public financial support (Ancona).

Table 1 - Specific services for family carers **(connected to section B of SPQ)** **ITALY (% values) ***	Provision (Q16)		Access (Q19)			Problems with carers' satisfaction (Q22)	Good practice (Q23)	Need for improvement (Q24)	Uncovered services (gaps) (Q25)
			Problems in access (Q19a)	Full utilisation (Q19b)	Problems with costs (Q19c)				
	A	B	C	D	E	F	G	H	I
1. Training courses on caring	19	61.3	26.3	57.9	5.3	5.3	68.4	57.9	19.4
2. Telephone service offered by associations to family carers	13	41.9	38.5	53.8	15.4	-	76.9	69.2	16.1
3. Internet Services	12	38.7	33.3	41.7	8.3	-	50.0	41.7	9.7
4. Support or self-help groups for family members	16	51.6	25.0	57.2	12.5	6.2	87.5	87.5	38.7
5. Counselling services for family carers	16	51.6	25.0	50.0	-	18.7	93.7	81.2	32.2
6. Regular relief home service (supervision of the elder for a few hours a day during the week)	17	54.8	41.2	52.9	23.5	5.9	64.7	82.3	48.4
7. Temporary relief home service (substitution of the family carer for brief periods of time, like a week)	2	6.4	100.0	-	50.0	-	-	-	35.5
8. Assessment of the needs	11	35.5	18.2	45.4	-	-	54.5	45.4	9.7
9. Monetary transfers	10	32.2	40.0	50.0	10.0	30.0	30.0	50.0	9.7
10. Management of crises	11	35.5	36.4	45.4	-	-	63.6	63.6	16.1
11. Integrated planning of care for the elder and families at home or in hospital	14	45.2	21.4	28.6	7.1	14.3	42.8	57.1	12.9
12. Services for family carers of different ethnic groups	1	3.2	100.0	-	-	-	-	100.0	6.5
13. Other services: segretariato sociale, assistenza legale, pratiche amministrative, uffici informativi (13.0)									

* A = organisations providing this specific service in absolute value;
B = % organisations providing this specific service on total 31 providers for carers (A/31);
C, D, E, F, G, H = % on number of organisations providing this specific service (A);
I = % on total 31 providers for carers

8.3.1.2. Analysis of services for older people that might relieve family carers

Goals and benefits

The objectives declared by services providers are:

- to assist non-self-sufficient older people who are physically dysfunctional or afflicted by diminishing cognitive powers, through actions aimed at providing help and assistance in decreasing the speed in which the illness evolves as much as is possible, recovering residual abilities and maintaining personal autonomy, providing social and domestic care (personal hygiene, bathing, preparation of meals and feeding, nursing assistance and rehabilitation, housekeeping and domestic cleaning);
- to monitor the health conditions of the older person, to postpone the older person's institutionalisation, and to sustain them thus, for as long as possible, near their home. Home-based care, therefore, is intended as supporting, for as long a time as possible, of the older person's autonomy, with support provided to families choosing domestic care as an alternative to institutionalisation or hospitalisation, who can thus enjoy a break, even if only for a few short hours, with the alternative of hiring a caretaker or selected attendants, or to turn to qualified personnel at a temporary residential care service provider for relief.
- to offer the older persons opportunities to socialize and to live in their own neighbourhood, to dispel their sense of loneliness and alienation, to guide them in completing bureaucratic practices and to guide them through the resources available in the territory.

The greatest benefits acquired from services, as reported by the interviewed service providers, are:

for older persons:

- to receive help that allows them increased physical and psychological integrity, improved living conditions, that makes them feel useful, protagonists not left alone to bide by themselves. It is important to psychologically help older persons to live the present with wholeness and to help them look at the future with hope, to keep them updated on social changes and, therefore, to be active and real participants under all aspects - psychological, social and physical - with further development of their inter-relational lifestyles;
- to continue living in their own family environment, full of stimulus and relationships, without being uprooted from their sense of safety and affections. Their well-being is, in fact, enhanced by the possibility of developing their relationships in a friendly, familiar and reassuring context;
- to be together with other older people, to share a project and to collaborate through practical initiatives (for instance projects for the parish);

for family caregivers:

- indirect benefits, such as practical and psychological relief from the burden of providing help and care to older people, support in the care and daily management of the older person, esp., if confined to their beds, with the possibility of better managing his/her own time;
- to feel relieved of a commitment they are not always able to face or bear, and to find someone who they can turn to in particularly trying moments, for ex., after the older person's return from the hospital, a situation wherein help is offered to the relatives who may have difficulties in nursing or caring for the older person because of inappropriate training. In this manner, the family's loneliness and social unease are reduced, their state of alienation are removed, and dignified help and a better quality of life are offered to the carers, and those cared for.

Coverage

In Italy, overall, the following care services for older peoples are provided, services than can provide relief to the carer as well:

social welfare and domestic care services:

- housekeeping (51%) (Palermo, Rome, Milan);
- transport services (51%) (Rome, Milan, Palermo, Lecco) with automobile equipped for transporting disabled and attendant (Ancona) to reach all the social and health care services, meeting and cultural venues, for tourism, trips and excursions (Milan);
- social home visits, psychological relief and companionship by priest or social welfare assistants (43%) (Rome, Avellino, Lecco);
- cleaning and laundry (39%) (Palermo, Cosenza);
- home meals/meals on wheels (26%) (Rome, Milan, Cosenza);
- surveillance and safety monitoring systems (22%) (Milan, Lecco, Bologna). Of note, the "Filo d'Argento/Silver Thread" that provides telephone-based companionship to older people at home (Ancona);
- housekeeping (14%);

domestic care services:

- general medical treatments (49%) with medication, nursing, bedsore prevention, monitoring of medicinal intake (Bologna, Lecco, Palermo);
- cognitive and physical rehabilitation, occupational therapy, physiotherapy (35%) (esp., in the South);
- integrated public health care assistance (ADI) of Milan, offering nursing, rehabilitation and physiotherapeutic assistance through a voucher system, public social welfare and health care vouchers that can be used exclusively for the purchase of integrated social and health care domestic services provided by professional carers working for certified public and private care service organizations;

non-domestic help and support services:

- semi-residential relief services (28%) (Northeast), relief support, day centres in general and, esp., for frail older people suffering from Alzheimer's and Parkinson's diseases (Rome), where various activities are undertaken, including, re-socialization and work-related integration of the older persons (Palermo). Particularly, hospitality is offered at voluntary centres; even though temporary, it is on a 24-hour basis, throughout which day- and night-time assistance is provided, including meals, personal hygiene, medicine dispensation, and the presence of a nurse are guaranteed for blood pressure checks, insulin. All this enables the families to deal with other matters during the presence of the volunteer carers. Furthermore, a nurse offering counselling to the families is present three times a week (Lecco). The volunteer also provides psychological assistance, taking the older person on small walks so as not to have the older person lose contact with the outside world, informs and provides news on current events to keep them participant, accompanies them to general recreational activities, clubs where the elderly meet, study, dance, do gymnastics, theatre and life-long education linked to the Open University of Self-management of Services & Solidarity (Autogestione dei Servizi e la Solidarieta/AUSER) (Ancona, Palermo). The voluntary organizations designate, furthermore, foreign women, chosen through long in-depth interviews as potential caretaker candidates for the families (Bologna);
- residential services (24%) (Northeast), such as rest homes, protected houses, Health Care Residences (RSA).Of note, the Substitution of the Nuclear Family Service and First Aid (SSNF-pi); in terms of beds available with the territory's RSAs to host the older person - arranged with the care service centre's and the ASL for a certain time -, to allow families to temporarily free themselves

of their tasks (Lecco). There are, then, multi-functional flats for older persons (Bentivoglio) and rest homes for those suffering from Alzheimer (Palermo). Also, the ASL's Older Person's Area Coordination in Bologna; despite not managing services for older persons directly, it coordinates and monitors the activity of day centres, protected houses, RSAs;

-social secretariats (16%) help process administrative practices (applications for invalidity, pensions, income tax returns, information and guidance for services available in the territory, as well as dealing with domestic care services through explanations, clarifying matters concerning the illness (Lecco, Rome), processing of application forms for requests to presidiums (diapers, baby carriage, etc…);

Assessment Tools

To improve the services offered, the assessment and monitoring of the older person's needs and their family carers makes use of professional analyses of the needs, the action plans required by social welfare assistants through individual in-depth interviews with the older person to be supported, their respective families, with the MMG and with the relevant service operators, municipal or from public health care, who were initially contacted by the interested parties. For more complex situations, there are meetings with geriatric specialists and other experts and a multi-disciplinary assessment is made – operated through UVG, UVD, UVA, depending on the case -, taking into account parameters such as age, income, health conditions (Milan). In the initial phases, a home visit is foreseen to verify the real health conditions of the future guest with regard to self-sufficiency and to verify that the care volunteers present are, in fact, able to care for the patient. For private care firms, the care operator is certainly the principal focal point who works alongside the relatives; of vital importance, of course, is an open dialogue with the older person (Milan).

The assessment meeting is made in the presence of family members; the ongoing daily presence of carers and professional staff allows a daily monitoring of the situation (Lecco). Following access, periodic home verification and monitoring take place and are elaborated with the collaboration of a team and, also, by speaking directly with the older person using the care service, or with the operators/assistants of the social welfare and health care services should the case involve an older person being looked after by the territory's care service. Important for monitoring the pathology, is diagnostic knowledge through information supplied by the carers as well as periodic medical and psychological assessments.

Also used are interviews, questionnaires, reports regarding social welfare and health care studies. Particularly, qualitative surveys regarding "costumer satisfaction" (i.e., perception of the quality of the service provided, suggestions to improve the service, etc.), and focus groups are organized (Bologna, Ancona). Investigations are also conducted regarding older people's needs using tools that are homogenous and applicable throughout the country, as in the UVG card, by now a consolidated procedure, and the assessment of the socio-economic situation with tools such as the Indicatore Situazione Economica Equivalente/Equivalent Economic Situation Index (ISEE), the infamous wealth indicator, or "riccometro" (Bentivoglio). Such an index, a calculation comparing the nuclear family's economic situation and index parameters, as in the detailed composition of the nuclear family, to establish in what measure the citizen has rights to economic facilitations in social welfare and health care services.

The voluntary associations also use a data bank of the requests produced by all the contacts made by the Filo d'Argento (Milan). In particular, the Filo d'Argento makes assessments with specific reports that survey the needs requested and the responses to those needs (Ancona). Instead, the Association for Voluntary Work in the Local Units of the Social Welfare and Health Care Services/L'associazione per il volontariato nelle unita locali dei servizi socio-sanitari (AVULSS) does not make assessments of its own, but rather, refers to local municipal surveys of the community wherein it is located (Ancona).

Observed gaps: uncovered services

There are areas of need for older persons and the family carers, however, that care service providers do not cover. First, there is a lack of financial support: scarcity of funds (Palermo) does not allow an adequate social, welfare and economic support service to be provided, and both the older person and their families must often finance themselves (Sassoferrato).

Furthermore, not to be underestimated is the partially autonomous older person (Bentivoglio), not yet requiring assistance, but who will eventually lose their self-sufficiency completely, or those who have practically no family network. This is a poorly perceived fraction of the population because harder to interpret, as yet too little studied: it involves older persons who are alone or carers who, in turn, are in need of support, for which there is no information network of services available.

Obvious gaps, for domestic care services, housekeeping (41%) (Rome, Avellino), transport services (39%) (Rome), home meals/meals on wheels (32%) (Rome, Avellino) and cleaning (30%) (Rome); AUSER does not cover the entire part of services involving intense home assistance and professional health care home assistance, (Milan), while private firms do not always cover home meals and counselling for the various bureaucratic procedures and practices (Milan).

In fact, professional care service responds principally to the older person's needs, leaving the area of general assistance unattended to, as a rule covered by unregulated non-professional resources such as caretakers or attendants (Bologna). Even relational needs are certainly left unsatisfied with, in fact, little psychological assistance. Furthermore, the services provided are limited in time, with assistance restricted to certain hours of the day, (Cosenza, Palermo), and are without coverage during holidays and night time shifts (Rome), for which there are also home care gaps in the afternoon and evening (Ancona).

For the ADI in Milan, which offers only medical treatments and rehabilitation, uncovered services are provided by the Centro Multiservizi Anziani, or the Multiservice Centre for the Elderly (CMA), with home care management and companionship. In fact, the Multi Service Centres (CMS) are polyvalent service centres wherein social welfare and health care services are, generally, integrated to battle cases suffering from depression, loneliness and isolation. The CMAs are territorial services whose function is to merge specific requests of the older persons with the possible responses supplied by the Administration and through referrals, activating services and, where necessary, sending the older persons to the service best capable of meeting his/her needs, which may be social welfare, secretarial, counselling, nursing, domestic collaboration, economic assistance.

Yet more uncovered services are the non-continuity of support and assistance after the older person's return home, especially if alone, or in medical services available (37%) (Palermo, Ancona, Lecco), rehabilitation (30%) (Ancona, Palermo, Avellino). For patients in advanced stages of Alzheimer's disease, there is no assistance with inadequate management in dealing with behavioural disturbances. As a whole, there is little assistance from the Technical Assistance Operators (OTA), innovative professional support resources operating under the direct responsibility of the nurse, who, however, are currently few in number (Avellino).

In addition, lacking, semi-residential care services (20%) (Avellino, Palermo, Rome), especially day centres, meant as places for activities wherein older persons meet, and where the burden of providing help and support are relieved from the carer for a short time.

Usage and access

Generally, access to care services for older persons occurs through personal initiative either by the family or by neighbours, or upon request of the older persons themselves, hence, by direct knowledge of the care services available as inhabitants of the neighbourhood or local district perhaps by word-of-mouth, a rolling snowball-effect, from someone who has already made use of the service or even through information obtained in local parishes (Palermo). At times, service is also accessed through referrals by the territory's social welfare services, or upon being signalled by the Servizi Assistenza Anziani/Elderly Assistance Service (Bologna, Ferrara), the MMG (for ADI it is compulsory that MMG make these indications), the UVG, the UVA (Rome), or through telephone contacts, and/or the various toll-free numbers activated by different voluntary organizations (Filo d'Argento, AIMA etc.) (Milan, Rome).

Less common, a relative's direct access to a sole listening focal point, through protected resignation/dimissione protetta, and use is made of brochures distributed in pharmacies to report news of the services available, (Ancona), in the daily newspapers, on television or fliers at recreational clubs and associations and during fund-raising events. In detail, AVULSS has a special agreement with the local municipality whereby needy cases are cared for by social assistants (Ancona), while home care services are contracted out to private firms and managed with the social services of the local municipality and access parameters are defined by the assessment structures of the local administration (Bologna).

Problems at times do exist in the use of care services by older persons and family carers. In the first place, little information regarding care services present in the territory is available (Lecco, Rome); there is little knowledge of the options on hand, such as medical treatment (25%), rehabilitation (41%) (Palermo, Milan), because the services are little known, or there is a lingering fear of reverting to the social welfare services unless the condition is particularly serious. For ADI, information is sometimes lacking even at the MMGs (Milan, Ferrara), making access difficult, esp., housekeeping (36%) (Rome, Milan, Palermo), cleaning and laundry (31%) (Milan, Palermo), home meals (31%) and social home visits (28%) (Rome).

Though there are places available for addressing request applications, there is, still today, an excessive amount of bureaucracy involved in accessing medical treatment and rehabilitation services with income parameters or criteria restricting usage. Currently for public welfare purposes, the income of the older person's children is not asked; consequently, demand has increased while resources have remained the same, meaning longer waiting lists (Ancona). Lengthy waiting times have also been recorded for gaining entry into some residential (33%) and semi-residential care services (28%) (Rome).

There are sometimes problems of mobility and transport (32%) (Rome, Milan, Palermo), in terms of the older person's and family members' schedule, or even timetable limitations in the relevant transport services. Residential architectural barriers also constitute a problem, with apartment buildings lacking elevators (Ferrara).

Some problems have also been reported by the Filo d'Argento (Ancona); namely, an older person without a family's distrust. Finally, problems arise from the lack or scarcity of available funds, personnel and venues (Avellino, Palermo). For private care services, access is a problem due to the cost (Milan).

There is also the family's psychological resistance due to the belief that care and support is reduced when addressing the needs of the older person; other obstacles stem from the sense of shame and the economic aspect; whoever has already been involved in providing care and support for some time and has relied on their own personal resources to cope, is sometimes averse to questioning themselves in group discussions with operators and social assistants.

As for the use of care services for older persons, and despite access difficulties, there are more requests for social welfare services compared to request for public health care services (Varese Ligure). Specifically, there is full usage concerning home meals (100%) (Rome, Milan), housekeeping (84%) (Palermo, Rome), transport (84%) (Rome, Palermo, Lecco) cleaning (79%) (Palermo), while there is less demand for monitoring services (36%), and psychological support (Milan). Good use is also made of medical treatment (75%) (Palermo, Lecco), rehabilitation (76%) (Palermo, Cosenza), residential services (83%) (Bologna) and semi-residential services (71%) (Rome, Palermo, Bologna). To be considered, relief services have other alternatives, such as ADI, and are hence not often required (Ancona)

Costs

Concerning public health care and social welfare services there are various exemptions from payment fees that are linked to income, age or different pathologies; in applying certain rules in different manners, the regions are producing some changes in the matter of social welfare and health care services.

Generally speaking, many public health care services are free, while public social welfare services foresee charging a fee to the consumer, a fee that is linked to income; this state of affairs also varies from town to town. More specifically, there are problems related to transport costs (40%) (Ferrara, Bentivoglio, Sassoferrato), housekeeping (40%) (Bologna and Bentivoglio), cleaning and laundry (37%) (Bentivoglio), semi-residential services (43%) (esp. Northeast) and residential services (33%) (Avellino, Bentivoglio). In Lecco, where the local municipality makes a contribution for semi-residential services provided, problems have been encountered for residential services such as RSAs and rest homes.

Even when there are income-based services available, and a part of the cost is covered by the consumer, especially for public social welfare services, satisfaction levels seem to be the same as are the number of claims and complaints made when compared to the completely free services (Bologna), except for some complaints regarding assessments of minimum income levels necessary for gaining for access to services, as in housekeeping (Bologna) and transport services (Ferrara). Potential problems are, however, appraised; if the result is favourable, they are resolved through reductions, exemptions and contributions to favour access to the more needy (Bentivoglio). Particularly, in Cosenza, the public social welfare service was free for everybody to August 2004, but since the coming into effect of a voucher system, (percentage of cost sharing by the consumer linked to family income) many families have renounced the service, thereby giving rise to many problems for both the older people and their families.

As for voluntary services, they are generally free to older persons (Milan), or even when a nominal fee is foreseen for the consumer, the family, in any case, is free to decide how much to pay, if anything, should there their economic conditions be inadequate (Lecco). Finally, it must be said that the services provided by private organizations - excluding special conventions had for the supply of the services themselves, with the local municipality and the ASL (Ferrara, Bologna) - are naturally through fees and are, therefore, used almost exclusively by the upper-middle classes (Ancona, Milan).

Attitude towards Family Carers

The involvement of the family carers in the process of assessment, monitoring and providing of services depends on the situations. In some circumstances, their involvement is unnecessary, as in the case of older persons partially or completely self-sufficient who contact the voluntary associations personally (Lecco, Ancona) and are, hence, themselves the focal references**.** In other cases, their involvement is simply not possible; the older person, for example, does not have relatives of reference and, therefore, contacts the services on their own initiative with all his/her loneliness, sadness and despair, and one’s concern is to provide relief and support, both physical and to their morale (Cosenza). This part of the process - evaluation, monitoring and providing services - belongs, primarily, to the domain of actions by public structures (Bologna), but is, where possible, developed with special care so as not to displace or replace the family but, rather, to support and cooperate with it in managing problems; where there are opportunities, the families are treated and, somehow, involved as partners on which one is able to count upon for better providing the care services. In most cases, however, it is the families themselves that contact the care services; they ask the questions, forward requests, and deal with the care service operators with matters pertaining to availability; they present the older person's medical and social situation, indicate needs and demands, whether he/she is self-sufficient or requires help in getting washed and dressed, and they inform the physicians about the possible evolution of the pathology, on type and dosage of the medicines taken.

