EUROFAMCARE

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

The Trans-European Survey Report

(Deliverable N° 19)

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Content

1 Introduction – Aims and structure of the EUROFAMCARE project and introduction to the Trans-European Survey Report (TEUSURE)

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1.1 Aims and structure of the EUROFAMCARE project

The main aim of the EUROFAMCARE project was to evaluate the **situation of family carers of older people in Europe** in relation to the existence, familiarity, availability, use and acceptability of **supporting services**, with the objective of formulating:

- at a **macro-level**, suggestions for the implementation of more comprehensive, carer-friendly elderly care policies in Europe;
- at a **meso-level**, suggestions for developing new partnerships between service providers, local authorities and caring families, and the implementation of innovative user-oriented services and
- at a **micro-level**, more systematic and adequately disseminated knowledge about caregiving, thus contributing to significantly improving the situation of cared-for older people and at the same time improving the caregivers' quality of life.

The main **core questions** the research aimed to address were:

- Which services are available and able to promote positive effects and to avoid negative consequences and implications in caring for elderly family members?
- Which approaches and services already exist in the different European countries?
- What is family carers' experience in using these?
- What are the barriers that keep family carers from using support services?
- Do these services really reach the persons in need of support and do they really fit with the needs and demands of caregivers?
- What are the criteria for effective, sufficient and successful services, where can such services be found, and what are their deficiencies?
- How can this information be implemented and disseminated?

The project intended to promote a **partnership approach in family care**, with the main focus being on the perspective of family carers and their dependent elderly relatives, rather than the currently predominant service provider-based approach.

It aimed to fill a knowledge gap concerning the characteristics, coverage and usage of services supporting family carers in Europe at both the trans-European and the pan-European levels.

At a **trans-European** level, a core group consisting of six national research teams – Germany (co-ordination), Greece, Italy, Poland, Sweden and the UK –, conducted primary research studies on family carers and the dependent older people they cared for, as well as of providers of relevant support services as follows:

- A baseline survey of ca. 6,000 family carers (1,000 per country) using an agreed protocol for sample selection and implementation of the survey, a Common Assessment Tool (CAT) for face-to-face interviews with the sample of family carers, data input, and mainly quantitative, but also some qualitative data analysis.
- A follow-up study on the original sample of family carers one year after the baseline interviews.
- A service-provider study, consisting of interviews with key personnel providing services to family carers and / or older people, analysed using mainly qualitative methods.

These surveys have provided the basis for an in-depth analysis of the factors involved in the interdependency between the family carers' needs and the needs of the cared-for older person, in order to better elucidate the effects of specific supporting services and informal networks on the different parameters of family care such as satisfaction and burden, self-rated health status, perceived quality of life, quality of support and costs, at two levels:

- At a national level: each of the six national partner's research studies has been described in individual **National Survey Reports (NASUREs)**, giving an overview on the spectrum and spread of measures in relation to different target groups and to the different types of welfare states.
- At a cross-national level: the NASUREs and the aggregated European data set have been the basis of the **Trans-European Survey Report (TEUSURE)** presented here, which provides an overview and synthesis of the results of the total survey sample, with relevant comparative analyses aimed at illustrating differences between country samples and specific sub-samples, as well as providing answers to the above mentioned research questions.

At a **Pan-European** level, the six core national research teams plus experts from further 17 European countries from the pan-European Network have also provided a description of the current situation of family carers in relation to social policies and services for their support, including examples of good and innovative practice. This material has been made available in the following documents:

- **23 National Background Reports (NABARES),** written according to a common Standardised Evaluation Protocol (STEP) and based on secondary analysis of existing materials, expert interviews and / or focus groups.
- A **Pan-European Background Report (PEUBARE),** based on the pool of information made available by the NABAREs, and produced through a synoptic integration of their contents to provide a pan-European overview of the situation of older people's family carers throughout the continent in terms of state of the art in Europe's family care policies, future challenges and necessary prerequisites for good quality integrated family care for older people.
- A collection of **Examples of Good and Innovative Practices in Supporting Family Carers in Europe,** based on the examples described in the 23 NABAREs.

To complete the information obtained from the above studies and to ensure optimum use of the results, the project included:

- A **socio-economic evaluation** (ECO) giving a cross-European overview on the costs of care-giving and support measures.
- A **political evaluation** at the European level, consisting of a European Policy Report, written by the EUROFAMCARE partner AGE- European Older Peoples' Platform, together with the organisation of events that focused on the dissemination of the project results, the implementation of policy change, the identification of opportunities and barriers in the implementation process, and the exploitation of the potential for improving the health and well-being of family carers and the older people they care for.

Finally, an integral part of the EUROFAMCARE project was the Research Action Phase **REACT** implemented by the Trans-European group and AGE throughout the three years of the project, but concentrated in the final year. REACT aimed at the dissemination of the findings at local, national and European levels, with the objective of implementing changes in policy and services for the support of family carers and initiating new partnerships in care for older people. The reactions of the target groups could also provide a feedback to the researchers on the utility of the research.