Usually the relatives are asked to participate in the care and support project and, therefore, in the planning, programming and monitoring of the service intervention, these through meetings with the care service operators and the supervision of experienced personnel. In practice, they are involved during the interview and the initial assessment visit of the older person made by the social welfare assistant, are involved in laying out the individual care plan, in the therapeutic choices and in being asked their collaboration in caring for their respective family member (Lecco, Ancona). In the presence of older persons with particular difficulties and needs, arrangements are made as to the quality and quantity of the activities that can be provided by the care volunteers, which take into account what the family is able to do for the older person, and whether or not they live together (Milan). Questionnaires are given to family members to measure the degree of satisfaction of the services provided (ADI in Milan).

Finally, the best solution is sought together with the relatives by informing them about care service typologies, asking their consent on the proposed operational program, through home-assistance team's educating them to perform some of the care assignments, and making them focal points for care teams concerning monitoring the relative's pain and symptoms. The family is, therefore, a resource, not one to overlap, but rather a resource to integrate into the process and support through a network of actions and by promoting a positive inter-active relationship.

A further aim is to increase the involvement of the families in the individual care projects through personalized interviews, cross-checking and comparing interview results of the different interlocutors with whom the families have come into contact, , i.e., the district social welfare assistant, MMGs, and others (Bologna). Unfortunately, to date, the effort to involve carers in the relief process has not yet been completely assimilated by all the care service operators and organizations, as is explicitly acknowledged by some of the interviewed care service providers themselves.

It must also be said that the participation of the family carers of older people in the assessment process, monitoring and providing of the care services can vary if the family assisted is a spouse, child, brother/sister, etc., or whether they live with the elder or not, circumstances that also entail a different sort of involvement by the operators. At times, the emotional proximity becomes an “a double-edged sword“, making it difficult to generalize and, hence, requiring appraisals on a case-to-case basis.

The dynamics inside the nuclear family and the family's expectations towards the care services influence the latter's real contribution. Often, when the older person and the carer are spouses, the situation is discomforting for both and providing adequate relief action requires more time. The matter also changes in the presence of children, and male carers (husband-brother-son) tend to show less potential for providing care compared to their female counterparts (wife-daughter-sister). Also, if the carer lives with the family being assisted, solutions which was often found inevitable with many non-self-sufficient older people, it has been observed that as a rule living together gives, by itself, rise to increased carer participation and involvement in assistance; instead, if the older person lives alone, the domestic care service has to act with the older person and the home environment.

Overall, it is important to be able to rely on a meaningful relationship with one family member of reference that is well acquainted with the older person to be supported and that he/she is available to mediate between the care services and the other family members. Of little influence, therefore, is the degree of kinship; more importantly, it is the concrete inter-relationship between patient and family, or between the assistant and the older person's family and, in any case, the family's awareness level with regard to the seriousness of the older person's clinical condition. Nevertheless, the carer/older person relationship also partly depends on the capabilities of the services to make the most of the family in so far as, in fact, it is up to the professionalism and ability of the multidisciplinary équipe to merge and merge the features of their approach with the family, and to act in the best possible manner.

Quality

Through individual in-depth interviews with the older persons, their families, various care service operators and MMGs, and by using questionnaires, reports concerning social welfare/health care surveys and qualitative research, information is drawn together to assess the satisfaction levels of the family carers concerning the services offered the older persons.

The families are generally satisfied/quite satisfied with much of the care services provided, because, in the first place, they are able to see that their family member is happier and more interested in life. However, reports also show that dissatisfaction is largely due to the small number of care service operators available for residential services (42%) (Bologna), domestic care (28%), housekeeping (28%) (Ancona), home meals (23%) and transport services (20%). At times problems involved the work of foreign caretakers (Ancona), or were due to the impossibility of extending domestic care services to cover the entire day (Bentivoglio), or because immediate and practical cares/cure was required and was, instead, delayed, as in certain medical treatment (21%) and rehabilitation (17%) -through vouchers provided by certified associations - both slow in satisfying consumer demands (Milan, Lecco). As for the services provided by private firms, the consumer is, on the whole, satisfied, and some older persons have even been assisted for years; of significance, the fact that families are very demanding, and if dissatisfied, immediately interrupt services (Milan).

Examples of good practise

Among the service features functioning properly that ought to be highlighted, esp. concerning the situation of family carers, is the manner in which the consumer comes into contact with the services to be used, the capability, interest, attention to the different needs and the helpfulness shown by the operators, the psychological "reception" of the older person and of the relation of reference (Lecco). Good practise is also the creation of service networks with a tutor that provides helps and support throughout the assistance process (Bentivoglio), personalized interventions takes into account both the needs of the older person and their family, hence, the development of a good relationship with the assisted parties and their relations that helps establish a relationship of mutual trust (Ferrara) A gratifying aspect is represented, in fact, by ongoing relationships between families and care operators beyond the terms of service (Rome), and is confirmed by the fact that the former return, or however, visit even after the problem for which help had been requested is resolved (Lecco). Also of importance is the good practise of communicating intervention changes to the relatives and not only to the older person, when the latter suffers from problems of memory (Milan).

Positive aspects are the offers of information concerning the territory's service availability (Lecco), legal counselling, support to the families through domestic care services (Rome), and the family's participation in the therapeutic and relief program, as well as the subsequent follow-up (Rome). Another element of good practise is certainly the immediate accessibility to services when requested, and when impossible, the provision of information towards guiding the consumer to the territory's other available resources, as well as answers to the requests made (Lecco). In some centres, in fact, the public health care assistance do not keep a record of waiting lists as domestic care services are provided the day following the application request (Ancona), and times for processing requests are rather immediate (Milan).

As for domestic care services, semi-residential services function in a proper fashion (93%) (North-east and Palermo), especially daily assistance to Alzheimer patients as well as response to emergencies with relief service (Ferrara). Also functioning are the university courses for older persons and recreational excursions for the elderly, which offer carers some leisure time (Palermo), social home visits (71%) (Rome, Lecco, Avellino), nursing/physician support (71%) (Lecco and Milan), physiotherapy (70%) (Ancona, Avellino, Milano) and meals service (69%) (Rome).

As for social cooperatives (Ferrara), positive results have been attained by the adoption of an admittance procedure to day centres, structures that enthuse and revitalize the older persons and provide relief to the families; these involve pre-admittance meetings, visits to the centre, individualization and assignment of a personal tutor, and ongoing relationships with the family, especially during the first week after admittance. Furthermore, other examples of good practise are activities of motor rehabilitation, recreational and cultural activities aiming at reinforcing the older person's residual cognitive abilities that go to maintaining and prolonging the elder's self-sufficiency, and allowing the carer to continue his/her assistance at home.

The private services are particularly concerned about clarifying service rules pertaining to operator turnover, to the presence of male personnel and employees of foreign nationality, to the supply of Devices of Individual Protection/Dispositivi di Protezione Individuale (DPI), to contact procedures with the organizational referrals of services (Bologna). The private services work satisfactorily because at the time of need there is maximum availability; 24 hours a day, and within an hour, care service is provided, sometimes even sooner. Such availability confers psychological comfort to people who are alone, especially during the holidays and summers, when the sense of abandonment are of greater frequency (Ancona). As for private firms, to be noted is the practise of keeping a register at the assisted older person's home to indicate the operator's identity, along with the types of services provided, health conditions and various other annotations for the relatives to consult (Milan).

The strong points of voluntary work are in providing a sense of solidarity and recreational support with which volunteers succeed in attracting even the idlest of older person, or even those with some ambulatory difficulties; what, essentially, is created is a basis for mutual support among the older participants, a social network of self-help groups (Ancona). Furthermore, when the older person attends the voluntary organization, they often become involved in entertaining situations wherein to laugh together and feel like an active participant by remembering the past with old games, poems, songs, theatrical performances, readings (Sassoferrato), activities that in families are not always possible. Still regarding voluntary work, Telefonia Sociale/Social Telephone (Filo d'Argento), considered by families to be excellent, a support service that is important and useful (Milan), as well as the multi-thematic proposals of AUSER (Milan), adept at expressing a great variety of voluntary actions and proposals for promoting social gatherings, leisure time, culture, etc.

Aspects to be improved

Despite the examples of good practise reported, what generally require improvement are the managerial and financial aspects, to create a broader and more widespread distribution of care services. The availability of increased funds and human resources, more volunteers and operators, would allow the territory's services to enjoy a greater presence for a greater amount of time (Avellino, Cosenza, Palermo). Also requiring improvement are promoting the existence and availability of services, a more widespread information network concerning the opportunities offered to reach a greater range of citizens, with services extended to the more elderly. Increased training of personnel is also needed, with more specialized operators available, and sensitization of the same towards consumer involvement in all the services, and to the personalization of interventions, with the purpose of creating a multidisciplinary team to define the projects that concern the elderly.

Increased funds are particularly necessary to offer an increased number of hours of care and assistance and to strengthen domestic care services, to give, for example, the possibility of patients being cared for within 24-36 hours (Ferrara), to assure more services such as social home visits (76%) (Rome, Lecco, Avellino), housekeeping (72%) (Palermo, Milan), domestic care (71%) and cleaning and laundry (63%) (Palermo, Milan).

Also important is the expansion of transport services for a broader range of consumers (76%) (Rome and Milan), and the creation of a more personalized transport service (Ferrara); instead, the current lack of resources has provoked a reduction of the service devoted to assisted transport (I Lick). Speeding up bureaucratic and administrative practices is also necessary, such as those for residential services (75%) (Bologna, Lecco, Varese Ligure) and semi-residential services (71%) (Rome, Palermo), as well as for medical treatment (58%) and rehabilitation (59%) (Palermo).

For ADI, executing public social welfare projects needs improving , a services currently, and on the whole, being developed by the private sector; to be improved, therefore, are contracts with organizations authorized to furnish care services on behalf of public institutions through a voucher system, for example (Milan). Regarding private firms, the initial understanding of the older person's expectations and those of his/her relatives should be better planned as concerns the care operator (Milan).

As to a centre's access assessment, the operations of scrutiny and the quality of information/data collection requires improvement, because in several circumstances in the past families have not been completely honest in describing the real conditions of the older person to be introduced into the process; this has resulted in the acceptance of people who were not completely self-sufficient, thereby causing volunteers difficulties in guaranteeing adequate care. Recently (Lecco) measures have been taken to insert a clause wherein a preventive home visit or inspection is made by two supervisors before accepting an older person into a centre in order to assess the real health and welfare conditions of the person, as well as asking families to accompany their dear ones personally.

Future development

For the future development of services, the "large numbers" are the first challenge: the number of older people is destined to grow and success in conferring adequate assistance and autonomy to older persons will become increasingly difficult, especially to those who are alone and not self-sufficient. In fact, an increase in the applications for help is particularly felt because of the increasing absence of filial support owed to work, but also because of requests for relief from the children who have had to deal with the family member without external assistance. In the present context, in which the families of a new generation are increasingly less present in providing care and assistance to older people (at times making it necessary to find a carer from outside the family environment), the expansion of present services throughout the territory, especially public services with which to interact, represents the principal policy requiring development for the future, along with providing increased information and expanding its reach.

It would certainly be a challenge to succeed in increasing domestic care coverage, and to provide improved support to both the older person and the carer, possibly by providing family tutoring (Bentivoglio), or singling out a tutor for the older person and related carer, and to definitively increasing the hours of assistance, for example, by furnishing qualified afternoon and evening support. Domestic care is in fact still, in some areas, almost entirely lacking and incapable of responding to the needs of people in difficulty, while improving the services would guarantee the possibility of being cared for in their own homes with the participation of a professional staff from the health care and social welfare sectors, thereby having access to the care they require without having to be hospitalised (Cosenza). To consider, domestic care services alleviate the burden borne by the family members assisting their own non self-sufficient family member; in fact, taking complete care of a relative who is not self-sufficient can often translate into a radical change of the family's life, involving tensions and conflicts amongst its members, and in loss of privacy, with a notable redimensioning of time and opportunities for rest and socialization, and significant changes to future projects. In these cases the domestic care services lessens the burden of care from the families by ensuring material and psychological support as well as by providing information and counselling.

Increasing domestic care services would, as a result, guarantee that all families are able to accompany their loved ones throughout the remainder of their lives in the best possible manner, offering assistance to disabled and/or ill older persons without institutionalising them in rest homes (Ancona). It is important to keep older persons at home, even if seriously ill, to increase the number of certified caretakers, with greater and more widespread support and relief coverage, with more day centres (Bologna, Ancona) to deal with risk situations. For those cases without solutions that are confined to a home, institutionalisation with help from the public administration is an answer. (Palermo). Rest homes are, more specifically, required, for older people with all care services being provided, not simply nursing, but also and above all a social welfare, health care and rehabilitation organization wherein diagnostic arrangements are performed with therapy, if and when necessary, with clear benefit to the families (Cosenza). It would also be appropriate to have an AIMA House in in every province, as a place of reference for Alzheimer patients and their families (Avellino).

The greatest challenge at the present time is, however, to have a greater number of persons available in order to increase domestic care (Varese Ligure), esp., psychologists (Rome), having more people available to allow the opening of a "family house" (Sassoferrato), to create a day centre where family carers can leave their elders for a few hours. More personnel are necessary to guarantee immediate substitutions in case of the operator's falling ill in order to ensure service continuity (Milano). There is great difficulty, instead, in attracting volunteers, and doing what needs to be done so that they give greater trust and make themselves available to helping and cooperating with the family carers, as far as possible, (Sassoferrato). Initially it was thought to be a problem of training personnel; in truth, the problem is that the people to be trained are actually few in number in some centres; despite appeals, the number of volunteers has not increased (Lecco). Also required, increased and more qualified training for carers and support operators in daily management, esp., domestic care services (Rome, Avellino), but also practical guides and manuals that, as an example, offer useful suggestions on the features necessary for residences housing non self-sufficient people (Avellino). In some centres, courses are organized for caretakers **(**Ferrara, Rome), and in the future it might be useful to extend courses to the families.

What may be implemented (Ancona) is a service of a free "Assistance Card", whose holders would be able to use additional services and benefits (for instance, telephone call-in for tele-checkups, periodic home care visit, transport from home to diagnostic centre, and more). The initiative has some difficulty in being implemented due to problems related to the lack of time and suitable personnel.

Of importance, organizing and promoting the older person's participation in the territory's social management with other associations and the government agencies in charge (Ancona), the development of social activities, increasing the qualitative effect of different sectors (Sassoferrato). To such end, it is necessary to extend and to strengthen the entire program of Social Telephone (Telefonia Sociale) (Milan), perfecting the taking in charge and response to the need, and also to organize and to promote mutual self-help groups. Also required, greater attention to the psychological and emotional aspects of the older persons and the carer without underestimating the importance of communicating the truth of the older person's clinical condition in the appropriate manner as well as in such sensitive moments such as separation and death.

In essence, a territorial broadening of services provided a network is clearly necessary, one that satisfies needs new and old, as well as a strategy that guarantees the service network and, consequently, its management. For ADI, "a network of companies" is also vital, one to whom to delegate the services provided using vouchers, and, furthermore, greater control public of the aforesaid (Milan). To be promoted, therefore, coordination between public and private organizations (Bologna), between social welfare and health care services (Ferrara), and all opportunities present in the territory (Sassoferrato). Of importance is the integration of social welfare and health care services according to Law 328 dated 8 November 2000, with costs being contained and a more ample diversification of the relief services offered that, in any case, largely depend on the availability of funds (Palermo), and are very often thwarted by the presence of responses unsuitable to the requests (Rome).

As for the Volunteer Services (AUSER in Milan), of concern are the socio-economic options of the central and regional governments that reduce, eliminate, re-deploy the quality and quantity of social welfare and health care services beginning with the decentralized areas. Supporting voluntary associations is, instead, fundamental to develop the potential of social and relief activities for the individual and the family. Financial resources are, of course, fundamental; for public social welfare services, viewed as having a difficult future because economic resources are progressively diminishing, with the institutions guaranteeing less and less to citizens in order to grant opportunities to the private sector, where access is not possible for everybody and appears to be increasingly difficult in the future.

To conclude, greater funds are required to create more care services in the future, a broader territorial network, new projects, to increase the number of operators and volunteers, to give them and family carers suitable training; to this end, institutions should change methods in distributing the necessary funds. More specifically, it would be appropriate to provide greater economic incentives for those dealing with the long-term care of non self-sufficient people (Cosenza). If the required financial coverage is not provided, potential developments may lead not to improved services in the future, but rather to a return to forms of low-cost under qualified assistance (Bologna).

Table 2 - Services to Older People (connected to section C of SPQ) ITALY (% values) *	Provision (Q28)		Access (Q19)			Problems with carers' satisfaction (Q34)	Good practice (Q35)	Need for improvement (Q36)	Uncovered services (gaps) (Q37)
			Problems in access (Q31a)	Full utilisation (Q31b)	Problems with costs (Q31c)				
	A	B	C	D	E	F	G	H	I
Social services at home									
1. Housekeeping (cooking, shopping etc.)	25	51.0	36.0	84.0	40.0	28.0	64.0	72.0	40.8
2. Cleaning and laundry	19	38.8	31.6	78.9	36.8	15.8	52.6	63.1	30.6
3. Meals on wheels	13	26.5	30.8	100.0	15.4	23.1	69.2	53.8	32.6
4. Transport services	25	51.0	32.0	84.0	40.0	20.0	60.0	76.0	38.8
5. Domestic care service (minor repairs, gardening etc.)	7	14.3	14.3	71.4	28.6	28.6	42.8	71.4	22.4
6. Social home visits (e.g. by pastor, social worker etc.)	21	42.8	28.6	66.7	19.0	14.3	71.4	76.2	20.4
7. Safety monitoring system (telealarm, telemedicine etc.)	11	22.4	27.3	36.4	18.2	9.1	54.5	63.6	10.2
Medical care services at home									
8. Medical treatment (medication, nursing etc.)	24	49.0	25.0	75.0	12.5	20.8	70.8	58.3	36.7
9. Rehabilitation (occupational therapy, physiotherapy etc.)	17	34.7	41.2	76.5	23.5	17.6	70.6	58.8	30.6
Other care settings									
10 Partly inpatient care (day care centre etc.)	14	28.6	28.6	71.4	42.8	14.3	92.8	71.4	20.4
11. Residential care (long-term care, sheltered housing etc.)	12	24.5	33.3	83.3	33.3	41.7	66.6	75.0	6.1
12. Other services: segretariato sociale, pratiche amministrative, informazione e orientamento, consulenze (16.0)									

* A = organisations providing this specific service in absolute value;
B = % organisations providing this specific service on total 49 providers for elder (A/49);
C, D, E, F, G, H = % on number of organisations providing this specific service (A);
I = % on total 49 providers for elder

8.3.2. Different types of support: service providers' and family carers' view on their importance and attainment

The types of support stated as very important by the service providers, with greater rates, are "information about support available" (92%), "training to develop skills for caring" (87%), "changes at home environment" (84.9%) and "more time with family" (79%) (Table 3).