One of the major outputs of the REACT phase was the contribution of EUROFAMCARE to the creation of a new European-level NGO for carers, EUROCARERS – European Association Working for Carers, which aims to establish a European network of carer's organisations and researchers in this field. The main objectives of the association are to promote knowledge about family care and to lobby for greater awareness of the immense work done by carers for society, as well as promoting the development of policies and practices for their support.

A draft of a European Carer's Charter has been completed and the idea of a European Carers Day has been undertaken as one of the tasks of EUROCARERs to inform the public and stimulate better support for family carers.

1.2 Introduction to the Trans-European Survey Report (TEUSURE)

In the following section, the main headings and chapters of this Trans-European Survey Report (TEUSURE) are briefly introduced.

Chapter 2 gives an overview on the state of the art of the literature on support services for family carers of older people in Europe, in particular focussing on the partnership approach and the international literature on this. It also refers to the bibliographies from the national NABAREs for the 6 countries.

In **chapter 3** the EUROFAMCARE Common Assessment Tool (CAT) as well as the CAT-Follow-Up Questionnaire (CAT-FUQ) are described in detail. The chapter focuses on the development of items and instruments, the piloting of questionnaires, questionnaire item transformation, scale development and the psychometric characteristics of scales used.

Chapter 4 deals with the sampling and recruitment procedures in the different countries and discusses the problem of representativeness.

In **chapter 5** there is an overview of the main characteristics of the national samples. The first part describes the profile of the cared-for older people: socio-demographics, financial situation, living and household situation, health and need for support. The second part describes the profile and situation of the family carers: socio-demographics, education and employment, financial situation, family, caring situation, health and quality of life.

While the earlier chapters are mainly descriptive, **chapter 6** deals with the development of a typology of care-giving situations in Europe, using a cluster analysis approach. It addresses and attempts to answer one of the core questions of the project concerning the relation between care situations, motivations for care and willingness to continue caring. After outlining the methodology the cluster and their distribution are described.

In **chapter 7** the analyses focus on the use of services and take up of allowances and the experiences of family carers: the costs of care, their preferences and satisfaction with services. This chapter addresses questions on service availability, family carers' experiences in using them, the barriers that stop family carers from using support services, the degree to which services reach those most in need of support and attempts to provide some answers to these questions.

The topic of **chapter 8** is the service providers' study. The aim is to add the providers' perspectives to the family carer's views. The methodology is initially described, followed by the study results that focus on coverage, usage, access and costs from the providers' perspective. Additionally their view on important quality characteristics and types of services for family carers as well as future developments in services are described.

In **Chapter 9** the one-year Follow-up Study provides a time-limited but important longitudinal dimension to the research, given the patterns of change in caregivers' and older people's situation and the need to understand the use and value of services. The present results are based on the preliminary CAT-FU dataset.

Chapter 10 summarises the main findings of TEUSURE and the implications of these findings for family carers, service providers and policy makers.

The results of the research project aim at aiding policy and decision-makers in different European countries to understand the critical importance of supporting family carers in the coming decades, of improving their situation and in particular of helping to increase support measures, thus maintaining family carers' high motivation and ensuring that they remain as a valuable resource in the growing work of caring. The in-depth knowledge from the six systematically chosen countries, covering very different welfare and socio-economic systems, offers the potential to other countries of using the findings as a guide to:

- How best to target support
- Which family carers need support
- What types of support and services are most needed
- How to create user-oriented services

The project results are being constantly discussed with a broad audience in various ways in each of the participating countries and at European level. However, readers are welcome to contact the researchers and make further comments.

The last stage of the EUROFAMCARE research is concerned with this feedback from all those involved or potentially involved in supporting family carers. One of the aims of the project is to identify suggestions for the implementation of strategies to support family carers at the national level. It is hoped that the overall national analyses, mainly described in the National Survey Reports (NASUREs), as well as this European analysis, will lead to further national and European analyses on family care situations and result in Action Plans to promote the partnership approach in family care.

2 Issues and challenges in carer support: A consideration of the literature

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2.1 Introduction

> ‘How can family carers best be supported in their difficult task?’
> (Mestheneos and Triantafillou 1993)

The above question is just as relevant today as it was over a decade ago, yet despite increasing awareness of the needs of family carers in several European countries (Phillips 2003), we are in many respects no closer to having a comprehensive answer. As Mestheneos and Triantafillou (1993) note, historically the study of family care has been relatively neglected by researchers and policy makers at a pan-European level. A series of important studies conducted under the auspices of the European Foundation for the Improvement of Living and Working Conditions during the early and mid 1990’s did much to raise awareness of issues to do with family care of older people in Europe (Jani-le-Bris 1993, Mestheneos and Triantafillou 1993, Steenvoorden et al. 1993, Salvage 1995).

These studies highlighted the fact that European countries share a common policy objective of keeping older people in their own homes, and that the family is central to the success of such a policy (Jani-le-Bris 1993). However, they also concluded that there was a virtual absence of effective support services for family carers (Jani-le-Bris 1993), and the limited support that was available differed widely both within and between countries (Mestheneos and Triantafillou 1993, Salvage 1995).

At this time political debates and policy initiatives in this area were limited. In many Northern European countries there was no expectation that the family would care for older people, as this was seen as the role of the state (Jani-le-Bris 1993). Conversely, in Southern European countries, the notion that anyone other than the family would care for dependent older people simply did not arise (Jani-le-Bris 1993). Whilst there were a limited number of specific policies directed at family carers’ needs, for example in France, and especially the UK (Jani-le-Bris 1993), the consensus was that there was a need for policy initiatives on a European level (Steenvoonden et al. 1993) and for member states to recognise how much they relied on the family to support older people (Salvage 1995). Salvage (1995) called for a ‘well grounded discussion’ as to how family and formal service systems could work in partnership, so that the needs of both older people and family carers were acknowledge and addressed.

More recently there have been a number of large-scale multi-country European studies that have directly or indirectly sought to address several of the above issues (CARMEN, OASIS, PROCARE, SOCCARE). The promotion of partnerships between family and professional carers features prominently in the conclusions of these studies (Alaszewski et al. 2003, Kröger 2003, Lowenstein and Ogg 2003, Banks 2004, Nies 23004a), as does a call for the development of more creative and innovative services to address the needs of both older people and family carers (Lowenstein and Ogg 2003). Indeed it is suggested that ensuring the wider availability of support for family carers should be amongst the foremost policy aims for Europe (Kröger 2003). However, notwithstanding the greater insights into carers’ circumstances provided by recent work, Cressen (2003) argues that our understanding of their role and needs remains ‘incomplete, fragmented and problematic’.

As noted in the introduction to this report, one of the primary aims of the EUROFAMCARE project was to evaluate the situation of family carers of older people in Europe in relation to the existence, familiarity, availability, use and acceptability of supporting services.

The main aim of this chapter is to identify several of the ‘unresolved issues’ relating to support for family carers (Pearlin et al. 2001), and in so doing to suggest areas that might be addressed by the results of the six national surveys, and the NABARE’s / PEUBARE, whilst also raising questions that require further exploration. It will draw upon recent academic, policy and practice literatures as well as highlighting key themes emerging from the PEUBARE (ref).

2.2 Supporting family carers: identifying some key issues

Studies exploring the circumstances, experiences and support needs of family carers have proliferated over the last 30 years, particularly in North America, certain European countries, notably the UK, and Australasia. The subject was ‘hardly mentioned’ in the 1960’s (Brody 1995), and yet by the 1990’s family care had become one of the most researched areas in the field of social gerontology (Kane and Penrod 1995). This ‘explosion’ in research activity (Fortinsky 2001) has generated a ‘voluminous literature’ (Schulz and Williamson 1997), much of it focussing on interventions designed to maintain family carers in their role. Yet despite this there is still little evidence for the effectiveness of existing models of support (Braithwaite 2000, Thompson and Briggs 2000, Cooke et al. 2001, Pusey and Richards 2001, Whittier et al. 2002). Indeed Pruchno (2000) suggests that 40 years of research has *‘only scratched the surface regarding our understanding of the caregiving experience’*, with Pearlin et al. (2001) concluding that there remain ‘several unresolved issues’ surrounding how best to support family carers.

In reflecting upon the ‘critical’ questions in caregiving intervention research that remain to be fully resolved, Schulz (2001) suggested several key areas including:

- WHO is the primary target of support?
- WHAT is the area targeted, for example, cognitive, affective or psychomotor domains?
- HOW is support delivered most effectively?

These are important considerations that will be addressed later. However, others have argued that an even more fundamental issue is that of WHY support family carers (Nolan et al. 2002); in other words, what are the underlying motivations and goals of supporting carers, particularly from a policy perspective?

2.3 WHY support family carers?

Early interest in family, or ‘informal’, care as it was originally called, was primarily academic, with the issue being brought into the spotlight by feminist concerns about the disadvantaged position of women as the main provider of family care (Jani-le-Bris 1993). Initially there was relatively little attention to carers’ needs in the policy and practice fields, however, over time, particularly in North America and the UK, family care became ‘highly politicised’ (Chappell

1996) and moved from the ‘margins’ of social policy to occupy ‘centre stage’ (Johnson 1998). But this trend is far from universal, and as the National Background Reports (NABARE’s) demonstrated, family care is still not on the policy agendas of several European countries, and has only recently figured in a number of others. Just as Jani-le-Bris (1993) noted, in the Northern European countries, typified by Sweden, family care was until recently a ‘non-issue’ as the state provided for the support needs of older people with there being no expectation that family help was needed. The situation was the exact reverse in several Southern European countries, typified by Greece, where the family is seen to have a ‘taken-for-granted’ role in supporting older members, with the state playing no role other than in cases of extreme economic hardship. Consequently, as will be highlighted later, support services for family carers vary considerably throughout Europe, being virtually non-existent in several countries and piecemeal, fragmented and ad hoc in a number of others (see PEUBARE for full account).