TABLE 3 - Importance of the following types of support
(% on 53 Service Providers and 990 Carers)

	Very important		**Quite important**		**Do you provide/receive this type of support?**	
	SP	Carers	SP	Carers	SP	Carers
Information/advice about type of help and support available and how to access it	92.5	81.0	7.5	14.6	88.7	33.3
Information about the disease that the older person has	56.6	71.7	37.7	22.5	49.1	52.4
Training to help family carers develop the skills they need to care	86.8	40.0	13.2	32.9	60.4	16.5
Opportunities to enjoy activities outside of caring	67.9	34.2	26.4	30.2	41.5	19.7
Opportunities to have a holiday or take a break from caring	73.6	48.6	24.5	30.5	39.6	27.8
Opportunities for the older person’s to undertake activities they enjoy	67.9	47.6	30.2	29.1	50.9	14.8
Help with planning future care	73.6	46.0	22.6	33.2	66.0	15.6
The possibility to combine care giving with paid employment	54.7	44.8	28.3	18.4	15.1	22.0
The opportunity to talk over their problems as a carer	73.6	30.6	24.5	43.3	73.6	27.7
Opportunities to attend a carer support group	62.9	20.7	32.1	35.1	35.8	7.7
More money to help provide things they need to give good care	50.9	48.6	32.1	29.4	17.0	11.4
Opportunities to spend more time with their family	79.2	39.0	18.9	32.5	34.0	37.1
Help to deal with family disagreements	58.5	19.6	34.0	30.9	41.5	16.4
Help to make the older person's environment more suitable for caring	84.9	40.9	13.2	30.6	41.5	18.4

The next three very important supports - holiday break from caring, help with planning future care, talk over problems - show the same value of 73%. The supports stated as quite important are above all "information about the disease of elder" (38%), "help to deal with family disagreements" (34%), "to attend a carer support group" and "more money for care" (32%). To highlight is the 17% of service providers that consider this last help not important, and the 7% that assert the same for the possibility to combine caring and paid employment. To remark that these two kinds of supports are also the least provided by the interviewees (17% and 15%). On the contrary, the service organisations provide most of the supports stated as very important, first of all "information and advice about the type of help and support that is available and how to access it" (89%).

The carers highlight the necessity to receive information, particularly about help available (81%) and about the elder's diseases (72%), and assert to receive these supports but mainly the latter (33% and 52% respectively). To consider is that "information about the disease that the older person has" is the only support stated as very important by a larger rate of carers than service providers (72% versus 57%). Other supports, stated as very useful by carers, are "more money for care", "holiday break from caring", "activities for elder", "help with planning future care", "help to combine employment with caring", with a percentage ranging from 49% to 45%. To highlight is that only the 43% of caregivers consider quite important the opportunity to talk over their problems as a carer, and that a lower 35% of them think the same about opportunities to attend a carer support group. To notice also that few carers receive the supports we have mentioned above, in particular "more money to help provide things they need to give good care", which is stated as very important by about the half of the carers interviewed but, on the contrary, received only by 11% of them.

TABLE 4 - First most important type of support among those "very important"

(% on 53 Service Providers and 990 Carers)

	Carers	**S. Providers**
Information and advice about the type of help and support that is available and how to access it	37.8	43.4
Information about the disease that the older person has	12.0	1.9
Training to help family carers develop the skills they need to care	3.7	7.5
Opportunities to enjoy activities outside of caring	2.2	0
Opportunities to have a holiday or take a break from caring	7.9	1.9
Opportunities for the older person’s to undertake activities they enjoy	7.7	3.8
Help with planning future care	4.0	9.4
The possibility to combine care giving with paid employment	3.5	0
The opportunity to talk over their problems as a carer	1.2	11.3
Opportunities to attend a carer support group	0.7	1.9
More money to help provide things they need to give good care	10.1	11.3
Opportunities to spend more time with their family	1.5	1.9
Help to deal with family disagreements	0.9	1.9
Help to make the older person's environment more suitable for	*4.6*	*1.9*
Missing	*2.0*	*1.9*

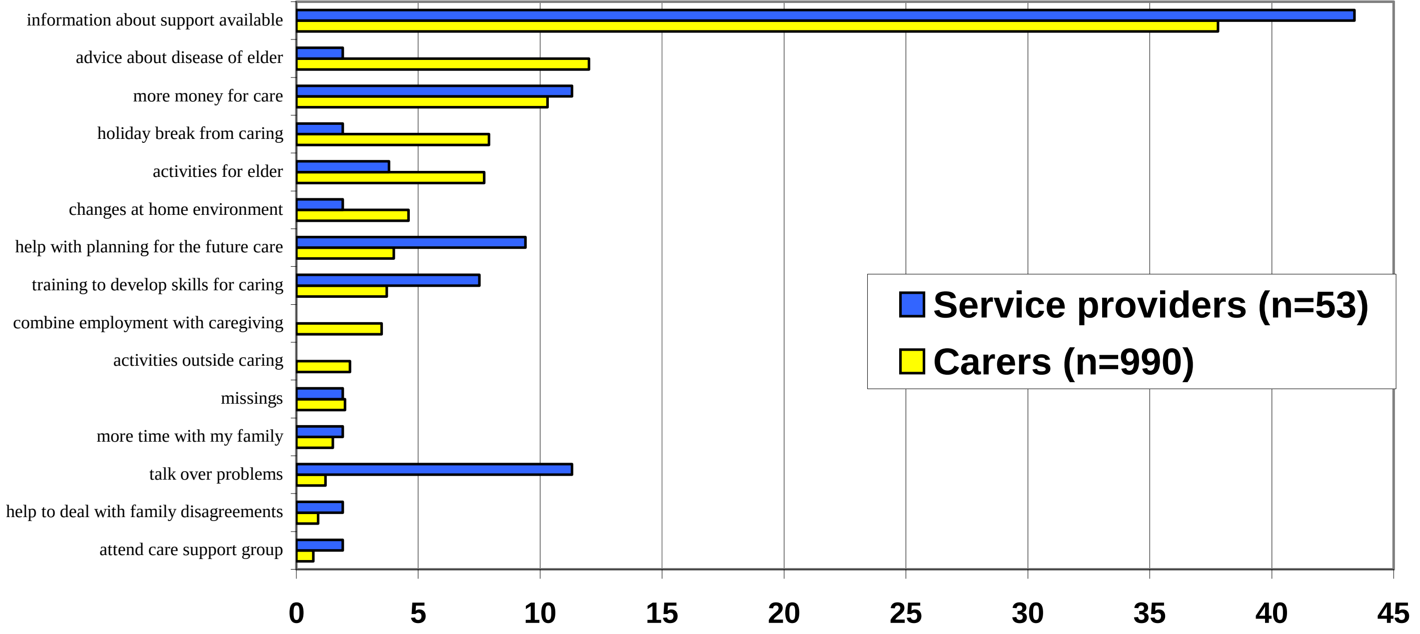

Figure 1: Kind of support retained as "first most important" in Italy (%)

Information and advice about the type of help and support that is available and how to access it" is rated as the first most important type of support, among those "very important", both by service providers and carers (43% and 38%); follow "more money" (10%) and "information on elder's disease" (12%) for the carers, and again more money and possibility to talk over problems (11%) for service providers. Moreover to highlight is that carers give first importance also to holiday break, and activities for elder, while service providers give first importance also to help with planning future care and training for carers. To observe that only caregivers consider " help to combine employment with care" and "activities outside caring" as first most important supports (Table 4 - Figure 1).

"Information about support available" is rated not only as the first but also as the second most important type of support by service providers (13%); in particular it's rated "first" in Central Italy (43%) and metropolitan sites (43%). The same kind of support is considered as most important by carers above all in the North West Italy (34%) and in urban sites (57%), while the second important help for them is "information about the disease the older person has" (17%)" (Tables 5-7).

TABLE 5: First and second most important support
(% on 53 Service Providers and 990 Carers)

	abs. V.		% V.	
	SP	Carers	SP	Carers
The first for SP and Carers: Information and advice about the type of help and support that is available and how to access it	23	374	43.4	37.8
The second for SP: Information and advice about the type of help and support that is available and how to access it	7	xx	13.2	xx
The second for Carers: Information about the disease that the older person has	xx	166	xx	16.8

TABLE 6 - First, Second important support by Region
(% on 53 Service Providers and 990 Carers)

	North East		North West		Centre		South & Islands		Italy	
	SP	Car	SP	Car	SP	Car	SP	Car.	SP	Car.
The first for SP and Carers: Information and advice about the type of help and support that is available and how to access it	21.7	19.5	17.4	34.2	43.5	23.3	17.4	23.0	23	374
The second for SP: Information and advice about the type of help and support that is available and how to access it	-	xx	28.6	xx	57.1	xx	14.3	xx	7	xx
The second for Carers: Information about the disease that the older person has	xx	12.0	xx	38.6	xx	21.7	xx	27.7	xx	166

TABLE 7 - First, Second important support by Locality Type

(% on 53 Service Providers and 990 Carers)

	Metropolitan		Urban		Rural		Total	
	SP	Car.	SP	Car.	SP	Car.	SP	Car.
The first for SP and Carers: Information and advice about the type of help and support that is available and how to access it	43.5	19.5	30.4	57.5	26.1	23.0	23	374
The second for SP: Information and advice about the type of help and support that is available and how to access it	28.6	xx	14.3	xx	57.1	xx	7	xx
The second for Carers: Information about the disease that the older person has	xx	13.9	xx	53.0	xx	33.1	xx	166

8.3.3. Quality characteristics of services-service providers' and family carers' view on their importance and attainment

The characteristics of a service for family carers, stated as very important by the service providers, are mainly that "help is available at the time they need it most", that "care workers treat older person and carers with dignity and respect", that "help provided improves the quality of life of the carer and of the older person", and that "care workers have the skills and training they require" (percentage values above 90%). These needs are mostly met by the services provided (percentage values from 81% to 89%), above all the attention to dignity of elder and the improvement of elder's quality of life (89%). The opportunity that help is provided by the same care worker each time and that the help provided is not too expensive, are stated as quite important (45% and 32%) and not important (13% and 6%) (Table 8).

TABLE 8 - Importance of the following characteristics of a service for family carers (% on 53 Service Providers and 990 Carers)					**Do services mostly meet these needs?**	
	Very important		**Quite important**		**Mostly Yes**	
	SP	Carers	SP	Carers	SP	Carers
Help is available at the time they need it most	94.3	93.2	3.8	6.6	81.1	52.7
The help provided fits in with carers own routines	66.0	55.5	26.4	36.	75.5	43.6
Help arrives at the time it is promised	79.2	87.1	18.9	11.8	83.0	55.6
Care workers have the skills and training they require	90.6	92.8	7.5	7.0	79.2	62.4
Care workers treat older person with dignity and respect	96.2	96.2	1.9	3.6	88.7	65.3
Care workers treat carers with dignity and respect	92.5	73.9	3.8	22.3	84.9	66.5
Carers views and opinions are listened to	73.6	59.0	22.6	37.9	79.2	61.7
The help provided improves the quality of life of the older person	94.3	92.6	3.8	7.0	88.7	59.6
The help provided improves the carers' quality of life	90.6	59.3	7.5	33.9	84.9	48.8
The help provided is not too expensive	60.4	76.3	32.1	21.4	54.7	38.9
Help is provided by the same care worker each time	39.6	48.6	45.3	35.9	62.3	39.5
Help focuses on the carers' needs as well as those of the older person	75.5	67.1	22.6	29.7	79.2	51.2

The carers also highlight some of these characteristics and with similar percentages (above 90%) (help available at the time they need it most, care workers treat elder with respect, help provided improves elder's quality of life, care workers are skilled), while they consider less important, if compared with service providers, that care workers treats carers with respect (74%) and that help provided improves carers' quality of life (59%). On the contrary, for carers are more important, with respect to service providers, the opportunity that help is provided by the same care worker each time, that help arrives at the time it is promised, and that help is not too expensive. In the carers' opinion, services mostly meet these kind of needs, and this is particularly true for the items "care workers treat older person and carer with dignity and respect" (66%).

Help availability, at the time the family carer need it most, is rated as the first most important characteristic of a service both by carers and service providers (38% and 30%); this is followed, in the opinion of both the groups, by training for carers, respect for elder and that help provided improves elder's quality of life (respectively 16%, 17%, 8% for carers; 21%,15% 15% for service providers). To highlight is that carers, but not service providers, consider among the first most important characteristics, that the help is provided by the same care worker each time and fits in with carers own routines, that it is not too expensive, and that carers views and opinions are listened to (Table 9 - Figure 2).

TABLE 9 - First most important characteristic of services among those "very important" (% on 53 Service Providers and 990 Carers)

	Carers	S. Providers
Help is available at the time they need it most	38.8	30.2
The help provided fits in with carers own routines	1.3	0
Help arrives at the time it is promised	7.9	5.7
Care workers have the skills and training they require	16.6	20.8
Care workers treat older person with dignity and respect	17.2	15.1
Care workers treat carers with dignity and respect	1.7	1.9
Carers views and opinions are listened to	0.5	0
The help provided improves the quality of life of the older person	8.4	15.1
The help provided improves the carers' quality of life	0.3	1.9
The help provided is not too expensive	3.5	0
Help is provided by the same care worker each time	1.1	0
Help focuses on the carers' needs as well as those of the older person	2.2	5.7
Missing	0.5	3.8

Help availability, at the time the family carer need it most, is rated also as the second most important characteristic of a service by service providers (21%); in particular it's rated as "first" in the North Italy (56%) and in urban sites (37%). This characteristic is the first most important also for carers in particular in North West and South Italy (60%) and in urban areas (58%). The carers have indicated the respect towards elder as the second most important characteristic (23%) (Tables 10,11,12).

Figure 2: Service characteristics retained as "first most important" in Italy (%)

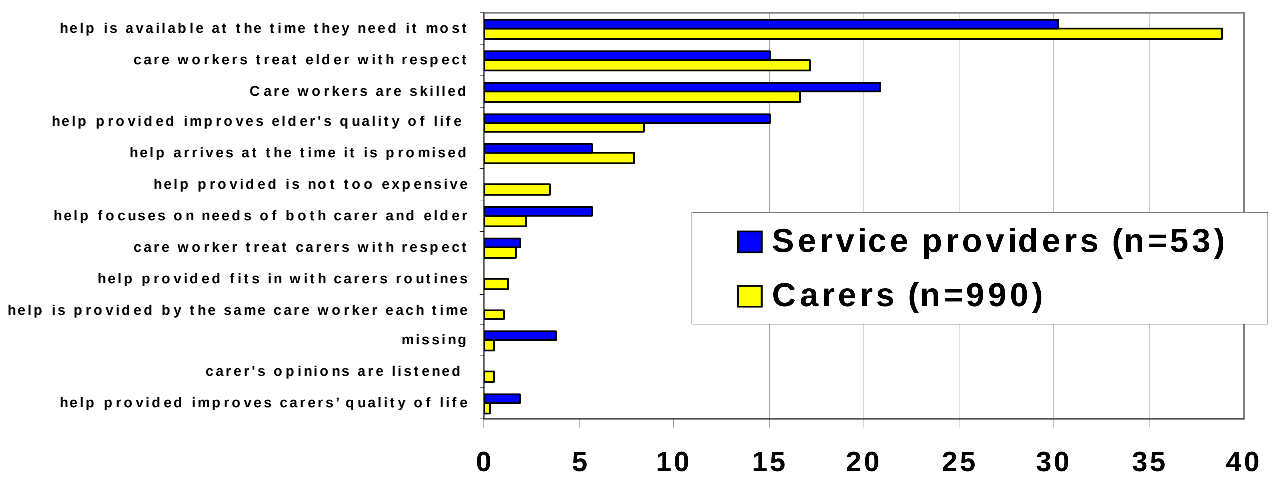

TABLE 10 - First, Second important characteristics
(% on 53 Service Providers and 990 Carers)

	abs. V.		% V.	
	SP	Carers	SP	Carers
The first for SP and Carers: Help is available at the time they need it most	16	384	30.2	38.8
The second for SP: Help is available when mostly needed	11	xx	20.8	xx
The second for Carers: Care workers treat older person with dignity and respect	xx	231	xx	23.3

TABLE 11 - First, Second important characteristics by Region
(% on 53 Service Providers and 990 Carers)

	North East		**North West**		**Centre**		**South & Isl.**		**Italy**	
	SP	Carers	SP	Carers	SP	Carers	SP	Carers	SP	Carers
The first for SP and Carers: Help is available at the time they need it most	31.3	18.8	25.0	30.7	25.0	21.6	18.8	28.9	16	384
The second for SP: Help is available when is most needed	18.2	xx	36.4	xx	36.4	xx	9.1	xx	11	xx
The second for Carers: Care workers treat elder with dignity and respect	xx	22.1	xx	26.8	xx	21.6	xx	29.4	xx	231

TABLE 12 - First, Second important characteristics by Locality Type (% on 53 Service Providers and 990 Carers)								
	Metropolitan		**Urban**		**Rural**		**Total**	
	SP	Car.	SP	Car.	SP	Car.	SP	Car.
The first for SP and Carers: Help is available at the time they need it most	31.3	19.0	37.5	58.1	31.3	22.9	16	384
The second for SP: Help is available when is most needed	45.5	xx	36.4	xx	18.2	xx	11	xx
The second for Carers: Care workers treat older person with dignity and respect	xx	19.9	xx	62.3	xx	17.7	xx	231

8. 4. Discussion

For the families supporting older persons, the care service providers carry out a very important role as they ease the burden of providing care with full acknowledgement of their role, esp. when they can ensure a certain continuity in their support and in their relationship with the care operators when they offer comparisons with other family members, when they succeed in avoiding permanent institutionalization of the older person and favor home-based recovery and maintenance of the older person’s residual abilities, when they form and inform on the problems encountered in various pathologies: when they offer, in other words, the opportunity to improve the quality of life, both of older people and of their families.

In essence, providing care to older people must be viewed as added indirect value with respect to the family carer, as support for the qualitative improvement of the older person’s daily life has repercussions on the carer, many of whom require both psychological and emotionally support, not to mention material and economical help. An example is the use of relief services for the older persons that grants a break of several days from the job of care for the family. At the same time, specific support services for carers also produce certain benefits for the elder’s relatives as in mutual self-help groups, which offer reciprocal support and the possibility of exchanging technical experiences, fact which benefits both. In other terms, when speaking of useful care services, the borderline between benefits for the disabled elderly person and the benefits for the family concerned fades and, consequently, there is a need for the adoption of a systematic holistic approach to planning and planning services to older people.

Across frequent evaluations and monitoring of the family carers’ needs, through qualitative and quantitative investigations, care service providers also attempt to understand the reasons for dissatisfaction, which are principally due to the lack of services available and its limited territorial reach and, also, to the reduced availability of care service operators for domestic care services, to cover the gaps and uncovered services still existent, and first of all, the temporary substitution of carers, and also by involving them in the management of support and therapeutic choices. Furthermore, attempts are also made to facilitate access to the territory’s resources and to remove obstacles to their usage, such as the little information regarding health care and social welfare services existent in the territory, or problems of mobility and transport to reach the services themselves, restrictive access prerequisites (services for which cost-sharing linked to income levels is foreseen), excessive bureaucracy, long processing times related to long waiting lists and to the small number of personnel available for domestic care services. Of vital importance is the ability of getting help at the moment in which it is needed most. As for the information on existing opportunities, it is important for the families to know whom to address, how to gain access, especially when income is insufficient, and to know the rules pertaining to fiscal and tax-related matters - in terms of deductions for assistance. To highlight is that the possibility to receive information and advice, about the type of help and support that is available and how to access it, is considered very important both by carers and service providers. Carers ask also more money for caring and opportunities to have a holiday or to take a break from caring, while service providers underline the necessity of training to help family carers develop the skills they need to care.

What is therefore necessary, despite the present offer of services however provided, is an expansion of said services throughout the territory, an increase in the number of available personnel and their relative training, all functioning as a network involving the entire community, the ASLs, hospitals and MMGs in the “management” of older people and relative carers with a real integration of health care, social welfare, hospital and territorial resources. Alas, resources required for invests are lacking; the scarcity of available funds and financing for the development of new relief strategies do not consent to a suitable social welfare, assistance and economic support of older people and their families. The context of the services appears to be going through a regressive phase, relative to the relationship between resources and qualification of the offer.

Services providers desire comparing and discussing matters with their peers on matters concerning the improvement of quality and substance of services provided; they want to mediate with institutions and create a link between the family and the network of care services to stimulate the creation of training centres for assisting the families themselves, to strengthen existing services and promote new ones, to succeed in offering, through an adaptable flexible organization, increased and better care, to develop a program of truly integrated care among the various typologies of existing services - that may be of public, private, voluntary, and religious origin - currently available.

The voluntary associations are a particularly valid contribution to the institutions and in many cases, they compensate the latter’s gaps and uncovered services; the more volunteers are working, the more family carers and the older people feel helped, comforted and hopeful. Associations and institutions could and should do a lot together, but the former require greater economic resources. The private service cooperatives, instead, at times struggle to individualize the correct management strategy, which is decidedly peculiar, when compared to voluntary services, in that it is often related to public assistance service through special agreements. Furthermore, besides the individual typologies of care service providers, the main point is to think of older people as resources and those planning their care and support should start with that consideration in mind.

Another fundamental consideration is to plan services expressly designed for family carers of older persons, both in the public and private sectors; instead, as things are at present, though samples of this type of care do exist, there is no homogenous distribution on the territory and what exists are often individual experiences of some local municipality, or are created as a form of support to the families through contributions, with income prerequisites, or social welfare designations are required to be granted funds for paying a caretaker, for example. This cannot be considered sufficient for a carer of older people; on the contrary, it is vital to give greater attention to those who provide care and support, to re-assess their central role and to promote the culture of support and safety where lacking, in order to avoid the risk of making the family assisting an older person, especially if suffering from Alzheimer’s, a “second victim“, a “second patient”. To notice is finally that both carers and service providers believe that the first most important characteristic of a service for family caregivers is that "help is available at the time they need it most". Thus it appears essential that a service is provided "at the right moment, in good time".

9. The One Year Follow-up Study: Preliminary Results*

By Barbara Bien, Heinz Rothgang, Giovanni Lamura, Judy Triantafillou, Eva Mnich, Kevin McKee, Birgitta Oberg, Roland Becker, Mikolaj Rybaczuk, Bożena Sielawa, Andreas Timm on behalf of the EUROFAMCARE Group

9.1 Introduction

Europe presents a rich cultural context for examining family caregiving. On the one hand, each of the six countries represents a very different European context, differentiated in terms of their unique traditions, demographic characteristics, health and welfare systems, levels of wealth, available infrastructures, technologies and many other features. On the other hand, all of them struggle with similar challenges with demographic ageing and supporting their older relatives.

Nevertheless, family care for dependent older people is not fixed in time but changes with the situation of the cared-for person, the family caregivers as well as their supportive framework available at any time [Beach et al 2000; Gräßel 2002; Hooker et al 2002; Arai et al 2002; Cannuscio 2002; Arai et al. 2002]. All of these prerequisites have an interactive and complex character, demonstrated in the foregoing chapters based on the results from the cross-cultural EUROFAMCARE study. Such a design is useful in providing a snapshot of the profound challenges of caregiving, as well as its correlates, however it is limited with respect to revealing the dynamics of the caregiving process over time. Additionally, only a longitudinal design is able to show the directions of change in objective stressors as predictors of subjective outcome measures [Warren et al. 2003, Gaugler 2003; Given et al 2004; Grunfeld et al 2004] as well as to clarify the interdependency between costs and the effects of supportive network and family well-being.

9.2 Aims of the chapter

The present report extends the cross-sectional analysis of the family caregiving situation identified in the six EUROFAMCARE countries (as presented in previous chapters) to an examination of the patterns of change that occurred over the 12 months separating the Follow-Up data collection (FU or T2) from the baseline data collection (T1). We were particularly interested in answering following questions:

- What are the socio-demographic changes in the studied population of carers and their older cared-for persons after 12 months of caring, especially in terms of:
    - mortality rates in the sample of older people cared-for?
    - institutionalisation rates amongst the older people cared-for and possible reasons for stopping caregiving?
    - the extent of discontinuity in the caregiving process, its reasons and predictors?
    - changes in care intensity?

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* This chapter represents a slightly revised version of chapter 9 of the Trans-European Survey Report (TEUSURE), which has been mainly prepared, for sections 9.1–9.3.2, by the Polish co-authors (Bien, Rybaczuk and Sielawa), and for sections 9.3.3- 9.3.5, by the Bremen partners (Rothgang, Becker and Timm).

  - changes in living arrangements, such as the distance between the carer's place of living and that of the cared-for person?
  - changes in the carers' occupational status, restrictions deriving from the caring activity and possible effects on professional career and income?
- What are the changes in the older people's psycho-physical functions in the 12-month follow-up? In particular:
  - what are the changes in I-ADL [Instrumental Activity of Daily Living] , mobility and P-ADL [Personal Activity of Daily Living] functions in the whole sample, and how do countries differ?
  - what are the dynamics of memory and behavioural disorders after a year. How have cognitive functions changed over time in different countries?
- What are the changes in the carers' subjective outcomes deriving from caring, in terms of positive and negative impact carers' quality of life, willingness to continue to care in the future in the whole sample, and by country? How do these relate to:
  - elders' age groups;
  - carers' gender;
  - living arrangements;
  - level of psycho-physical dependency;
  - typical care situations;
  - carers' economic situation;
  - change in service' usage after a year?
- What impact did services have on modifying/improving the carers' situation? In particular:
  - how did service use change in relation to carer's and elder's situation?
  - which services are considered most and least helpful in the carers' opinions?
- What are the predictors of positive and negative outcomes of care?

9.3 Methodology used to collect, analyse and present the data

9.3.1 Study design and procedure

The baseline data (T1) were collected (with the face to face method of interviewing) by means of a Common Assessment Tool [CAT], i.e. the extensive EUROFAMCARE questionnaire. The study was performed between November 2003 and June 2004 in six European countries (Germany, Greece, Italy, Poland, Sweden and UK), in the approximately 1000-person per country cohorts of family caregivers who were giving support or care to their old relatives (age 65 or over) for more than four hours a week. The total European sample consisted of 5923 cases, which were convenient representations of family caregivers in each of the six countries.

The FU data (T2) were collected approximately 12 months after the baseline study (T1), plus/minus one month of tolerance, between December 2004 and July 2005 (for details regarding tools and methodology of the baseline data collection, please refer to chapter 3 and 4). The aim was to resurvey all caregivers originally interviewed in the baseline study (except for those who didn't wish to be contacted again) when they were asked about the follow up during the initial interview.

The FU study was carried out using an ad-hoc questionnaire (see chapter 3), distinguishing "former carers" (i.e. those who had given up caring for different reasons, e.g. older person’s death, etc.), from those family carers still caring for the same older relative. Former carers were asked to complete a short version of the FU questionnaire, with a special paragraph focusing on reasons and circumstances related to the interruption of the caring role. Those still caring were administered a longer FU questionnaire, including several items from the baseline questionnaire [CAT], especially those related to the time flow, integrated by new ones (see paragraph 9.2.4. for details).

9.3.2 Subjects, sample size, response rates and reasons for non response

The size of T1 and T2 samples and the main reasons affecting FU response rates are reported in **Table 1**. Although most countries had originally planned to re-survey all subjects initially recruited, financial constraints (in Greece) and high primary refusal rate (in Germany) prompted two of them to contact only part of the original sample, so that about 350 completed interviews in Greece and 600 in Germany were aimed for.

Table 1: Size of T1 and T2 samples: Reasons for non response, and response rates

COUNTRY	**T1: Sample Size**	A priori excluded from resurvey (1,3)	Reasons of for non response						Lack of contact or response from respondent	Successful interviews		Response Rate (in %) (2)	**T2: Final FU Sample Size**
			Carer died			Carer refused to take part in FU							
			Elder alive	Elder died	Lack of data about Elder	Elder alive	Elder died	Lack of data about Elder		Short interview	Full interview		
Germany	1003	400(3)	0	0	3	5	4	89	51	179	272	74,8	**451**
Greece	1014	396(1)	0	0	0	61	1	38	236	88	194	45,6	**282**
Italy	990	0	1	0	1	12	3	40	70	184	679	87,2	**863**
Poland	1000	0	3	1	0	40	4	22	55	161	714	87,5	**875**
Sweden	921	0	0	0	0	0	0	59	281	200	375	62,4	**575**
UK	995	0	0	0	0	1	3	48	626	102	214	31,8	**316**
Total:	5923	796	4	1	4	119	15	296	1319	914	2448	65,6	**3362**

(1) Due to shortage of funding, Greece had to limit *a priori* the size of the FU samples.
(2) Cases excluded from resurvey was not included in the calculation of the response rate
(3) These carers were excluded because they refused in the baseline study to take part in the follow up

In case of unsuccessful contacts, an attempt was still made to collect information at least about carers' and elders' survival at T2, registering information in a special annex (columns 3-8). Given the problems mentioned above in contacting them, the information acquired in this way was scarce (indicating for instance that only 9 family carers and 16 older persons died between T1 and T2) and not included in the final dataset. More in-depth information about the death rates for older persons was available in case of successful contacts, through the short form of the FU questionnaires.

Table 2 presents the changes that occurred between T1 and T2 samples. Eventually 3362 family carers, i.e. 57% of initial European sample (45% of German, 28% of Greek, 87% of Italian and 88% of Polish samples, 62% of Swedish and 32% of the UK sample), were resurveyed, and asked whether they still provided support to their elderly relative for at least four hours a week. Those of them who had stopped caring were asked to answer the short version of the FU questionnaire, and those still caring the full version of it.

Table 2: Transition of the T1 sample into the T2 sample

	De	EL	IT	PL	SE	UK	Total
Size of the T1 sample	1003	1014	990	1000	921	995	5923
No of dropped cases	552	732	127	125	346	679	2561
Size of the T2 sample	**451**	**282**	**863**	**875**	**575**	**316**	**3362**
% of T1 sample resurveyed in time T2	44,9	27,8	87,2	87,5	62,4	31,8	56,8
With short interview	179 39,7%	88 31,2%	184 21,3%	161 18,4%	200 34,8%	102 32,3%	914 27,2%
With full interview	272 60,3%	194 68,8%	679 78,7%	714 81,6%	375 65,2%	214 67,7%	2448 72,8%

9.3.3 Representativeness of the national T2 samples compared to T1 samples

This paragraph tries to answer the question whether the re-surveyed carers represent the whole initial sample, both overall for all countries and within national samples. After one year, there was attrition from the initial sample as well as technical difficulties with approaching all initial respondents, and both samples (T1 and T1’, i.e. T2 in the FU study)[12] have been compared with regard to selected demographic features derived from the baseline study. **Figure 1** shows an ideogram reflecting samples' sizes at the European level. **Table 3** shows the distribution of chosen variables in both country and overall EU samples. The distributions of the compared variables, between T1 and T1', were tested with Chi-square Pearson's test.

Comparisons of the key demographic characteristics between T1 and T2 samples show almost full representativeness of the latter at the European level. Nevertheless, somewhat more often residents of rural area and carers cohabitating with the cared-for persons entered into the second wave of the study. Both samples (T1 and T2) did not differ significantly in terms of other demographic characteristics, nor with levels of physical and cognitive impairment in the cared-for elders, nor in terms of outcome measures, such as negative impact of care and carers’ quality of life.

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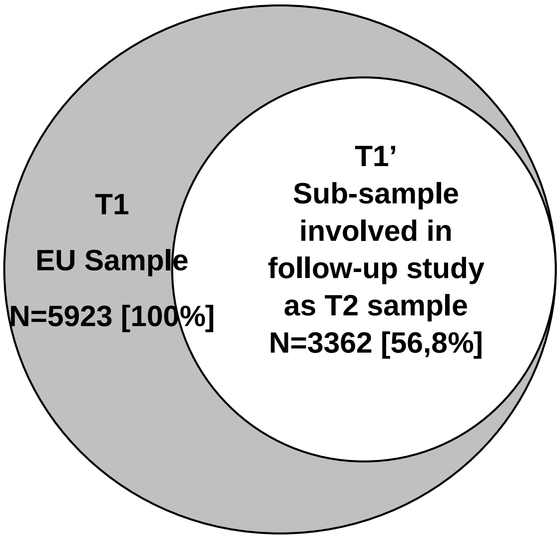
[12] T1 sample refers to the baseline sample; T1’ sample is a sub-sample of T1 sample, which was accessible for the Follow-up study. It is an equivalent of T2 sample.

Figure 1: Comparison between T1 and T1’ samples (ideogram at European level)



The Italian, Polish and Swedish T2 samples show the same distribution of key characteristics as in T1 samples (p=NS). Thus a very high level of representativeness with respect to the baseline sample can be assumed. Any change in the compared characteristics between Time 1 and Time 2 may thus be ascribed exclusively to time flow, and conclusions from FU results may be generalized to the situation of the original national sample of caregivers in those countries.

The German and Greek FU samples are similar to T1 ones with respect to demographic characteristics. Nevertheless, caregivers of more severely dependent older people, those experiencing a more negative impact from caring and a worse quality of life were more often willing to enter the FU study. The British FU sample reveals the highest divergence from the baseline characteristics. In this case, not only is there a relatively low response rate, but also systematic bias may have happened (the share of the metropolitan residents in the FU sample being almost four times lower than in the baseline sample). Although the poor representativeness of some national T2 samples does not decrease the value of the FU data obtained in the longitudinal projection, these countries’ findings cannot be referred to the baseline characteristics, but only to the same group of respondents who have been followed up.

Table 3: Comparison of sample T1 with sample T1' with regard to the distribution of the chosen CAT characteristics (in %)

	Germany		Greece		Italy		Poland		Sweden		UK		Total	
	T1 N=1003	T1' N=451	T1 N=1014	T1' N=282	T1 N=990	T1' N=863	T1 N=1000	T1' N=875	T1 N=921	T1' N=575	T1 N=995	T1' N=316	T1 N=5923	T1' N=3362
LOCALITY														
Metropolitan	32,8	36,8	16,1	11,4	21	20,9	36,3	34	3,7	2	20,5	5,7	22	25
Urban	45,2	39	44,7	47,5	57	58	27,1	27,3	61,9	62,9	48,7	62,6	47,2	37,8
Rural	22	24,2	39,2	41,1	22	21,1	36,6	38,7	34,4	35,1	30,8	31,7	30,8	37,2
	NS		NS		NS		NS		NS		P=0.00000		P=0.00000	
Elder's gender														
Male	31,5	29,3	35,5	34	28,8	29,2	27,2	26,5	42,3	41,6	30,5	31	32,5	31,2
Female	68,5	70,7	64,5	66	71,2	70,8	72,8	73,5	57,7	58,4	69,5	69	67,5	68,8
	NS		NS		NS		NS		NS		NS		NS	
Carer's gender														
Male	23,8	22,6	19,1443%	12,8	22,9	22	24	23,4	28	27,1	24,6	17,1	23,7	22,1
Female	76,2	77,4	80,9	87,2	77,1	78	76	76,6	72	72,9	75,4	82,9	76,3	77,9
	NS		P=0.0142		NS		NS		NS		P=0.0055		NS	
Cohabitation with the care-for person														
Other place	49,5%	46,6	33,9	30,5	44,5	44,5	25,6	24,7	52,3	53,2	57,9	48,7	43,8	40,3
The same building	50,5	53,4	66,1	69,5	55,5	55,5	74,4	75,3	47,7	46,8	42,1	51,3%	56,2	59,7
	NS		NS		NS		NS		NS		P=0.0040		P=0.001	
Cognitive disorders in Elder														
No	28,7	22,9	45,8	38,4	38,4	38,2	41,8	42,4	37,2	36,4	43,9	37,6	39,3	36,9
Yes	71,3	77,1%	54,2%	61,6	61,6	61,8	58,2%	57,6	62,8	63,6	56,1	62,4	60,7	63,1
	P=0.023		P=0.028		NS		NS		NS		P=0.049		NS	
Negative impact of care dichotomized														
Lower	44,8	37,7	26,7	19	40,6	40,4	69,8	70,5	38,9%	39,3	54,6	42,9	45,9	46,1
Higher	55,2	62,3	73,3	81	59,4	59,6	30,2	29,5	61,1	60,7	45,4	57,1	54,1	53,9
	P=0.011		P=0.0008		NS		NS		NS		P=0.0003		NS	
Quality of Life dichotomized														
Worse	44,3	54,1	64,8	67,3	62,8	61,3	47,2	46,9	37,9	35,9	40,3	51,3	49,8	51,7
Better	55,7	46,9	35,2	32,7	37,2	38,7	52,8	53,1	62,1	64,1	59,7	48,7	50,2	48,3
	P=0.0022		NS		NS		NS		NS		P=0.00067		NS	

9.3.4 The Follow-up Questionnaire and the mode of its administration

The questionnaire used for the follow-up was developed as a shortened form of the CAT instrument. The idea was to repeat as few of the CAT's questions as necessary in order to discern any possible changes during the course of one year in the care arrangements of the family carer and their cared-for person.

The FU questionnaire was comprised of the following sections:

- Identifying data (number of questionnaire as in the initial study, interviewer's details, date of interview);
- Mode of FU questionnaire administration;
- Filter question identifying "present carers" still caring for their older relatives (for whom the full version of the FU questionnaire was used) and "ex-carers" who had stopped caring (who completed the short version of the FU questionnaire);
- Time, reasons and circumstances of withdrawal from the caring process (only for "ex-carers");
- Current quality of life (for "still caring" and "ex-carers");

The section for "still caring" carers was comprised of the following themes:

- Living arrangements;
- Occupational status and the economic consequences of caring;
- Restrictions on carers and on their professional career;
- Level of psycho-physical disability of the older person;
- Subjective outcome of caring, measured with COPE-Index;
- Older Persons' and carers' usage of services (the same as at the baseline study)
- Helpfulness of services in carers' opinions;
- Willingness to continue care.

The FU questionnaire consisted of 36 questions (compared to the 193 questions of the CAT applied in the baseline study) and used the same wording as the similar questions present in the CAT.

Table 4: Mode of administration of the FU questionnaires

	Germany N=451		Greece N=282		Italy N=863		Poland N=875		Sweden N=575		UK N=316		Total N=3362	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Postal	441	*97,8*	0	*0*	1	*0,1*	0	*0*	574	*99,8*	277	*87,7*	719	*25,8*
Phone call	10	*2,2*	238	*84,4*	503	*58,3*	98	*11,2*	0	*0*	39	*12,3*	888	*31,9*
Combined postal, phone	0	*0*	2	*0,7*	19	*2,2*	2	*0,2*	1	*0,2*	0	*0*	22	*0,8*
Face-to-face	0	*0*	42	*14,9*	340	*39,4*	775	*88,6*	0	*0*	0	*0*	1157	*41,5*
Total	451	*100*	282	*100*	863	*100*	875	*100*	575	*100*	316	*100*	2786	*100*

Financial constraints prevented most countries from using the same mode of administration used for the baseline study - the "face-to-face" interview - also in the FU, since only Poland (89%) and to some extent Italy (39%) were able to followed it (see **Table 4**) . In Germany and in the UK the postal method dominated (98% and 88% respectively), while in Greece and Italy the predominant method used was the telephone (84% and 58% respectively).

The FU intended to resurvey the family carers 365 days after the baseline study with 1 month of tolerance. This aim was accomplished in most countries, with an overall average delay of 20 days for the whole European sample (**Table 5**), lesser delays in the UK (3 days), Germany (4 days), Italy (7 days) and Poland (15 days), and longer ones in Greece (52 days) and Sweden (55 days).

Table 5: Interval between T1 and T2 studies (in days; STD)

Germany N=451	Greece N=282	Italy N=863	Poland N=875	Sweden N=569	UK N=310	Total N=3350
369; ±27,5	417,8; ±73,9	371,6; ±18,8	380,8; ±25,5	419,9; ±30,6	368,3; ±49,1	385,5; ±40,1

9.3.5 Analyses and Statistics

All the FU data were entered using a common template created in SPSS software. The cleaning procedures were performed twice - at national and European levels - and the merging and matching procedure allowed the creation of the integrated CAT-FU dataset.