However, there is now a growing awareness, albeit by no means universal, of the importance of supporting family carers. Following a ‘state of the art’ review of comparative social care research across Europe, Kröger (2001) concluded *that ‘after a long period of disregard informal carers are finally now recognised as the bedrock of care for older people’* thereby giving far more prominence to their hitherto *‘mainly invisible and undervalued role’*. So, for example, in Italy where there have never been specific policies for family carers (Polverini et al. 2004) the debate on carers’ rights is now growing (Colombo 2002). Similarly, the German NASURE notes that, despite a wealth of social research into the needs of older people, little of this has focussed on family carers. But, as in Italy, the issue is now receiving greater attention. In contrast the Polish NASURE reaffirms the traditional and largely taken-for-granted role of the family as supporters of older people, with there being no data on the provision and availability of services for family carers. This latter position is reinforced in the PEUBARE, which suggests that, despite some advances, family carers remain ‘invisible and undervalued’ in many states.

This lack of recognition requires urgent attention if the major policy goal of providing ‘integrated’ care for older people in Europe is to be achieved (Banks 2004, Nies 2004a). As these authors note, supporting family carers and strengthening the integration between formal and informal systems of care is essential (Banks 2004), with one of the most important future research objectives being to find better ways of supporting family carers (Nies 2004b) and, as noted earlier, ensuring that they work in ‘partnership’ with formal systems (Nies 2004a). However, to date the interplay between informal carers, professionals and other paid workers has received little attention (Nies 2004b), and the ‘well balanced’ dialogue required is notably absent (Nies 2004a). Therefore, whilst the need for greater synergy between family and formal carers is widely recognised, the challenge is to get them to cooperate more fully (Soderno 2004). Clearly carers’ needs must be seen as a legitimate and important policy objective in all European countries if the necessary dialogue is to be initiated.

Even in countries where carers’ needs are high on the policy agenda, such as the UK and the Netherlands, and where there have been ‘striking’ recent developments in carer support (Moriarty and Webb 2000), the motivation underlying such initiatives is still primarily instrumental, driven largely by economic and pragmatic concerns rather than altruistic or humanistic ones (Ward-Griffin and McKeever 2000). Kröger (2001) concludes that the greater recognition now afforded family carers was motivated by the realisation that Europe would face a ‘crisis in care’ within 20 years unless policies to support family cares were instigated.

Therefore, implicit within most policy initiatives designed to support family carers is the goal of either maintaining existing family carers in their role and / or ensuring an adequate supply of future carers, a goal that is particularly important given that future generations may be less involved than current ones (Klie and Blaumeister 2002).

More recently there have been calls in these countries to consider more fully carers' rights as citizens. This has stimulated a renewed focus on their well-being and quality of life (Nies 2004a), and ways of compensating them for the missed opportunities that caring can occasion (Banks 2004). In policy terms this development is reflected in the recent 'bold new vision' for carers launched by the Scottish Executive (Scottish Executive / Office of Public Management 2005a). These new proposals are based on the belief that the contribution that carers make to society must be fully recognised, the economic impact of that contribution accepted, and that carers have to be wholly included in a society that provides adequate support for their needs. Interestingly, the term 'unpaid carer' is preferred to family carers, signalling another shift in emphasis with 'unpaid carers' being seen as the major **providers** of care rather than as clients or recipients of services per se. This 'bold new vision' is underpinned by two key principles:

- greater recognition of, and respect for unpaid carers as key partners and providers of care;
- the development of a rights based policy framework to support unpaid carers who are seen as 'people first' and unpaid carers second.

The goal is to ensure that people have the opportunity to choose when, how, and if to care, and to promote unpaid caring as a 'positive life choice'. In order to achieve these aims it is argued that carers should have rights to:

- flexible employment;
- adequate financial support and planning;
- accessible information and technology;
- practical support;
- regular breaks from caring;
- adequate housing;
- training and health care;
- good transport links;
- accessible leisure and recreational opportunities.

Essentially, therefore, carers should have rights to the same opportunities as other citizens, including the right not to care, to choose an appropriate level of care, and to receive appropriate support from agencies adequately resourced to do so. The Scottish Executive recognises that many of its recommendations will require significant changes in existing professional culture and practice. This is an area that will be returned to later.

In summary, therefore, the answer to the question WHY support family carers varies considerably, the topic is not currently on the policy agenda in several countries, is seen as an increasingly important in others, and is already a priority in a small number. Despite this, motivations for supporting family carers remain primarily pragmatic, but there is evidence of an emerging ‘rights’ based framework in some countries. A closely related issue is WHO to support and it is to this question that attention is now turned.

2.4 WHO to support: Older people, family carers, or both?

The question of who to support simply does not arise in several countries, as no formal support for family carers exists, and support for frail older people is often limited as well. In compiling the PEUBARE, an analysis of the 23 NABARE’s suggested the existence of three main models of support:

- Scandinavian model – where the emphasis has traditionally been on supporting the older person. Whilst this remains the case, dedicated services for family carers are beginning to emerge.
- Southern European, or family model – where the primary responsibility for supporting older people rests with the family and where public services to support family carers are limited or non-existent.
- A smaller group of countries – where carers are recognised as citizens with specific (albeit still rather limited) rights. These include the UK, Ireland and the Netherlands.

Nevertheless, in all of these countries the majority of support is still targeted at the older person, and most of this is instrumental. Debates about whether to support the older person or the family carer have been evident for some time, with Jani-le-Bris (1993) advocating a two pronged approach, with the majority of services supporting older people, but with there also being a range of services specifically for family carers. More recently others have reached a similar conclusion, calling for wider and more creative services both for older people and family carers (Lowenstein and Ogg 2003). Therefore, whilst it seems that most effort will still be directed at supporting the older person, such support can have indirect benefits for carers themselves. Furthermore, dedicated support services for family carers are emerging with the PEUBARE identifying several examples of good practice. What is notably absent are well developed forms of support aimed at the caregiving dyad or the wider family unit, despite recent calls to consider dyadic or triadic relationships as the unit of intervention (Fortinsky 2001, Nolan et al. 2003).

A closely related issue is WHO currently provides support to family carers. The NABARE’s would suggest that carers’ first point of call, and most frequent form of support, is informal, with help being provided by family, friends or neighbours. Increasingly, family carers are also purchasing their own help, often in the form of ‘live in’ support workers frequently employed illegally and with the tacit acknowledgement of the authorities. This is particularly prevalent in Southern European countries, resulting in a growing, and largely unregulated workforce, with few safeguards on the quality of care provided. Recently, however, initiatives to regulate such workers have been introduced in a number of countries (see PEUBARE). In many countries the only formal source of support for carers comes from voluntary, charitable or religious organisations, with groups such as the Alzheimer’s’ Society or affiliated bodies playing an increasingly important role (see, for example, the Italian and German NASURE).

As noted earlier, the NABARE’s would suggest that generally speaking formal state support for carers is either non-existent, is targeted indirectly at the older person, or is fragmented, ad hoc and reactive rather than systematic, planned and proactive. This raises the question of WHAT is meant by carer support.

2.5 WHAT do we mean by carer support?

The question of what is meant by carer support is not straightforward. As noted above, such support can either be direct (that is targeted at the carer themselves) or indirect (targeted at the older person with potential benefits for the carer) (Twigg and Atkin 1994). The only form of carer support mentioned in all 23 NABARE's is the provision of respite care, usually seen as providing indirect benefits for carers. Respite is one of the most requested forms of help (Briggs and Askham 1998, Pickard 1999, Zarit et al. 1999, Scottish Executive 2005b), but despite the NABARE's indicating that it is more or less universal, there is considerable variation in the number of places available, and the range, quality and flexibility of provision. Even in the UK where 'breaks for carers' (the preferred term to respite, which is seen to have pejorative undertones) were an explicit and resourced target of the 'Carers National Strategy' (DoH 1999), provision remains inadequate (Scottish Executive 2005b).

As noted previously, much support for carers is indirect, and there is a need for an expanded definition if more innovative services are to emerge. Askham (1997) has suggested that support for carers should be defined as any intervention that helps carers or potential carers to:

- take up, or decide not to take up, a caring role;
- continue in a caregiving role;
- end a caregiving role.

Implicit within this definition is the suggestion that carers may need varying types of support at differing points in their caregiving history (see later for fuller discussion). This has been recognised by others who argue that support should be tailored to 'successive stages' of caring which often have their own specific needs (Jani-le-Bris 1993). However, reflecting the instrumental motivation underpinning much carer support, most effort is currently directed at services intended to maintain carers in their role. So systematic efforts to prepare carers for their role, for example following a sudden episode like a stroke, are notably absent and such carers often enter the caring role without having exercised an informed choice, or being given the necessary skills and information they need to provide effective care (Brereton and Nolan 2003). Similarly, little support is provided when carers have to select a nursing or care home, and on-going attention to carers needs post-placement is the exception rather than the rule (Davies and Sandberg 2000, Davies 2003, Sandberg et al. 2003).