Figure 2: Design of the Follow-up Study

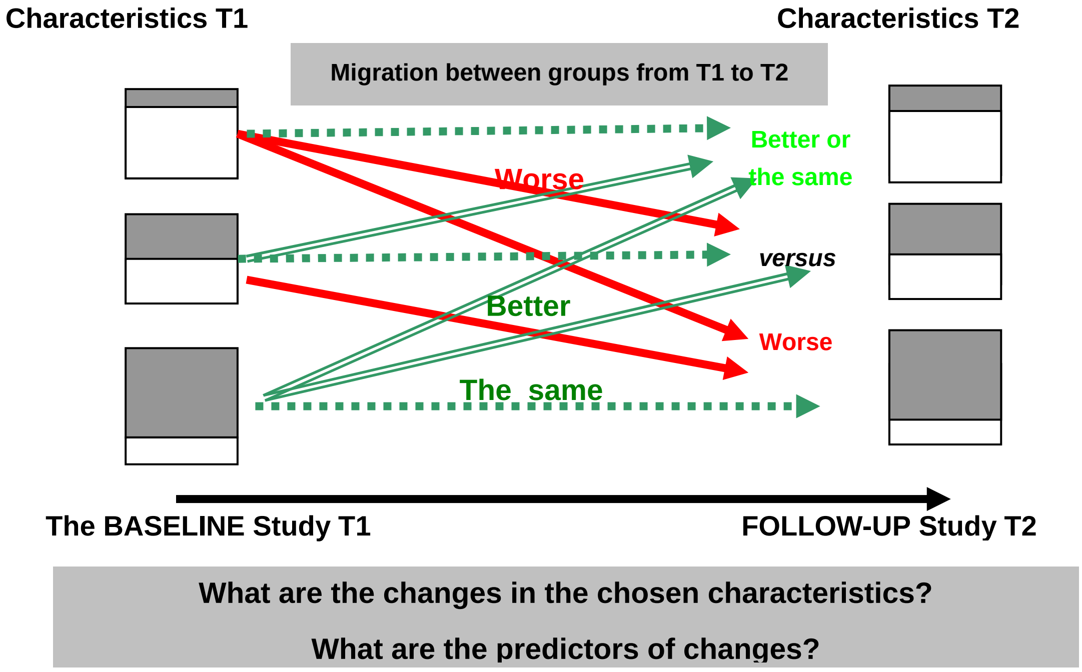


Figure 2 presents the overall design of the Follow-up study. The main aim was to find or discriminate between those carers whose characteristics "changed into a better state" (and/or those unchanged) versus those reporting a "worse" situation with respect to each of the analysed variables. The purpose was to examine carers' transitions from one to the other modalities within the T1 - T2

timeframe, in order to address some crucial questions: What are the changes over time in the chosen characteristics? What are the predictors of changes (both positive and negative)?

To enable such assumptions to be examined, the same syntaxes as for the baseline dataset, but adapted to the FU records, were run on the merged CAT-FU dataset to create the FU derived variables, thus ensuring comparability between T1 and T2 analogous variables. To reveal changes over time, the analogous T1 and T2 ordinal variables/measures were subtracted (e.g., scores on the scales), and the obtained values dichotomised/trichotomised into two/three modalities, those which improved/stayed the same and those which worsened.

To reveal the dynamics of change over time with regard to nominal variables, cross-tabs (T1 by T2 within analogous variables) were created. The significance of change between the T1 and T2 waves of study was tested by means of the chi square Pearson's test.

Integrated measures of subjective outcomes from caring:

The development of an integrated measure for the QoL enabled the coverage of more dimensions or components of such complex and subjective phenomena as well-being or quality of life. Two aggregated outcome measures were created through the method of clustering using K-means, based on the following five outcome measures (used both at T1 and T2):

(1) carer's self-perceived health status;

(2) 5-item QoL;

(3) QoL in the last two weeks;

(4) negative impact of care based on 7-items of COPE Index;

(5) positive value of care based on 4-items of COPE Index;

(6) overall impact of care-giving based on the final item of the COPE-Index.

The first of the two aggregated measures expresses "**the global carer's well-being**". Based on the five domains of carers quality of life mentioned above, this measure was developed for "still caring" carers, as it includes positive and negative outcome of care in carers in T2. These outcomes of caring could not be measured in "ex-carers", as they gave up caring before the T2 study. In order to be comparable between the two points of time, the syntaxes for this variable were run separately on the CAT data and on the FU data referring to carers caring for their elders at both points of time, so as to reveal any changes.

Table 6: Transition in "global carer's well-being" between time T1 and T2 amongst "still-caring carers" (n=1966; missing 482)

		T2 Higher well-being	**T2** Intermediate well-being	**T2** Lower well-being	Total
T1	Higher well-being % of row	478 64%	228 30,5%	41 5,5%	747 100%
T1	Intermediate well-being % of row	258 32,5%	379 47,7%	157 19,8%	794 100%
T1	Lower well-being % of row	50 11,8%	134 31,5%	241 56,7%	425 100%
	Total N % of row	786 40%	741 37,7%	439 22,3%	1966 100%

Based on the results from the baseline study, three clusters of carers were recognizable (total no = 2344; missing 104): those with "higher global well-being", those with an "intermediate global well-being" and those with a "lower global well-being". Based on the data from the FU study, analogous categories of clusters were identified (total no = 2037; missing 411). By cross-tabulation, the changes in global well-being are shown in **Table 6**.

In T2 most carers still show the same modality (1,098 out of 1,966 = 56%). However, there is also movement in both directions. 426 (=22%) carers are in cells above the diagonal line i.e. their global well-being has decreased. A similar number of carers 442 (=22%), however, showed an improved well-being. Thus there is mobility, but no clear trend for either improvement or changes for the worse.

Based on newly created variables, a derived dichotomised variable was created in order to discriminate between carers who had experienced an improvement or maintained their global well-being versus carers reporting a worsened level of well-being. The second integrated measure concerning the outcome from caring was developed in the same way, but based only on the first three of the five components of global well-being listed above. This measure, termed the "**overall quality of life**", could be used for both "still caring" carers and "ex-carers".

Table 7: Transition in the "overall quality of life" between time T1 and T2 in all resurveyed carers (n=3186; missing 176)

		T2 Higher QoL	T2 Intermediate QoL	T2 Lower QoL	Total
T1	Higher QoL % of row	589 51,4%	430 37,6%	126 11%	1145 100%
T1	Intermediate QoL % of row	270 21,9%	627 50,9%	335 27,2%	1232 100%
T1	Lower QoL % of row	103 12,7%	269 33,3%	437 54%	809 100%
	Total N % of row	962 30,2%	1326 41,6%	898 28,2%	3186 100%

Three clusters of carers were identified based on the data from the baseline study (total no = 3,320; missing 42): those with "higher quality of life", "intermediate quality of life" and "lower quality of life". Similar cluster categories of the same carers after one year were recognised (total no = 3,326; missing 36). **Table 7** shows the transition in the overall quality of life in all resurveyed carers between time T1 and T2. Once again, for more than half of the carers (1,653 carers representing 52% of the sample) there was no change between T1 and T2. For this variable the move to the worse, that is into cells above the diagonal line, is more prominent (n= 891 representing 28% of the sample) than the move to the better, that is below the diagonal line (n = 641 that is 20%).

Services' comparison between T1 and T2

As a first step all partners were asked to send to Poland the lists of those services, which were exactly applied in both the T1 and T2 waves of studies. As a second step, all services that had not got exactly the same counterparts in both points of study were removed from the comparison, leaving only those properly matched (e.g. service no 1 from T1 and service no 1 from T2 study, etc.). Two new CAT variables (services for elders and services for carers after matching) [tot_se_r; tot_sc_r], as well as two new analogical FU variables [f_tot_se_r; f_tot_sc_r] were created. After detracting from the CAT variables the FU analogical variables, the next two new variables were obtained: d_tot_se_r (difference in total number of services used by elder between T1 and T2, after matching), and d_tot_sc_r (difference in total number of services used by carer after matching).

These variables were dichotomized (more versus less or the same) or trichotomised (more or the same or less services) in the next phases of analyses. This kind of reasoning enables the comparisons between numbers of types of services between two points of the study, thus it shows the scope or range in services usage, and it does not show a change in intensity of the particular service.

An intensity of service usage was defined as the number of services' units per particular service received by elder/carer in the last six month prior to T1 and T2 study. Comparison of these numbers of units with reference to each service listed in the national questionnaires between T1 and T2 allows the estimation of change in intensity of service usage over a year.

In the first step of the procedure, the partners were ask to convert different units per single service applied in their national CAT at T1 study into one unit per service recorded in the FU questionnaire, at T2 study (at T1 the respondent was free to choose, given a choice of relevant unit per relevant service). The unification of different units of services for both waves of the studies was the condition for comparison of the numbers of units received by elder/carer in the last six months between T1 and T2 study. All partners, except Greece, sent to the Polish partner the estimated equivalents of the relevant services' units (e.g. GP's advice expressed in hours in T1 study had to be converted into one or two or three visits, arbitrarily established by the national partner). Then the relevant syntaxes for number of units for six months per each comparable service were identified for each of the countries (except Greece). However, due to shortage of time and funds, the analysis concerning the change in intensity of services' usage had to be postponed, and could not be included to this chapter. Due to different codes of the different services applied in each of the countries, the further analysis can be done on a national level only. In the subsequent analyses, particularly in section 9.3.4, a simpler analysis is pursued. For the original survey and follow up for each service, a dichotomous variable is constructed with use or non-use. Then the changes in these variables are analysed for all services with numbers of usage in T1 being sufficiently high for the analyses.

9.4 Main findings

9.4.1 Socio-Demographical changes in the caregiving situation

9.4.1.1 Continuity versus discontinuity in care: Reasons for discontinuity in care

In the European sample, as many as 73% of the original family caregivers were continuing the caregiving process after one year. The highest percentages of "still caring" carers were present in the Polish (82%) and Italian samples (79%), and the lowest in the German sample (60%). The withdrawal from the caregiving process concerned 27% of carers in the whole European sample. The highest percentage of ‘withdrawers’ appeared in the German (40%), Swedish (35%) and British (33%) samples (**Table 8**). More than half of those stopped because of the elders' death.

Table 8: "Continuity" versus "discontinuity" in caregiving for the older relatives over one year

	Germany	**Greece**	**Italy**	**Poland**	**Sweden**	**UK**	**Total**
No of valid	*N=451*	*N=282*	*N=863*	*N=875*	*N=575*	*N=316*	*N=3362*
Still caring	272	194	679	714	375	212	2446
% by country	60,3%	68,8%	78,7%	81,6%	65,2%	67,1%	72,7%
Stopped caring*	179	88	184	161	200	104	916
% by country	39,7%	31,2%	21,3%	18,4%	34,8%	32,9%	27,3%
Due to:							
Elder's death	115	62	130	106	107	57	577
% by country	25,5%	22%	15,1%	12,1%	18,6%	18%	17,2%
Other family member provides care now	13	13	27	32	7	8	100
% by country	2,9%	**4,6%**	**3,1%**	**3,7%**	1,2%	2,5%	3%
Professional carer provides care now	5	3	8	4	15	6	41
% by country	1,1%	1,1%	0,9%	0,5%	2,6%	1,9%	1,2%
Transferred to nursing home	40	1	18	5	71	18	153
% by country	**8,9%**	0,3%	2,1%	0,6%	**12,4%**	**5,7%**	**4,6%**
Lack of data, or other reason	6	9	1	14	0	15	45
% by country	1,3%	3,2%	0,1	1,5%		4,8%	1,3%

* Number of stopped caring can be lower than number of other reasons, because if elder died, carer could tick the last carer before death

The most common cause of withdrawal from caring was the older person's death (17,2% of re-surveyed carers). Death rates were highest in Germany (25,5%), Sweden (18,6%) and the UK (18%), and the lowest in Poland (12,1%) and Italy (15%). Reasons for withdrawal of care other than older persons' deaths are shown in **Table 9**.

Table 9: Reasons for withdrawal of care, other than older person's death (N=339)

	Germany	**Greece**	**Italy**	**Poland**	**Sweden**	**UK**	**Total**
No of valid	*N=64*	*N=26*	*N=54*	*N=55*	*N=93*	*N=47*	*N=339*
Transfer to nursing home	40	1	18	5	71	18	153
% by country	62,5%	3,8%	30%	9,1%	76,4%	38,3%	45,1%
Transfer to professional carer	5	3	8	4	15	6	41
% by country	7,8%	11,5%	13,3%	7,3%	16,1%	12,8%	12,1%
Transfer to other relative	13 20,3%	13 50%	27 45%	32 58,2%	7 7,5%	8 17%	100 29,6%
Other events/ missing data	6 9,4%	9 34,7%	1 11,7%	14 25,4%	0	15 31,9%	45 13,2%
Total	64	26	54	55	93	47	339
% in column	100%	100%	100%	100%	100%	100%	100%

The second most common reason for withdrawal was the older person's transfer to a nursing home (5% of withdrawals in the European sample, and 45% of other reasons than cared-for person's death), while the third was the transfer of caring to another family member (3%, and 30% respectively).

The predominant causes of withdrawal from caring varied from country to country.

The transfer of the cared-for persons to a nursing home or to other care units was most common in Sweden (76% of ex-carers), and to lesser extent in Germany (63%), UK (38%), and Italy (30%), whilst in Greece and Poland the relevant proportions did not exceed 10%. Institutional care, as the most expensive form of care, is probably more available in the more wealthy countries, especially when family's carers' resources are limited and where strong intergenerational ties or moral expectations in the national traditions are missing.

The transfer of the older person to another relative was most prevalent in Poland (58%), in Greece (50%), and also in Italy (45%), whilst this was least common in Sweden, UK and Germany (**Table 9**).

Being in the care of professional carers, as a form of public community support, concerned relatively higher percentage of elders in Sweden and UK when carers' withdrew from care.

9.4.1.2 Mortality in the care-for elders sample

In the whole European sample the death rate was 17,2%. The highest rates were observed in Germany, and the lowest in Poland. Despite the fact that the Polish sample of family carers was not the youngest amongst the national samples, it consisted of relatively less dependent persons. This may explain the lowest mortality rate in Poland. Due to the different structure of recruitment channels used by the partners, however, a comparison of the death rates between countries is not appropriate. Higher mortality was evident especially amongst the older group of cared-for elders and those in metropolitan and urban localities, and the lowest in the rural ones.

Table 10: Mortality rates per chosen characteristics and country [% by category & by country]

	Germany	Greece	Italy	Poland	Sweden	UK	Total
	N=451	N=282	N=863	N=875	N=575	N=316	N=3362
Died by T2 (n) **Mortality rate (%)**	115 **25,5**	62 22,0	130 15,0	106 12,1	107 18,6	57 18,0	577 17,2
Age							
Age <80 n=1459	35 21,2	27 20,0	36 11,6	41 8,4	38 16,5	17 12,9	194 13,3
Age >=80 n=1885	77 27,6%	35 23,8%	94 17,0%	65 16,8%	67 19,8%	40 22,0%	378 20,0%
Type of locality							
Metropolitan n=704	46 **27,7%**	9 **28,1%**	38 **21,1%**	45 **15,2%**	2 18,2%	4 **22,2%**	144 **20,5%**
Urban n=1603	45 25,6%	34 25,4%	64 12,8%	28 11,7%	67 **18,9%**	36 18,2%	274 17,1%
Rural n=1044	24 22,0%	19 16,4%	28 15,4%	33 9,7%	35 17,7%	17 17,0%	156 14,9%
I-ADL dependency							
Low to moderate n=1011	18 23,1	10 12,2	15 6,1	21 5,8	24 14,7	10 10,1	98 9,7
More severe n=2324	96 **25,8%**	51 **25,9%**	46 **18,1%**	83 **16,5%**	82 **20,3%**	46 **21,7%**	473 **20,4%**
Cognitive disorders							
Intellectually able n=1235	20 19,6	19 17,9	35 10,6	28 7,5	39 18,8	21 17,8	162 13,1
Probable/suspected n=2109	93 **27,1%**	40 **23,5%**	95 **17,8%**	78 **15,5%**	67 **18,5%**	36 **18,4%**	409 **19,4**

More severe physical and to a lesser extent psychical disability in the older cared-for person predicted a higher probability of death in all of the studied countries. Details are presented in Table 10.

9.4.1.3 Institutionalisation rates in the cared-for sample

Transfers to nursing homes concerned 4,6% of the sample re-surveyed after the year. The highest percentage was observed in Sweden and Germany, the lowest in Greece and Poland (**Table 11**). The strongest predictors of that decision were cognitive disorders, more severe ADL dependency in the cared-for elders and higher initial negative outcome of care in family carers. Institutionalisation was more common amongst the older than the younger cohort of elders, also for those living in urban areas compared to those in rural areas.

Table 11: Institutionalisation rates per year and per country [in % of category within country]

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	*N=451*	*N=282*	*N=863*	*N=875*	*N=575*	*N=316*	*N=3362*
In whole sample % of country	40 8,9%	1 0,3%	18 2,1%	5 0,6	71 12,4%	18 5,7%	153 4,6%
In age <80 n=1459	16 9,7%	1 0,7%	5 1,6%	2 0,4%	22 9,6%	7 5,3%	53 3,6%
In age >=80* n=1885	24 8,6%	0	13 2,4%	3 0,8	48 14,2%	11 6%	99 5,3%
Type of locality							
Metropolitan n=704	14 8,4%	1 3,1%	9 5,0%	0	0	0	24 3,4%
Urban n=1603	16 9,1%	0	3 0,6%	4 1,7%	49 13,8%	10 5,1%	82 5,1%
Rural n=1044	10 9,2%	0	6 3,3%	1 0,3%	20 10,1%	8 8,0%	45 4,3%
I-ADL dependency							
Low to moderate* n=1011	4 5,1%	0	2 0,9%	1 0,3%	7 4,3%	2 2,0%	16 1,6%
More severe* n=2324	36 9,7%	1 0,5%%	16 2,5%	4 0,8%	63 15,6%	16 7,6%	136 5,9%
Cognitive disorders							
Intellectually able n=1235	7 6,9%	0	3 0,9%	1 0,3%	9 4,3%	1 0,9%	21 1,7%
Probable/suspected n=2109	33 9,6%	1 0,6%	15 2,8%	4 0,8%	62 17,1%	17 8,7%	132 6,3%
Working conditions of carer							
Nonworking n=2093	17 5,9%	1 0,6%	10 2,0	4 0,8%	45 11,5%	13 5,8%	90 4,3
Working n=1249	22 13,9%	0	8 2,2%	1 0,3%	26 14,4%	5 5,7%	62 5%
Negative impact of care in T1							
Lower negative impact n=1536	15 8,9%	1 1,9%	3 0,9%	0	20 9,0%	2 1,5%	41 2,3%
Higher negative impact n=1793	25 10%	0	15 2,9%	5 2,0%	50 14,5%	16 9,0%	111 6,2%
Carer's self-perceived health in T1							
Better health (1-3) n=1989	26 8,5%	0	8 1,6%	2 0,5%	47 12,7%	15 7,1%	98 4,9%
Worse health (4-5) n=1357	14 9,8%	1,0%	10 2,8%	3 0,7%	24 12,8%	3 3,0%	55 4,1%

9.4.1.4 Discontinuity of care - possible predictors

The withdrawal rate from the caregiving process over one year was quite high. As shown above, of those carers who stopped caring for their older relatives, as many as 37% took such a decision for reasons other than the death of the person cared-for, representing 10% of the whole followed-up sample. It would be interesting to know the reasons or events that led to the carer stopping being the main care-giver, excluding those carers who stopped caring because of the death of the cared-for person.