Conceptually, carer support has been primarily informed by a stress-burden model (Nolan et al. 1996, Schulz and Williamson 1999, Zarit et al. 1999, Fortinsky 2001), with this having become a *'major tenet of gerontological policy and practice'* (Zarit et al. 1999). This remains the dominant theoretical perspective (Guberman 2005, Huyck 2005, Turner 2005). While it would be wrong to underestimate the important insights that research into stress and coping has provided, an unintended consequence of this work has been a preoccupation with the negative or pathological aspects of care to the relative neglect of sources of satisfaction and reward (Twigg and Atkin 1994, Nolan et al. 1996, 2003). Compounding this largely unidimensional view, many interventions fail to capture the dynamic nature of family caring, with several commentators calling for support that pays more attention to the context of care and the ways in which caring demands change over time (Qualls 2000, Dilworth-Anderson 2001, Whitlach et al. 2001).

Others have suggested that the pre-occupation with burden has resulted in support that carers do not always see as relevant to their needs (Qureshi et al. 2000), and has ignored the potential of a ‘strengths-based’ approach in which support is designed to help carers to find balance and meaning in their role (Berg-Weger et al. 2001). Whittier et al. (2002) argue that there is a growing literature on the potential benefits / rewards of caring and that this should be harnessed to better effect in designing more innovative forms of support. They conclude that there is *‘increasing support for the ‘gains’ perspective as a potentially meaningful area for program development’*. However, a recent meta-analysis of 78 intervention programmes for carers suggests that there is some way to go before this is likely to happen, with 57 / 78 studies targeting burden, 40 / 78 depression, and only three including uplifts or satisfactions (Sorensson et al. 2002). As Ory (2000) notes, there is a need to move beyond the *‘usual recitations of burdens experienced’* if appropriate and innovative forms of support are to emerge.

Another key consideration when addressing the ‘WHAT’ of carer support is to reflect upon the primary target domain (Schulz 2001). So, for example, is the target cognitive, with the intention of changing the way carers think about their role or the knowledge they have of it? Is it affective, seeking to influence the way they feel about caring, or is it psychomotor, with the aim of changing behaviour or developing specific skills and abilities? All are legitimate goals but as yet there is little evidence as to what works best and when. This is often because the goals of an intervention are unclear, lack a sound theoretical basis, or because the measure(s) used to indicate success are inappropriate.

Recently several authors have reflected upon these issues and an emerging consensus is apparent. Ideally therefore interventions should be underpinned by a sound theoretical rationale (Schulz and Williamson 1997, Bond 2000, Ory 2000, Schulz 2001, Zarit and Leitsch 2001) and whilst a stress-coping model has been the most consistently applied it is also important to incorporate other theoretical frameworks which reflect the temporal dimension of caregiving and its relational and dynamic nature. However, even in studies which have been explicit about their theoretical basis, the way in which the effects or outcomes of interventions have been operationalised has often been unrelated to the intended goals of care (Kane 1997). Zarit et al. (1999) suggest that all too frequently outcomes are insensitive, inappropriate or unrelated to the intervention, or too global and grandiose in their scope (Zarit and Leitsch 2001). Schulz (2001) argues that outcomes can be considered in terms of their ‘distance’ from the intervention, with ‘proximal’ outcomes being directly related to the intervention while ‘distal’ outcomes are at least one step removed.

As Zarit and Leitsch (2001) note, the tendency to use outcomes which are ‘too global or grandiose’ means that studies often make a leap of faith from a relatively discrete intervention (such as an educational programme) to a distal outcome such as reduced burden or improved general well-being without paying adequate attention to intervening effects. Interventions should be targeted on aspects of caregiving that are the most amenable to change (Braithwaite 2000), and it is therefore important to identify what is ‘reasonable and modifiable’ within a given context (Zarit and Leitsch 2001).

The sort of carefully tailored approach that is increasing advocated within the research based literature is not reflected in the way that support services are delivered to family carers. Most of the NABARE’s, to the extent that they describe support services for carers at all, talk in terms of support that is reactive, ad hoc and fragmented. Most still focus on reducing burden, often indirectly via services aimed at the older person. Whilst services such as counselling and personal support are increasing in some countries, supply is often limited and there is a need for a more expansive range of interventions and better systems of care and case management (Kofahl et al. 2003). The type of comprehensive support for carers identified in the National Family Caregiver Support Program in the USA (see Whittier et al. 2002), or envisaged by Kröger (2001) or the Scottish Executive (2005a) (see Table 1), is not widely evident in Europe. Even where services are fairly well developed, relative to other countries, gaps are particularly apparent between urban and rural areas (Schultz and Nieswandt 2000), for black and minority ethnic (BME) groups (Wingenfeld 2003) and gay / lesbian carers (Scottish Executive 2005a). The design of the CAT questionnaire used for the national surveys was intended to throw light on the existence and availability of services for older people and family carers, and to more clearly identify gaps in provision (see chapter 3).