Table 12: Predictors of withdrawal from care (dependent on older persons)

	"Ex-carers"	"Still caring" carers	Total
	Elder alive but carer stopped care	*Elder alive and carer still continues caring*	
	N=336 (MD=3)	N=2436 (MD=10)	N=2772 (MD=13)
Elder's age at T1 (p=0,056)			
80+	59,2%	53,7%	56,4%
Cohabitation with carer at T1 time (p=0.0000)			
The same household	32,7%	55,6%	40,3%
Older person was living alone at T1 (p=0.00000)			
Yes	42,5%	25,5%	27,6%
Older person was living with child at T1 (p=0.00000)			
Yes	30,8%	49,8%	47,9%
Memory problems in older person at T1 (p=0.0007)			
Yes	56,3%	46,5%	47,7%
Elder's behavioural disorders or probable dementia (p=0.0000)			
Yes	62,4	49,4	53
IADL disability (p=0.04)			
More severe dependency	71,9	66,3	69,7
V414 Elder's needs for physical/ personal support (p=0.03)			
Yes	69,8	64,4	67,9

In order to investigate in depth the reasons or events that led the carer to stop being the main caregiver (excluding the death of the cared-for persons), 80 chosen characteristics related to the older person and to the family caregivers were tested (with chi-square test). All variables showing a significantly different distribution ($p<0.05$) between the group of "ex-carers" and that of the "still caring" carers are presented in **table 12** (related to the older persons) and in **table 13** (related to the carers).

Amongst the variables dependent on the older person, the most significant in predicting the change in the carer over one year were, the older person being over 80 years of age, living alone, with memory or behavioural problems, more ADL-dependent and demanding more physical or personal carer's help. On the other hand, cohabitation with the carer in the same household, cohabitation with their own child/children, especially with those having their own children aged over 14 years, predicted continuity of care by the same carer (**table 12**). Urban/rural areas of living, older person's gender, and number of needs for help or support (medical, physical, personal, domestic, organisational, etc.) did not influence the withdrawal from care during the follow-up year.

Amongst predictors dependent on the carer withdrawing from care (**table 13**) was the shorter duration of caring, lower involvement in different spheres of help (medical, physical, personal, domestic, organisational), poorer emotional bonds with older person, lower religiosity in the carer and lower engagement in the caring process. Additionally, higher support from formal services, and accidentally taking the decision to care also predicted withdrawal from caring after a year.

No connection was found between discontinuing care and the carer's gender, his/her marital status, level of education, employment status, self-perceived health, outcomes of care, or possible restrictions on life or professional career.

Table 13: Predictors of withdrawal from care (dependent on carer) [in % in column within category]

	"Ex-carers"	**"Still caring" carers**	**Total**
	Elder alive but carer stopped care	***Elder alive and carer still continues caring***	
No of valid	*N=336 (MD=3)*	*N=2436 (MD=10)*	*N=2772 (MD=13)*
Duration of caregiving process (p=0.0001)			
More than two years	59,6%	69,9%	68,2%
Carer's engagement in medical help (p=0.00000)			
Yes	73,5%	87,3%	85,5%
Carer's engagement in physical/ personal help (p=0.00000)			
Yes	74,0%	87,9%	86,1%
Carer's engagement in help in mobility (p=0.00007)			
Yes	85,4%	92,5%	91,6%
Carer's engagement in housework help (p=0.0007)			
Yes	81,5%	88,3%	87,5%
Carer's engagement in financial management (p=0.00000)			
Yes	83,9%	92,4%	91,4%
Carer's engagement in organisational support (p=0.0007)			
Yes	87,8%	93,4%	92,8%
Percentage of needs covered by the main carer (0.00000)			
More than 50%	91,5%	95,8%	95,0%
Percentage of needs covered by formal services (0.0002)			
More than 50%	5,5%	1,7%	2,6%
Emotional bonds as a motive of care (0.0002)			
Yes	90,3%	95,1%	94,5%
Religious beliefs as a motive of care (0.0003)			
Yes	30,1%	40,3%	39%
"By chance" as a motive of care (0.02)			
Yes	47,5%	40,8%	41,6%
A personal sense of obligation as a motive for care (0.02)			
Yes	73,2%	78,7%	78,1%
Additional costs for medicines (0.00000)			
Yes	36,87%	50,51%	48,9%
I am quite or very religious (0.00000)			
Yes	68,7%	81,3%	79,8%
Child (children) in carer's household (0.05)			
Yes	13,9%	18,2%	17,7%

9.4.1.5 Changes in intensity of caring for elders and other cared-for persons

Intensity of caregiving after a year was measured as in the baseline study, namely, as an average number of hours per week supporting or helping the older person. A comparison of these two numbers shows changes in the intensity of caring. The comparison was carried out on the FU sub-sample of "still caring" carers interviewed with the extended version of the FU questionnaire.

Table 14: **Changes in the intensity of care (no of hours/week) amongst carers still caring between T1 and T2**

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	*248*	*192*	*667*	*708*	*335*	*194*	*2364*
An average change in number of hours of care/week	-7,8	+20,9	-2,7	-4,8	+4,5	-9,5	-1,4
STD	±51,4	±68,5	±32,1	±43,7	±45,7	±51,1	±45,9

For the whole European sample, intensity of care after a year was somewhat lower than at the time of the baseline study, by an average of 1.4 hours per week (**Table 14**). The phenomenon is apparent in all countries with the exception of Greece and Sweden, where a higher or lower increase in the intensity of care was observed. If Greece is excluded, the amount of care-giving decreases by 4.9 hours a week on average. One explanation of this result can be that caregivers became more accustomed to their role and responsibilities and can better cope with everyday tasks.

The distributions of categories of carers in terms of an increase, maintenance or decrease in the number of hours for care after a year, is presented in **table 15**.

Table 15: **Distribution of caregivers by change in an intensity of care during a year**

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	*248*	*192*	*667*	*708*	*335*	*194*	*2364*
Less hours per week than at T1	108 43,6%	70 36,5%	245 36,7%	311 43,9%	134 37,7%	80 41,2%	948 40,1%
The same hours per week as at T1	40 16,1%	18 9,4%	145 21,7%	86 12,2%	66 18,6%	40 20,6%	395 16,7%
More hours per week than in T1	100 40,3%	104 54,1%	277 41,5%	311 43,9%	155 43,7%	74 38,1%	1021 43,2%

In two countries (Germany, UK) the number of people with reduced hours of care-giving is higher than that of those with increased hours of care; in Greece, Italy, and Sweden it is vice versa. As the average hours of care was also reduced in Italy and Sweden, there must be a greater reduction in the group of reducers than there is an increase in the group of increasers.

In seeking an explanation for the lower intensity of care after a year, the amount of care was compared within two sub-categories: (1) a category of persons cared-for with improved or the same I-ADL dependency *versus* (2) a category with worsened I-ADL dependency during the follow-up year. (**Table 16**).

Table 16: Difference in the intensity of care between T1 and T2 by categories: "I-ADL better or the same" *versus* "I-ADL worse" than at T1

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Better or the same I-ADL dependency than at T1							
No of valid	*173*	*116*	*447*	*485*	*202*	*114*	*1547*
An average difference in hours per week (T1-T2)	**-9,4**	**+16,5**	**-5,1**	**-4,6**	**+4,3**	**-16,0**	**-3,3**
STD ±	54,2	68,6	33,1	48,6	44,7	47,0	44,4
Worse I-ADL dependency than at time T1							
No of valid	*60*	*60*	*209*	*203*	*130*	*66*	*728*
An average difference in hours per week (T1-T2)	**+0,1**	**+28,9**	**+2,8**	**-6,7**	**+8,0**	**+0,1**	**+2,8**
STD ±	37,9	70,7	28	53,7	44,6	54,2	47,5

Despite a slight decrease in the intensity of care in the whole European sample, measured in terms of the average number of hours of care per week, differences in the number of hours of care related to the physical condition of the older persons were found. In the sub-group of "Better or the same I-ADL dependency than at T1", the average number of hours per week decreased by 3.3, whilst in the sub-group "Worse I-ADL dependency than at T1" , it increased by 2.8. The same direction of change was found in all countries with the exception of Poland (**Table 16**). It is likely that a carer cohabiting with the cared-for person, which is a widespread arrangement in Poland, finds it difficult to measure accurately the intensity of care, counted in hours per week, as it is really difficult to estimate how many hours might be ascribed to supporting the older person given the continuity of days and nights living together.

A significant connection (p=0.0003) was found in the European sample between changes in the intensity of care (lower than at T1; the same; higher than at T1) and changes in the negative impact of care (better than at T1; the same; worse than at T1). Carers with more intensive care-giving at T2 more often experienced a greater burden from caring than before (T1).

9.4.1.6 Change in living arrangements in relation to the distance of the carer's home from the cared-for person

The distance between the carer and her/his cared-for person’s place of living may be strongly connected with reciprocal support, help, and the elders' level of dependency, especially when caregiving is provided by spouse. Less distance may make the caring process easier, although sometimes cohabitation might be a result of other factors e.g. a shortage of apartments, carers' or elders' financial situation, better access to service networks, etc.

Changes in living arrangements between time T1 and T2 of the FU study are presented in **table 17**. The changes between categories of initial carers' and elders' mode of cohabitation were recoded into two modalities: those living in the same household or building versus those living in another place, at least within walking distance.

The lapse of time did not cause a big change in the mode of cohabitation for carers and their elders in the vast majority of cases (88%) in the European sample. On average, only every tenth carer in the European sample (of those living initially in different buildings) moved from his/her own home to the elder's household/building or moved the older person to the carer’s own house during the last year. However, if we look at those initially living in different houses, this direction of moving concerned almost every fourth older person or carer.

Table 17: Changes in the mode of cohabitation between time T1 and T2.

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	*N=262*	*N=193*	*N=671*	*N=714*	*N=372*	*N=208*	*N=2420*
Moved from different to the same houses (n)	41	37	91	69	8	7	253
% of initial residents of different houses within countries	30,8	47,4	24,5	34,3	4	7,9	23,6
(% column)	**15,7**	**19,2**	**13,6**	**9,6**	**2,1**	**3,4**	**10,4**
Moved from the same to different houses (n)	5	7	9	14	7	3	45
% of initial residents of the same houses within countries	3,9	6,1	3	2,7	4	2,5	3,3
(% column)	**1,9**	**3,6**	**1,3**	**2**	**1,9**	**1,4**	**1,9**
Without change (n)	216	149	571	631	357	198	2122
(% column)	**82,4**	**77,2**	**85,1**	**88,4**	**96**	**95,2**	**87,7**

This change was more prevalent in Greece (47%), Poland (34%) and Germany (31%), whilst marginal in Sweden (2%) and UK (3,4%). Nevertheless, in the European sample transfers to the same buildings were five-times more prevalent than the opposite (from the same house to different houses), ranging from tenfold in Italy, eight-times in Germany, five-times in Greece and Poland to equal in Sweden and UK. This may support the hypothesis that the lapse of time and the progress of disability in older persons probably leads to common cohabitation. This will be explored in further analyses.

9.4.1.7 Changes in carers' occupational status in connection with restrictions of care on professional career

As many as 89% of the European carers did not change her/his employment status. 56% of them remained still unemployed, and 33% still working. Only 5,6% of the European sample came employed, and almost the same proportion stopped her/his employment.

Table 18: Transition of the employment status between time T1 and T2

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	*N=268*	*N=190*	*N=671*	*N=714*	*N=352*	*N=205*	*N=2400*
Began work between T1 and T2	11 4,1%	17 9%	27 4%	66 9,2%	10 2,8%	4 1,9%	135 5,6%
% of initial non-workers within country	*6%*	*14,2%*	*7,2%*	*15,6%*	*4,3%*	*2,8%*	*9,2%*
Stopped working between T1 and T2	7 2,6%	13 6,8%	28 4,2%	48 6,7%	16 4,6%	12 5,9%	124 5,2%
%of initial workers within country	*8,1%*	*18,6%*	*9,4%*	*16,5%*	*13,5%*	*19,1%*	*13,4%*
No change (% of country)	250 93,3%	160 84,2%	616 91,8%	600 84%	326 92,6%	189 92,2%	2141 89,2%

However, if one observes the changes within the sub-groups of initially non-working carers as well as in the initially working carers, one finds that withdrawal from employment prevails over the taking up of a new job over the one year in all of the countries (**Table 18**). The most equal proportions between "new workers" and "ex-workers" were found in Germany, Italy and Poland, although in the latter the rates were almost twice as high in both directions. In Sweden and UK those who stopped working over the year significantly prevailed over those who began a job.

Being employed and caring for an older person generates potential restrictions on the carer's professional career. Sometimes the need for care forces a reduction in working hours or the necessity to quit the job. **Table 19** shows carers' opinions on possible restrictions due to caring on professional life amongst the sub-groups of currently working and currently not working (at T2).

Table 19: Restrictions on professional career in the groups of "current workers" and "current non-workers" (at T2)

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Working at T2							
No of valid cases	*N=78*	*N=49*	*N=277*	*N=303*	*N=105*	*N=48*	*N=860*
Despite caring, my working hours are unchanged	58 74,4%	44 89,8	250 90,3%	287 94,7%	82 78,1%	37 77,1%	758 88,1%
Because of caring I had to reduce my working hours	17 21,8%	5 10,2	25 9%	9 3%	15 14,3%	11 22,9%	82 9,6%
I had to reduce my working hours for another reason than caring	3 3,8%	0	2 0,7%	7 2,3%	8 7,6%	0	20 2,3%
Not working at T2							
No of valid cases	*N=135*	*N=80*	*N=208*	*N=359*	*N=197*	*N=113*	*N=1092*
Because of caring I could not carry out my job at all	16 11,9%	48 60%	17 27,4%	10 2,8%	192 97,5%	31 27,4%	314 28,7%
Because of caring I had to give up my job	20 14,8%	1 1,2%	5 2,4%	7 2%	1 0,5%	8 7,1%	42 3,9%
I stopped work for another reason than caring	99 73,3	31 38,8%	186 89,4%	342 95,2%	4 2%	74 65,5%	736 67,4%

The vast majority of currently (at T2 time) working carers (88% of the total sample) is struggling with caring responsibilities without any reduction in working hours. That is especially visible in the Polish (95%), Italian and Greek (90%) samples. In the other countries the proportions of those who reported restrictions on their professional careers were much higher. In Germany, Sweden and UK, almost every fourth carer had had to reduce their working hours, mainly because of caring for their older person.

Amongst currently non working carers, most stopped work for another reason than caring (67% in the EU sample). The highest proportion of carers making such statements was found in Poland (95%), where the unemployment rate is still quite high (17,3% in 2005), and almost every fourth Pole is a retiree or pensioner (GUS, 2005). Also similarly high proportions were found in Italy (89%) and Germany (73%), and to lesser degree in UK (66%), where it may be connected with the retirement age of carers. Surprisingly, an extremely high percentage of carers in Sweden (98%) admitted that they could not carry out their work because of caring. Other than Sweden, the highest percentages of carers with restrictions on work due to caring were found in Greece (61%), Italy (30%), and Germany (26%).

Table 20: Other restrictions from caring (at T2)

	Germany	**Greece**	**Italy**	**Poland**	**Sweden**	**UK**	**Total**
I can/could not develop my professional career or studies due to caring (at T2)							
No of valid cases	*227*	*189*	*648*	*714*	*320*	*182*	*2280*
YES	28 12,3%	38 20,1%	24 3,7%	28 3,2%	31 9,7%	39 21,4%	188 8,3%
I can/could work only occasionally (at T2)							
No of valid cases	227	189	636	707	271	156	2186
YES	36 15,9%	30 15,9%	19 3%	24 3,4%	15 5,5%	50 32,1%	174 8%
If you needed a break from your caring role is there someone who would look after ELDER for you (at T2)							
No of valid cases	262	192	671	714	112	207	2395
Yes, quite easily	69 26,3%	87 45,3%	260 38,8%	446 62,5%	86 24,6%	49 23,6%	997 41,6%
Yes, I could find someone, but with difficulty	115 43,9%	38 19,8%	349 52%	173 24,2%	151 43,3%	91 44%	917 38,3%
No, there is no one	78 29,8%	67 34,9%	62 9,2%	95 13,3%	112 32,1%	112 32,4%	481 20,1%

On the contrary, restrictions on professional life concerned a minority of carers. Difficulties in developing professional careers or studies were declared by 8% of the carers in the EU sample, but within countries these figures ranged from about 20% in UK and Greece to 3% in Poland (**Table 20**). The possibility of taking up work, even odd jobs, was raised by 32% of carers in UK, 16% in Germany and Greece, and only 3% in Italy and Poland.

Table 21: Change in the possibilities of making a break in caring for older person

	If you needed a break from your caring role is there someone who would look after ELDER for you?	**T2** Yes, I could find someone quite easily	**T2** Yes I could find someone, but with some difficulty	**T2** No, there is no one	Total
	No of valid	N=997	N=917	N=477	N=2391
T1	Yes, I could find someone quite easily % of row	700 60,8%	361 31,3%	91 7,9%	1152 100%
T1	Yes I could find someone, but with some difficulty" % of row	232 31,8%	351 48,1%	147 20,1%	730 100%
T1	No, there is no one % of row	65 12,7%	205 40,3%	239 47%	509 100%
	Total N % of row	997 41,7%	917 38,3%	477 20%	N=2391 100%

Other restrictions relate to everyday life (**Table 20**). More than 50% of carers complained of difficulties in finding someone to step in for them occasionally in his/her role as a carer, simply to provide a break in caring (at T2). Most of them could find such person with difficulties, but every fifth carer in the European sample could not do it at all, especially in Greece (35%), UK and Sweden (32%) and Germany (30%).

Are these opinions stable over a year? **Table 21** shows the alterations in the individual statements over a year of longitudinal observation. Amongst those who were convinced about easily finding someone to step into the caregiver's role, as many as 61% kept the same opinion, but the rest of them changed their minds towards more pessimistic answers. Amongst those who could not find someone at the baseline study, only 47% confirmed the same statement, and the rest changed their opinions to a more optimistic response. To summarise, as many as 54% of carers kept the same opinion as the year before (double frame boxes), 21% of respondents changed their opinions in a more positive direction than a year before, and 25% changed for a more negative opinion (shadowed boxes). Thus there is more improvement in the group of the carers with highest burden than there is deterioration in the carers with lowest burden with respect to this item. Overall, i.e. also including those who could find someone, but with some difficulty at T1, 54% (n=1,290) stuck to their answers while 25% (n=599) saw an deterioration (cells above the diagonal line) and 21% (n=502) saw an improvement. Thus there is slightly more deterioration than improvement.

9.4.2 Changes in the level of the older people’s psycho-physical conditions

One-year of time may see an alteration in the level of disability of the persons cared-for, both physical and mental. Both are explored in the following subsection.

9.4.2.1 Physical disability after a year

Table 22 presents changes in I-ADL functioning, measured in terms of the number of I-ADL dysfunctions. Those whose number of dysfunctions between T1 and T2 diminished, were labelled as "improvement", those who gained new dysfunctions were labelled as "worsening", and the rest as "no change".

Table 22: Changes in I-ADL dependency between T1 and T2 [in % from columns]

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Number of dysfunctions defined as "not able or able with help"							
No of valid cases	*N=252*	*N=188*	*N=661*	*N=694*	*N=348*	*N=196*	*N=2339*
Less dysfunctions IMPROVEMENT	7,5%	19,2%	16%	31,6%	11,5%	15,8%	19,3%
The same as in T1 NO CHANGE	65,5%	48,9%	52,2%	38,7%	48,8%	49,5%	48,6%
More dysfunctions WORSENING	27%	31,9	31,8%	29,7%	39,7%	34,7%	32,1%
Number of dysfunctions defined as "not able"							
No of valid cases	N=252	N=188	N=661	N=694	N=348	N=196	N=2339
Less dysfunctions IMPROVEMENT	22,2%	25%	20,6%	27,7%	12,9%	27,5%	22,7%
The same as in T1 NO CHANGE	43,2%	21,3%	50,8%	41,8%	36,5%	45,9%	42,4%
More dysfunctions WORSENING	34,5%	53,7%	28,6%	30,5%	50,6%	26,6%	34,9%

Depending on the assumed definition of I-ADL dependency, the proportions of older people show different changes during the one year. Accepting a wider definition of dependency (number of dysfunctions defined not only as "not able" but also as "able only with help" to perform one of six I-ADL functions) the proportions both "improving" and "worsening" in I-ADL dependency were fewer in comparison to the more ambiguous definition as "not able" (compare percentages at table 22). Consequently, there is slightly more change in the group with higher grades of dependency.