Table 1: Suggested constituents of comprehensive carer support programmes

National family caregiver support programme (USA)	Kröger (2003)	Scottish Executive (2005a)
▪ Information about available services ▪ Assistance to access services ▪ Individualised counselling, support groups, training, problem solving ▪ Respite care ▪ Supplemental services that complement the care provided for caregivers	▪ Services to ease carers' workload ▪ Advocacy ▪ Information and advice ▪ Financial support ▪ Emotional support ▪ Respite ▪ Networking ▪ Training	▪ Training and information ▪ Expert carer programmes ▪ Assessment of need for support ▪ Benefits, entitlements and employment ▪ Respite and breaks ▪ Practical support ▪ Counselling and psychological support ▪ Aids and adaptation ▪ Using new technologies

2.6 WHEN to support carers?

Askham's (1997) definition of carer support cited earlier suggested the need to tailor support to specific stages of caring, and this has been reinforced in a number of studies that have been completed over the last decade or so. These indicate that carers' needs change over time and that support should be tailored so as to reflect these differing needs. These studies do not suggest that caring follows a uniformly similar path but rather that it is possible to identify 'threads of continuity' (Aneshensel et al. 1995) or to 'discern consistency' (Montgomery and Kosloski 2000) in the caregiving experience that provide 'markers' for the type of support that is most appropriate at a given point in time. The implications of this for the design and delivery of appropriate support for carers were eloquently captured by Aneshensel et al. (1995) as follows:

> 'The form, content and timing of interventions should depend to a considerable extent on where carers are in their careers, and involve an understanding of what has passed before, and what is likely to be ahead. That is, the problems encountered today should be viewed against the backdrop of yesterday and with an eye towards tomorrow.'

Bearing in mind that services must be responsive to carers' changing needs, Nies (2004a) suggests that good support needs to be:

- simultaneous – that is provide several services in a coherent way that are consistent with daily routines;
- sequential – that is able to adapt to changing needs over time.

The importance of services being available 'on time' and the impact of this on their acceptability to carers will be discussed more fully later.

Several temporal models of care have been developed (see for example Wilson 1989a, b, Willoughby and Keating 1991, Kobayashi et al. 1993, Wuest et al. 1994) with numerous authors highlighting the importance of paying greater attention to caregiving transitions (Aneshensel et al. 1995, Schulz and Williamson 1997, Montgomery and Kosloski 2000, Ory 2000, Qualls 2000, Whitlach et al. 2001). Aneshensel et al. (1995) used the metaphor of caring as a 'career' and identified three broad phases characterised by:

- preparation for, and acquisition of, the caregiving role;
- enactment of caregiving;
- disengagement from caregiving.

Others have likened caring to a career with a *'beginning, discernable temporal extension or direction, and an end'* (Montgomery and Kosloski 2000), but probably the most extensively developed and tested of these temporal models is that proposed by Nolan and colleagues (Nolan et al. 1996, 2003). Here caring is seen as comprising 3 broad sequential phases more or less consistent with those of Aneshensel et al. (1995) above. These are termed:

- recognising the need / taking it on;
- working through it;
- reaching the end / a new beginning.

This model has been used to compare and contrast the varying experiences that carers have with services. For example, the ways in which carers 'recognise the need' for care and 'take on' the role differ widely in conditions such as dementia (Keady and Nolan 2003) and stroke (Brereton and Nolan 2003), and these differences have numerous implications for the nature and type of help that is most appropriate. Although most carers would welcome some formal support at an early stage, their initial experiences of professional help are often not positive and carers can easily lose confidence and trust in services, which limits their subsequent use (Thorne et al. 2000, Brereton and Nolan 2003). Consequently, many of the difficulties carers face in their early career are the result of 'system induced setbacks' (Hart 2001) that inhibit further contact with formal support.

Similarly, experienced carers develop a very strong sense of their own 'expertise' (Nolan et al. 1996, 2003) and expect formal services to recognise and respect this. Indeed the 'bold new vision' of carer support promoted by the Scottish Executive (Scottish Executive 2005a, b, c, d, e) is largely underpinned by the notion of the 'expert carer' and the development of 'expert carer programmes'. These reports advocate an 'induction' programme for all 'new' carers including a consideration of their:

- basic rights and entitlements;
- practical skills and implications of the caring role;
- personal coping strategies;

- managing transitions. (Scottish Executive 2005a)

It is suggested that such an induction is particularly important at the outset and needs to be repeated at major transitions in order to help carers to plan for the 'critical junctions' in their caregiving journey.

Such phased support was advocated several years ago in the 'PREP' model (Archbold et al. 1994), with the acronym standing for:

PRepardness	with early support focusing on providing carers with the knowledge and skills that they need to care;
Enrichment	highlighting the importance of working with carers and the cared-for person to try and 'enrich' the experience of caring and to enhance the caring relationship;
Predictability	helping carers to focus on potential future events and plan for these in a proactive fashion.