In general, the time lapse caused two-way changes, both positive and negative, in older persons in their level of ADL-dependency, although the negative change significantly prevailed for both groups, i.e. for those defined as “not able” and those defined as “able only with help”. A comparison between countries allows the deduction that progress of changes depended primarily on initial levels of disability.

The same direction in changes related to personal ADL [P-ADL] measured by the number of dysfunctions ("not able or able with help") on the Barthel scale (**Table 23**).

Table 23: Changes in P-ADL dependency between T1 and T2 [in % from columns]

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Number of dysfunctions defined as "not able or able with help"							
No of valid cases	*N=244*	*N=173*	*N=648*	*N=700*	*N=334*	*N=178*	*N=2277*
Less dysfunctions IMPROVEMENT	18,4%	36,4%	21,9%	28,9%	16,8%	18%	23,7%
The same as in T1 NO CHANGE	29,1%	20,8%	28,9%	32,6%	17,7%	26,4%	27,6%
More dysfunctions WORSENING	52,5%	42,8%	49,2%	38,6%	65,6%	55,6%	48,7%
DECREASE on '0 -100 Barthel-Index Scale' (T1 - T2)							
	-8,3	-8,9	-4,6	-2,8	-10,9	-2,9	-5,5

The progress in dependency in older people is far more visible on the Barthel scale. The percentages of persons whose disability level worsened were approximately twice as high as those percentages of people whose conditions improved. The average decrease on the 0-100 Barthel scale was 5.5 per person cared-for per year, ranging from 11 in Sweden to 3 in Poland.

9.4.2.2 Mental disability after a year

In addition to physical disability, mental abilities are usually susceptible to change over time.

Table 24: Changes in memory problems [MP] between time T1 and T2

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	*N=257*	*N=193*	*N=670*	*N=714*	*N=357*	*N=208*	*N=2409*
Without MP at T1 & T2	28,9%	41,4%	44,2%	44,7%	44,1%	36,1%	41,8%
MP retreated	9,3%	11,4%	9,5%	11%	9,5%	15,4%	10,6%
MP newly appeared	9,7%	19,2%	10,8%	14,7%	7,9%	9,1%	11,9%
MP persisted up to T2	52,1%	28%	35,5%	29,6%	38,4%	39,4%	35,7%

Table 24 presents the results concerning carer reported memory impairment during the year. Most of the older people were stable in terms of memory status; thus 42% in the EU sample did not show any symptoms, either at T1 or at T2, while in 36% there was a problem but it remained stable over the year. More than one in every ten persons cared-for began to show memory problems, whilst almost the same proportion stopped complaining of this problem. So, by and large, im-

provement and deterioration (i.e. the shaded cells) are balanced. These results confirm the findings that memory problems alone, without other cognitive dysfunctions, can be ascribed to a mild memory impairment syndrome, which can show progress to dementia but also recovery over time.

Behavioural disorders, co-existing with memory impairment, are usually manifestations of dementia if other cognitive functions are impaired. The proxy assessment of the older persons applied in the study, based only on an interview, makes it difficult to provide precise judgement about the presence or absence of disease. Nevertheless, even with these limitations, it is interesting to recognise the dynamics of changes amongst the re-surveyed.

Table 25 shows changes in the behavioural disorder scale between T1 and T2. Those amongst the older people who showed lower scores on the behavioural disorder's scale [**BDS**] than for the baseline study were ascribed to category "less BD", those who had shown more disorders to category. "more BD", and those who kept the same scoring were labelled "no change". Each category was described with average scores' numbers based on T2 results.

Table 25: Changes on the Behavioural Disorder Scale [BDS] between time T1 and T2; average scoring on the BDS (T2) per category

	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid	N=238	N=191	N=661	N=714	N=326	N=203	N=2333
Less BD	26,5%	22,8%	22,8%	25,1%	18,1%	12,8%	23,5%
Mean scoring	2,6	0,8	1,7	1,6	1,9	2,6	1,7
No change	27,7%	32,5%	51,1%	44,5%	39%	38,9%	42,7%
Mean scoring	1,4	0,9	1,1	0,4	0,6	0,9	0,8
More BD	45,8%	30,4%	26%	29,4%	42,9%	48,3%	33,8%
Mean scoring	4,0	3,9	4,5	3,7	4,1	3,9	4,0

The most prevalent category was those who did not change their behavioural status (43% in the EU sample, ranging from 28% in Germany to 51% in Italy). Of those older people without any behavioural disorders, who on average had a score on the behavioural scale oscillating between 0,4 and 1,4, as many as 73% of them did not manifest any memory impairment, suggesting that they are cognitively healthy.

More than one third of the cared-for (ranging from 26% in Italy to 48% in the UK) experienced a deterioration of their behavioural status. This direction of change is more prominent than that of improvement. Nevertheless, as many as 24% of the older persons in the EU sample (ranging from 13% in UK to 27% in Germany) manifested fewer disorders than at the baseline study. The regression of disorders over time, as well as the low value of the BDS (not exceeding 3 on 0-9 BDS) does not suggest dementia. However, in every second person of this category memory problems exist, so they may be at risk of future dementia.

One third of older people in the EU sample (from 30% in Greece to 48% in UK) fulfil the criteria for probable dementia. Significantly higher results on the BDS (mean value = 4,0), a progression in behavioural disorders during the year as well as coexisting memory impairment (in 66% of this category) supports this rationale.

It is interesting to distinguish the transition in mental status during the year within each of the baseline categories in the European sample: in the group of intellectually able; in the group with behavioural disorders only; in the group with memory impairment only and in the group with memory and behavioural disorders (with probable dementia). The results are shown in **Table 26**.

Table 26: **Transition in older people' mental status between T1 and T2 within categories from the baseline study** (in % within categories)

		T2	**T2**	**T2**	**T2**	
		Intellectually able	Behavioural disorders only	Memory impairment only	Memory and behavioural disorders	TOTAL
	No of valid	*N=850*	*N=380*	*N=184*	*N=909*	*N=2323*
T1	Intellectually able *% of row*	614 64,7%	163 17,2%	53 5,6%	119 12,5%	949 100%
T1	Behavioural disorders only *% of row*	100 31,8%	109 34,6%	17 5,4%	89 28,2%	315 100%
T1	Memory impairment only *% of row*	61 24,5%	36 14,5%	57 22,9%	95 38,1%	249 100%
T1	Memory and behavioural disorders *% of row*	75 9,3%	72 8,9%	57 7%	606 74,8%	810 100%

The double frame and shadow boxes in the table show the proportions of older persons who were stable over a year, i.e. did not change their category. The boxes to the right of them depict the proportions with progress in mental disorders (or shifting from behavioural disorders to memory impairment only), while boxes to the left depict a regression of disorders (or shifting from memory impairment to behavioural disorders only).

The most stable categories of older people assessed at the baseline study were persons intellectually able (65% of them kept such conditions over a year) and those with memory and behavioural disorders, i.e. with probable dementia (75% of initially recognised conditions had the same criteria after a year).

Behavioural disorders and memory impairment as problems had the same likelihood of evolving into probable dementia as well as to recovery. Nevertheless, memory impairment significantly more often predicts progress to probable dementia (in 38%), than behavioural disorders as a single problem (28%). Every third person with behavioural disorders as reported by carers at T1 loses the problem after a year, whilst in the group with memory impairment this is true for every fourth person.

Thus as many as 60% of older persons were within the same category with respect to their mental status after one year, 23% showed progress and 17% regression in mental status. It should be stressed that the study has some limitations. The most important of them is that the data were based on the carers' proxy estimates only.

9.4.3 Changes in the carers‘ subjective outcomes of care-giving

Care-giving has serious effects on the well-being of the carer. This sub-section describes changes in the subjective outcomes of care-giving between the original survey and the follow up. Four different kinds of outcome measures are considered (see also chapter 3 for a discussion of these outcome measures):

- the ability to cope with care-giving, i.e. positive and negative effects of care-giving as measured with the COPE instrument (9.3.3.1),
- the quality of life of caregivers (9.3.3.2),
- the health status of caregivers (9.3.3.3), and finally
- the willingness to continue care-giving, which can also be regarded as an expression of how burdensome care-giving is felt to be (9.3.3.4).

As some of the scales are positive, i.e. the higher the value on the scale the better (e.g. the scale on positive value of care-giving), while others are negative (e.g. the scale on the negative effects of care-giving), confusion may arise on the results. In order to prevent such mis-interpretations, “negative change” is always used to express a deterioration of outcomes – irrespective of the scale used, while “positive change” always refers to a “brightening” of life, i.e. an improvement of outcomes.

9.4.3.1 Change in the carers’ ability to cope with care-giving

Most common outcome measurements focus on the care-givers burden. However, care-giving also provides positive effects. Therefore, the COPE index has been developed which allows to measure the negative impact of care-giving as well as its positive effects. Within the COPE instrument “negative impact” is measured on a scale with 7-Items, while the “positive value” scale, which is used to measure the positive aspects of care-giving is based on 4-Items (compare chapter 3 of this report). Although the negative impact and the positive value scale measure different things, it is nevertheless interesting to get an idea on the item “overall impact” of care-giving, i.e. the balance of positive and negative effects. Rather then constructing a sum score we use one item from the COPE instrument to estimate this overall effect, that is the last item of the battery: “Overall, do you feel well supported in your role of caregiver?”. Table 27 shows for which part of the carers the positive, negative and overall value of care-giving has improved, worsened or remained constant.[13]

From a methodological point of view for all indices the question arises how to deal with missing values in single items of an instrument that consists of several items. Either the respective case is regarded as missing or the lacking values are imputed. If there are up to one (positive value) or up to two (negative impact) items missing, in the following missing values for the particular items of the scale were replaced by the mean value for the other items of scale in order to minimise the loss of cases.

Looking on the negative impact we see in all countries that the share of interviewees whose situation has deteriorated (i.e. more negative impact) is considerably higher than the share of those whose situation has improved (i.e. less negative impact). This negative tendency is particularly pronounced in the UK, Germany and Sweden, and is the least distinct in Italy.

With respect to the positive value of care-giving the same pattern is found; in all countries the share of those with improvements is smaller than the share of those with deterioration. The highest negative change with reference to satisfaction of care over a year is found in Sweden and the lowest in Greece, where almost as many interviewees experienced an improvement than a deteriora-

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[13] In this table, as in tables 28-30, positive and negative changes are compared. The higher of both numbers are highlighted.

tion in the positive value of care-giving. So it seems that over time the caregivers' burden is increasing while the positive value of care-giving is diminishing.

Looking at the overall impact of care we find more negative than positive change in all countries – although at a lower rate. Moreover, there is a high share of those who see no change in overall impact (from 38% in Sweden to 47% in Italy).

Table 27: Change in the negative impact, positive value, overall impact from T1 to T2

	Negative change (% of carers)	No change (% of carers)	Positive change (% of carers)	Valid answers (No.)	Missing (No)
	%	%	%	N	N
Germany					
Negative impact	61.1	15.3	23.7	262	10
Positive value	49.4	22.1	28.5	263	9
Overall impact	35.9	44.2	19.9	251	21
Sweden					
Negative impact	59.9	13.3	26.8	366	9
Positive value	66.9	17.9	15.2	363	12
Overall impact	48.5	38.1	13.4	359	16
United Kingdom					
Negative impact	63.3	15.5	21.3	207	7
Positive value	54.6	21.7	23.7	207	7
Overall impact	33.6	43.1	23.3	202	15
Poland					
Negative impact	45.2	27.5	27.3	714	0
Positive value	44.4	24.1	31.5	714	0
Overall impact	33.8	45.1	21.1	714	0
Italy					
Negative impact	42.6	22.6	34.8	669	10
Positive value	47.8	23.6	28.7	670	9
Overall impact	29.3	47.4	23.3	666	13
Greece					
Negative impact	51.3	7.3	41.5	193	1
Positive value	44.0	13.5	42.5	193	1
Overall impact	35.3	40.1	24.6	187	7

9.4.3.2 Change in carers' quality of life

Measurement on the quality of life is based on the question "Overall, how would you rate your quality of life in the last two weeks?" with five modalities from 1 (very good) to 5 (very poor). As Table 28 clearly demonstrates, for about half of the carers (from about 40% in Greece to about 58% in Italy) the overall quality of life has remained the same. For those with changes in the quality of life, however, a change to the worse is more prominent than a change to the better. This is particularly true for the German, Swedish and Greece sample where about twice as many carers experience a deterioration than experience an improvement.

Table 28: Change in the quality of life from T1 to T2

	Negative change (% of carers)	No change (% of carers)	Positive change (% of carers)	Valid answers (No.)	Missing (No)
Germany	38.4	50.0	11.6	268	4
Sweden	42.7	44.4	12.9	363	12
United Kingdom	34.4	49.3	16.3	209	5
Poland	25.8	53.2	21.0	714	0
Italy	22.8	57.6	19.6	672	7
Greece	38.6	39.7	21.7	189	5

9.4.3.3 Change in the carers' health status

The health status is based on the question "In general, would you say your health is: 1 (excellent) to 5 (poor). Once again stability, i.e. no change, is the predominant result – at least for 5 countries with the mere exception of Greece. In 5 countries changes to the worse are more often than changes to the better. In Poland alone there are marginally more improvements than there is deterioration (table 29).

Table 29: Change in the health status of carers from T1 to T2

	Negative change (% of carers)	No change (% of carers)	Positive change (% of carers)	Valid answers (No.)	Missing (No.)
Germany	28.2	60.2	11.6	266	6
Sweden	32.1	51.7	16.2	371	4
United Kingdom	29.5	52.2	18.4	207	7
Poland	25.1	47.6	27.3	712	2
Italy	29.1	54.2	16.7	675	4
Greece	42.5	41.9	15.6	186	8

9.4.3.4 Changes in the carers' willingness to continue care-giving

In the baseline survey and in the follow up carers were asked whether they are willing to continue caring for their older relatives in the next year. Answers were scored on a scale from simple "yes" to "no" with 3 qualifications in-between. Table 30 shows how this measurement of the willingness to care has changed in the course of one year. As before, stability is the most common result – in all countries except Sweden. If there is change, however, on balance the willingness to care has decreased in Germany, Sweden, the UK and Italy, while it has increased in Poland and Greece.

Table 30: Change in the willing to continue to provide care to elder from T1 to T2

	Negative change (% of carers)	No change (% of carers)	Positive change (% of carers)	Valid answers (No.)	Missing (No.)
Germany	36.9	48.7	14.4	236	36
Sweden	44.7	40.8	14.5	358	17
United Kingdom	36.9	51.4	11.7	179	35
Poland	16.0	61.5	22.5	714	0
Italy	25.2	57.3	17.5	656	23
Greece	7.4	63.7	28.9	190	4

9.4.3.5 Summary

The above analyses have produced some remarkable results: Firstly, the situation of carers has become worse in all countries. On balance the negative impact has grown and the positive value of care-giving has diminished. Consequently, the overall impact has decreased for more carers than it has increased – in all countries. For a minority of carers, however, the situation has improved with less negative effects and more positive value of care-giving.

Second, the health status and the quality of life remains more or less unchanged for about half of the carers. If there are changes, however, changes to the worse predominate over changes for the better, indicating a growing burden of care with loss of quality of life and health. Consequently, in four out of the six country samples a decreasing willingness to care results.

9.4.4 Impact of services on modifying the carers‘ situation

In section 9.3.3 the “changes in the carers‘ subjective outcomes of caring“ only have been described. Throughout this section we focus more on explanations and analyse whether changes in service use may explain respective changes in outcome measurement.

If service use is dichotomised in T1 and T2, four possible combinations result:

- no service use in T1 but in T2;
- service use in T1 but not in T2;
- service use in T1 and T2;
- no service use in T1 and T2.

The original aim of this section is to analyse the impact of all kinds of service use. Due to the small sample size in T2, however, it is only possible to analyse the effects of “health needs”[14] service use of elder on carers’ subjective outcomes of caring, because this is the service that has been used most often in T1 and T2, so that there are sufficient cases in all cells of the tables, to yield enough statistical power.

9.4.4.1 Effects of health services on outcome measures

As mentioned before there are four possible combinations of service use in T1 and T2. They build the modalities of the independent variable. For each of these combinations the change in the de-

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[14] The category of "Health services" means those national services which were addressing the health needs of older persons (cf. details in chapter 7th).

pendent variable, i.e. outcome measures is analysed. Once again these variables are trichotomised. Table 31 shows the results for “negative impact”.[15] If we assume that service use in general reduces the burden of care, we could expect that the dropping of service use, i.e. use in T1 and no use in T2 would produce a deterioration, while the uptake of service use, i.e. use in T2 without use in T1 would produce an improvement. In Table 31 one can see this assumption is not generally true. In Germany, the UK, Poland and Italy the highest figure for negative change indeed occurred within the group that has dropped service use, but this is not true for Sweden and Greece. Moreover, in no country is the highest positive change within the group that has taken up services use.

The positive direction of change in the negative impact of care was connected with no services' usage in both waves of the study, except for Germany and Greece. It might be explained by lack of adequate indices for usage of health services, probably due to better health status of the persons cared-for by this category of carers.

These results indicate that factors other than service use are more important in explaining changes in outcome measures. Thus multivariate analyses are necessary which are provided in section 9.3.5.

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[15] In table 31 to 34 for each of the four combinations the one with the highest number in negative change and in positive change is highlighted in order to provide an optical impression on the dominant patterns.

Table 31: Effects of "health needs" service use of elders on changes of "negative impact" from T1 to T2 by elder from T1 to T2

Independent variable		Change of „negative impact“ (Dependent Variable)			
Service use		**Negative change**	**No change**	**Positive change**	
T1	T2	%	%	%	N
		Germany			
No	Yes	54.5	27.3	18.2	33
Yes	No	64.4	17.8	17.8	45
Yes	Yes	61.3	9.7	29.0	31
No	No	61.4	13.1	25.5	153
		Sweden			
No	Yes	69.2	3.8	26.9	26
Yes	No	64.3	11.9	23.8	42
Yes	Yes	62.3	14.0	24.0	50
No	No	57.4	14.3	28.3	251
		United Kingdom			
No	Yes	63.6	20.2	16.2	99
Yes	No	75.0	8.3	16.7	12
Yes	Yes	60.4	15.1	24.5	53
No	No	62.8	7.0	30.2	43
		Poland			
No	Yes	36.6	32.3	31.2	93
Yes	No	48.6	27.9	23.5	179
Yes	Yes	41.9	33.6	24.5	265
No	No	51.4	15.3	33.3	177
		Italy			
No	Yes	48.2	17.9	33.9	56
Yes	No	50.0	21.4	28.6	98
Yes	Yes	44.6	21.1	34.3	289
No	No	35.4	26.1	38.5	226
		Greece			
No	Yes	51.3	5.1	43.6	39
Yes	No	47.8	8.7	43.5	46
Yes	Yes	46.2	7.7	46.2	65
No	No	62.8	7.0	30.2	43

Table 32 shows the results of a similar bi-variate analysis with positive value of care-giving as the dependent variable. Once again the picture is not clear-cut. In Germany, UK and Greece, the uptake of services has let to an increased positive value of care-giving, and in Germany and Sweden a drop of service use goes together with the highest reduction in positive value. However, on balance a clear effect of service use is not visible.

Table 32: Effects of "health needs" service use of elders on changes of "positive value" of care-giving from T1 to T2 by elder from T1 to T2

Independent variable		Change of „positive value" (Dependent Variable)			
Service use		Negative change	No change	Positive change	
T1	**T2**	%	%	%	N
		Germany			
No	Yes	36.4	27.3	36.4	33
Yes	No	55.6	20.0	24.4	45
Yes	Yes	54.8	29.0	16.1	31
No	No	49.4	20.1	30.5	154
		Sweden			
No	Yes	66.7	22.2	11.1	27
Yes	No	76.2	16.7	7.1	42
Yes	Yes	70.0	14.0	16.0	50
No	No	64.1	18.3	17.5	251
		United Kingdom			
No	Yes	50.5	22.2	27.3	99
Yes	No	25.0	58.3	16.7	12
Yes	Yes	64.2	13.2	22.6	53
No	No	60.5	20.9	18.6	43
		Poland			
No	Yes	48.4	22.6	29.0	93
Yes	No	43.0	24.0	33.0	179
Yes	Yes	44.5	26.8	28.7	265
No	No	43.5	20.9	35.6	177
		Italy			
No	Yes	50.0	21.4	28.6	56
Yes	No	48.5	21.2	30.3	99
Yes	Yes	52.9	19.7	27.3	289
No	No	40.3	30.1	29.6	226
		Greece			
No	Yes	38.5	7.7	53.8	39
Yes	No	39.1	21.7	39.1	46
Yes	Yes	44.6	16.9	38.5	65
No	No	53.5	4.7	41.9	43

The resulting analysis on the "overall impact" (Table 33) only reinforces the above findings: no clear effect of changes in service use on changes in outcomes with "expected results". Probably inter-relations between positive, negative and overall impact of being supported versus services' usage are much more complex and compound, as well as services' networks or systems differing from country to country.

Table 33: Effects of “health needs” service use of elders on changes of “overall impact” of care-giving from T1 to T2 by elder from T1 to T2

Independent variable: Service use		Change of „overall impact“ (Dependent Variable)			
Service use		Negative change	No change	Positive change	
T1	**T2**	%	%	%	N
Germany					
No	Yes	40.0	33.3	26.7	30
Yes	No	21.4	52.4	26.2	42
Yes	Yes	51.9	25.9	22.2	27
No	No	36.2	47.4	16.4	152
Sweden					
No	Yes	58.3	29.2	12.5	24
Yes	No	52.4	45.2	2.4	42
Yes	Yes	40.0	42.2	17.8	45
No	No	48.1	37.8	14.1	241
United Kingdom					
No	Yes	32.3	44.8	22.9	96
Yes	No	41.7	41.7	16.7	12
Yes	Yes	35.8	35.8	28.3	53
No	No	31.7	48.8	19.5	41
Poland					
No	Yes	33.3	39.8	26.9	93
Yes	No	34.6	43.6	21.8	179
Yes	Yes	34.0	49.1	17.0	265
No	No	32.8	43.5	23.7	177
Italy					
No	Yes	18.5	61.1	20.4	54
Yes	No	30.6	48.0	21.4	98
Yes	Yes	31.6	46.9	21.5	288
No	No	28.3	44.7	27.0	226
Greece					
No	Yes	36.8	42.1	21.1	38
Yes	No	47.6	19.0	33.3	42
Yes	Yes	23.4	50.0	26.6	64
No	No	38.1	45.2	16.7	42

Something similar applies if quality of life (Table 34) and health status (Table 35) are used as dependent variables: the expectation that positive change would be highest if services were taken in T2, but not in T1 or that negative change would be highest if service use had been stopped are not realised in most cases. This conclusion also holds for the willingness to continue care-giving (Table 36).

Table 34: Effects of “health needs” service use of elders on changes of “quality of life” from T1 to T2 by elder from T1 to T2

		Change of „quality of life“ (Dependent Variable)			
Independent variable					
Service use		Negative change	No change	Positive change	
T1	T2	%	%	%	N
		Germany			
No	Yes	33.3	46.7	20.0	30
Yes	No	28.7	56.3	14.9	87
Yes	Yes	41.9	45.2	12.9	31
No	No	36.7	44.6	18.7	289
		Sweden			
No	Yes	50.0	46.2	3.8	26
Yes	No	44.2	44.2	11.7	77
Yes	Yes	42.0	46.0	12.0	50
No	No	37.5	45.8	16.7	408
		United Kingdom			
No	Yes	38.6	49.5	11.9	101
Yes	No	25.0	50.0	25.0	44
Yes	Yes	34.6	50.0	15.4	52
No	No	21.3	40.7	38.0	108
		Poland			
No	Yes	24.7	54.8	20.4	93
Yes	No	27.8	47.8	24.3	255
Yes	Yes	25.7	55.8	18.5	265
No	No	30.7	47.9	21.5	261
		Italy			
No	Yes	21.4	64.3	14.3	56
Yes	No	31.3	48.9	19.8	182
Yes	Yes	16.4	58.7	24.8	286
No	No	25.0	54.6	20.4	324
		Greece			
No	Yes	39.5	39.5	21.1	38
Yes	No	37.4	39.4	23.2	99
Yes	Yes	40.6	40.6	18.8	64
No	No	40.0	38.7	21.3	75

Table 35: Effects of “health needs” service use of elders on changes of “health status” from T1 to T2 by elder from T1 to T2

		Change of „health status“ (Dependent Variable)			
Service use		Negative change	No change	Positive change	
T1	T2	%	%	%	N
Germany					
No	Yes	28.1	59.4	12.5	32
Yes	No	38.1	44.0	17.9	84
Yes	Yes	25.8	67.7	6.5	31
No	No	32.3	54.0	13.7	285
Sweden					
No	Yes	38.5	53.8	7.7	26
Yes	No	35.5	51.3	13.2	76
Yes	Yes	32.0	56.0	12.0	50
No	No	32.2	49.3	18.5	416
United Kingdom					
No	Yes	31.0	51.0	18.0	100
Yes	No	43.2	29.5	27.3	44
Yes	Yes	27.5	52.9	19.6	51
No	No	26.4	49.1	24.5	106
Poland					
No	Yes	21.5	50.5	28.0	93
Yes	No	22.1	49.8	28.1	253
Yes	Yes	28.7	44.9	26.4	265
No	No	26.6	47.5	25.9	259
Italy					
No	Yes	21.4	66.1	12.5	56
Yes	No	35.3	49.5	15.2	184
Yes	Yes	28.5	54.5	17.0	288
No	No	27.8	52.2	20.1	324
Greece					
No	Yes	48.6	29.7	21.6	37
Yes	No	45.0	40.0	15.0	100
Yes	Yes	38.1	46.0	15.9	63
No	No	52.9	30.0	17.1	70

Table 36: Changes in the " willingness to continue to provide care to elder " from T1 to T2 contingent on „health needs" service use by elder from T1 to T2

Service use		Negative change	No change	Positive change	
		Change of „willing to continue to provide care to elder" (Dependent Variable)			
T1	T2	%	%	%	N
Germany					
No	Yes	36.7	43.3	20.0	30
Yes	No	39.0	46.3	14.6	41
Yes	Yes	35.7	42.9	21.4	28
No	No	36.5	51.8	11.7	137
Sweden					
No	Yes	34.6	50.0	15.4	26
Yes	No	46.5	39.5	14.0	43
Yes	Yes	36.7	46.9	16.3	49
No	No	47.2	38.2	14.6	246
United Kingdom					
No	Yes	38.4	48.8	12.8	86
Yes	No	60.0	30.0	10.0	10
Yes	Yes	32.6	56.5	10.9	46
No	No	32.4	56.8	10.8	37
Poland					
No	Yes	14.0	59.1	26.9	93
Yes	No	21.2	60.3	18.4	179
Yes	Yes	13.2	65.3	21.5	265
No	No	15.8	58.2	26.0	177
Italy					
No	Yes	12.5	71.4	16.1	56
Yes	No	28.6	49.0	22.4	98
Yes	Yes	29.9	59.0	11.2	278
No	No	21.0	55.4	23.7	224
Greece					
No	Yes	5.3	57.9	36.8	38
Yes	No	10.9	63.0	26.1	46
Yes	Yes	6.3	68.8	25.0	64
No	No	7.1	61.9	31.0	42

9.4.4.2 Most and least helpful services in carers' opinions

The above analyses were based on service use – without distinguishing between those services that are ranked high or low by users. In order to fill this gap, table 37 present those services that were ranked most helpful by interviewees.[16]

In Poland, Italy and Greece, the general practitioner (GP) was ranked as the most helpful service for elder. The highest percentage of positive answers for this service can be found in Italy. In Germany and the United Kingdom GPs are ranked as the second most important service for elder and in Sweden they are not mentioned at all.

With respect to services for carers national differences prevail. While in Germany medical counselling is by far the most important service for carers, in Italy it is the GP, which is also the mode service (on first rank) in the UK and on second rank in Sweden. Generally speaking, the GP is particularly important in those countries which have only few particular services for elder and carers.

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[16] Interviewees were asked to name the most, second most and third most helpful service. The services mentioned in table 37 are those with the highest number of entries (the mode).

Table 37: Most, second most and third most helpful services for elder in carers' opinions

	Germany	UK	Sweden	Poland	Italy	Greece
	%	%	%	%	%	%
Services for elder						
Most helpful	Service counselling hotline (36.3)	Home care worker (15.0)	Personal care food (9.9)	General practitioner (26.0)	General practitioner (62.3)	General practitioner (32.7)
Second most helpful	General practitioner (17.9)	General practitioner (9.3)	Cleaning service (8.9)	Specialist doctor (19.8)	General practitioner (15.4)	Help lines (52.6)
Third most helpful	General practitioner (13.5)	General practitioner (6.0)	Cleaning service (13.2)	Visits of nurse at home (13.7)	General practitioner (11.2)	Help lines (25.0)
Services for carer						
Most helpful	Medical counselling (30.0)	General practitioner (17.1)	District nurse (38.2)	Doctor's counselling for carer (73.7)	General practitioner (21.2)	Respite care home/Temporary nursing home (61.5)
Second most helpful	Medical counselling (25.0)	Self help group (15.8)	General practitioner (30.8)	Nursing counselling for carer (41.8)	General practitioner (21.2)	Respite care home/Temporary nursing home (100.0)
Third most helpful	Medical counselling (28.6)	Home based services (17.4)	Physiotherapist (40.0)	Rehabilitation services for carer (33.3)	General practitioner; Help lines (8.7)	(0.0)

9.4.5 What are the predictors of negative, positive and overall outcomes of care?

As section 9.3.3 has clearly demonstrated, service use is only one factor influencing the outcome of care-giving. In this section therefore multivariate analyses are used to identify predictors of changes in outcome measurements. Since changes for the better or the worse can be conceptualised as a dichotomous variable, logistic regression is the obvious method.

The logistic regression model is a non-linear transformation of the linear regression. The "logistic" distribution is an S-shaped distribution function which is similar to the standard-normal distribution but easier to work with in most applications (the probabilities are easier to calculate). The logit distribution constrains the estimated probabilities to lie between 0 and 1.

The dependent variable in a logistic regression is usually dichotomous. That means the dependent variable can take the value 1 with a probability of success q, or the value 0 with probability of failure 1-q. This type of variable is called a Bernoulli (or binary) variable.

The independent or predictor variables in a logistic regression can take any form. A logistic regression makes no assumption about the distribution of the independent variables. The aim of a logistic regression is to predict correctly the category of outcome for individual cases using the most parsimonious model. To accomplish this aim, a model is created that includes all predictor variables that are useful in predicting the response variables.

In Table 38, 39 and 40 one can see the change of “negative impact“, “positive value“ and “overall impact“ from T1 to T2 dependent on the domains “Single service used by carer“ and “Single service used by elder“ under control of the domains “Restriction of elder“ and “Situation of carer“. Most of the variables measure the change from T1 to T2 except the indicators of the domain “Situation of carer“. Inside the tables one can see the odds and not the estimated coefficients. The table contains only odds for predictor variables that are significant on the 5% level. An odds of 1 means no change of the dependent variable from T1 to T2, an odds less than 1 means a deterioration and an odds greater than 1 means an improvement of the dependent variable.

Table 38 shows the results of the logistic regression on negative impact. Generally speaking, the explanatory power of the model is very low. Only in Greece does the explained variance exceed 30 percent. Thus, all results must be treated extremely carefully. Looking at the single predictor variables we find that for Germany and the UK none of them is significant. For the other countries most significant predictor variables refer to restrictions of elder. A deterioration of behavioural problems (in the Swedish, Polish and Italian sample) and the ability to perform instrumental activities of daily living (in the Italian sample) goes along with an increase in the burden of care, while improvements with respect to behavioural problems (the Greek sample) or I-ADLs (the Polish and Greek sample) are associated with decreasing negative impact of care-giving. Interestingly in Sweden the burden tends to be reduced if elder is transferred into a nursing home. According to table 38 the chance of a reduction in the negative impact is seven times higher for those who have seen a transfer of elder to a nursing home.

In the domain “situation of carer” only two variables are significant, and only for one country each. So, finally, what can be said about service use, which is of particular interest? As specific services for carers do not exist or are hardly used, only services for elder are included in the regression analysis. As table 38 shows, significant effects are only to be seen in Poland, with health needs services and emotional/psychological/social services. The uptake of health needs services use reduces the burden of care, while stop using emotional/psychological/social services increases the likelihood of a deterioration in negative impact. At least the direction of the influence is as expected. When other potential predictors are controlled for, however, the impact of up-taking or stopping service use seems to be very limited.

Table 38: Change of “negative impact” from T1 to T2 (Logistic Regression)

Variable	DE	UK	SE	PL	IT	EL
Restriction of elder						
Behavioural problems (worse)			0.4	0.5	0.4	
Behavioural problems (better)						3.2
IADL (worse)					0.4	
IADL (better)				1.5		3.4
Nursing home			7.7			
Situation of carer						
Income of carer					0.9	
Woman				0.7		
Single service used by carer						
Specific support services used in T1 but not used in T2				0.6		
Single service used by elder						
Health needs services not used in T1 but used in T2				2.9		
Emotional/psychological/social services used in T1 but not used in T2				0.4		
R2	0.17	0.27	0.22	0.15	0.18	0.34
*. Only significant changes have been reported in this table						

Table 39 shows the result of the logistic regression on positive value. Once again the model fit is poor with only a small proportion of the variance being explained by predictive variables. Significant effects of changes in elders’ restriction are only visible in Italy. A deterioration of behavioural or memory problems increases the likelihood of an increase in the positive value of care-giving here. Effects of a change in service use can only be detected for physical/personal needs services in Greece and other services in Poland. Once again the direction is as expected: the uptake of a new service increases the probability of an increase in the positive value and stopping using the service reduces this probability.

Table 39: Change of “positive value” from T1 to T2 (Logistic Regression)*

Variable	**DE**	**UK**	**SE**	**PL**	**IT**	**EL**
Restriction of elder						
Behavioural problems (worse)					0.5	
Memory problems (worse)					0.3	
Situation of carer						
Income of carer				0.9		
Single service used by elder						
Physical/personal needs services not used in T1 but used in T2						0.1
Other services not used in T1 but used in T2				3.8		
R2	0.15	0.25	0.11	0.06	0.12	0.25
*. Only significant changes have been reported in this table						

With respect to “overall impact” the results of the logistic regression are similar. Once again there are some significant variables in the domain “restriction of carer”, which point in the expected direction. There are, however, no significant effects of service use and the r-square is poor.

Table 40: Change of "overall impact" from T1 to T2 (Logistic Regression)

Variable	DE	UK	SE	PL	IT	EL
Restriction of elder						
Behavioural problems (worse)				0.5		
IADL (worse)				0.7	0.6	
IADL (better)						4.3
R2	0.16	0.22	0.10	0.11	0.08	0.31
*. Only significant changes have been reported in this table						

In summary, the analyses have shown that improvements in elders' restriction tend to improve the caregivers' situation while a deterioration goes together with increased burden or decreased positive value of care-giving. If changes in service use have a significant impact, the uptake of a service increases the likelihood of improvements in the caregivers' situation while the caregivers' situation is likely to deteriorate if the use of services is stopped. Overall however, these effects are only visible in some country samples and the explanatory power of all models is limited. Thus, the interplay of predictors is more complicated than simple logistic regression models can reveal.

9.5 Summary remarks:

1. The vast majority of initial family caregivers were still caring after a year.
2. Mortality amongst the cared-for persons was the main reason for primary carers to stop caring (17% of all cases). The second cause (6-12% of all cases) was the transfer of the cared-for person to a nursing home (predominantly in Sweden, Germany and UK), while the third cause (3-5%) consisted in the transfer of the main care tasks to another family member (predominantly in Poland, Greece and Italy).
3. The most important predictors for discontinuing care (excluding mortality) related to the older person's characteristics were: more advanced age, living alone or apart from caregiver, presence of memory or behavioural problems, more severe physical and mental disability and need for personal support.
4. The most significant predictors for discontinuing care related to the caregiver were: shorter duration of care, longer distance from older person's residence, less direct involvement in care, lack of motivation in caring for the older person, lack of children in carer's household, lower religiosity.
5. Amongst family carers who still provided care, the intensity of caring (hours of care per week) over one-year remained almost unchanged with a slight decreasing tendency. This care intensity dropped however for those caregivers whose cared-for persons showed improvement in their I-ADL dependency, and increased for those older persons who manifested a worse physical condition.
6. The carer's/elder's living arrangements showed little alteration over time, except for an increased tendency towards cohabitation (in the same building or house).
7. Few changes occurred in the employment status of carers over the year, especially in Germany, Italy, Sweden and the UK, while in Poland and Greece the proportion of carers becoming employed (and partly also of those leaving employment) was much higher than in other countries.

8. Caring for an older person negatively affected the caregiver's professional career. This concerned mainly non working caregivers who had to give up work or could not carry out a job due to caring duties, especially in Sweden, the UK and Greece. Caring for older people also negatively influenced everyday life, causing difficulties in taking a break, especially in Greece, Sweden, the UK and Germany.
9. Physical disability in the cared-for persons worsened over the one-year of observation. Progressive dependency in the older persons was evident especially with respect to the Basic ADL (5.5% per year on the 100-item Barthel scale), and to a lesser extent on an Instrumental ADL scale.
10. The memory status seemed to be rather stable over the year of observation. Only amongst a tenth of the cared-for persons does memory loss appear, while for the same proportion memory impairment improves.
11. Behavioural disorders in the persons cared-for showed high variations in intensity - disorders diminished in every fourth older person, and increased for every third after a year.
12. The degree of progression in cognitive disorders over the one-year observation period depended on the initial level, being lower in people without any memory problems, and highest in people with memory and behavioural disorders (and vice versa with respect to possible regression of disorders.
13. With respect to the outcome of care-giving for caregivers the analyses show that the negative impact increased significantly and the positive value of care-giving decreased over time. For the overall impact of care-giving we also see more change to the worse than to the better – in all countries. While there is a majority of carers who experience an improvement in their situation, for a much higher share of all carers all outcome measures changed to the worse.
14. The health status and the quality of life remained more or less unchanged for about half of the carers. Changes to the worse, however, predominated over changes for the better, indicating a growing burden of care with loss of quality of life and health.
15. Consequently, in 4 out of the 6 country samples a decreasing willingness to care resulted.
16. Considerable impacts of service use on care-givers outcomes could not be demonstrated. The analyses rather imply that the mere question of service use alone does not influence the caregivers' well-being, health or burden significantly.
17. Nevertheless, some services are clearly more helpful than others. The respective importance, however, differs greatly between countries. Generally speaking, general practitioners play a very important role – but particularly in those countries with few specific services for dependent elderly and family carers.
18. The logistic regression on changes in outcome variables could not prove significant effects of service use on the positive value scale and the overall impact scale of the COPE index. A relief of negative impact, i.e. burden of care, due to the uptake of service use can only be demonstrated for specific support services, health needs services, and emotional/psychological/social services in Poland. There is no respective effect in any of the other countries. In the Greek and the Polish sample there is some impact of changes in service use on positive value, while there is no significant influence in any of the countries of changes in service use on overall impact. To summarise, therefore, the analyses could not establish a decisive influence of service use on carers' outcome.

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