Such a structured model stands in marked contrast to the largely instrumental, ad hoc and reactive support services described in most of the NABARE's. The provision of inappropriate support may explain why several studies in a number of countries have indicated the ongoing problems that carers have in their contact with formal services, particularly when caring for someone with dementia (Lundh et al. 2003a), or learning disabilities (Grant and Whittell 2003, Llewellyn 2003).

Assistance with transitions in the later stages of caring is also often deficient, with carers frequently being left to make difficult decisions, such as selecting a care home without adequate information and advice (see for example Davies 2003, Pearson et al. 2003, Sandberg et al. 2003). Carers' need for support does not end when the cared-for person is placed in a care home or dies, however, such needs are often ignored post-placement, despite the potentially valuable contribution that carers can make to life in a care home (Davies 2001, Lundh et al. 2003b, Sandberg et al. 2003). A recent survey of over 4000 carers in Scotland indicated that more than 50 % would value some form of post-caring counselling, yet such services are often conspicuous by their absence (Scottish Executive 2005a).

There is much to be learned from considering caring as a temporal experience, as the insights that such an approach provides can indicate the type and acceptability of help needed (see later), and how it can be delivered.

2.7 How and where should support be provided?

With respect to HOW and WHERE support is best provided Schulz (2001) raises several questions, to which there are as yet no definitive answers. For example, should support be delivered on an individual or group basis, face-to-face or remotely, using the growing availability of information and communication technology (ICT), is support best provided in the carers own home or elsewhere? To a large extent answers to such questions will depend on the purpose of the intervention and the goals of support. However, one area in which there is considerable potential for the development of innovative services is in the application of ICT. Enabling older people to engage fully with the new 'information society' by promoting 'e-inclusion' and 'e-accessibility' are key EU policy priorities (EC Research Directorate General 2003, Ministerial Declaration on E-inclusion 2003), and a recent extensive review of the available research evidence indicates that with appropriate training and support older people can develop IT skills with beneficial effects, including increased self-esteem, better subjective mood, reduced social isolation, and enhanced social networks / intergenerational ties (Magnusson et al. 2004). The benefits of ICT should also be available to family carers and recent studies have indicated the numerous advantages that can be achieved by helping carers feel better prepared, assisting carers to identify the rewards and satisfactions that they experience, as well as reducing carers' social isolation (Magnusson et al. 2005). However, such interventions need to be provided early in the caregiving experience, indicating the inter-related nature of the WHAT, WHEN, HOW and WHERE of supporting carers.

2.8 Developing better carer support services

One of the enduring paradoxes in providing carer support is that despite the currently limited provision and carers' obvious needs, not all the available support is necessarily used. This was highlighted in several of the country specific National Survey Reports (NASURE), and has been identified in a number of studies (see for example Moriarty 1999, Pickard 1999, Braithwaite 2000, Qureshi et al. 2000, Zarit and Leitsch 2001). The reason that carers do not always accept the support offered may be because they do not see current services as relevant to their needs (Pickard 1999, Braithwaite 2000), or have concerns about the quality and continuity of care provided (Moriarty 1999, Pickard 1999, Qureshi et al. 2000, Brereton and Nolan 2003). For example, a recent evaluation of the CARER 300 initiative in Sweden, that was designed to stimulate the development of carer support services within municipalities, indicated that carers often did not use such services because of concerns over quality and costs (National Board of Health and Welfare 2003). Similarly, the chapters on carer support from the German and Italian NASURE's indicated that not all available services are necessarily utilised in these countries. The key question is WHY?

Good quality support is valued and highly appreciated by carers (Lowenstein and Ogg 2003), but usage and uptake is influenced by several factors including: family culture (that is readiness to use services); family norms and their preferences for certain types of care and the availability, accessibility, quality and costs of the support available (Lowenstein and Katz 2003). In respect of usage of services for older people more generally, Bojo and Ancizu (2003) argue that this is primarily determined by knowledge, image and availability. In situations where public knowledge of services is high, such services have a positive image, and there is easy access, then uptake is likely to be good.

Whittier et al. (2002) have suggested that there are five reasons why carer support may not be used. These are:

- Availability
- Accessibility
- Appropriateness
- Acceptability
- Affordability

These seem to distil the key messages from several studies and are useful in considering how better support services might be developed.

2.9 Availability

Clearly services cannot be used if they are not available, and the NABARE's provided eloquent testament to the widely divergent nature of carer support. In many countries this is non-existent, and in most cases the services that are available focus primarily on the older person, albeit with some indirect benefits for the carer. Even in those countries where support for carers has become a policy priority, services remain largely reactive rather than proactive, and innovation is relatively limited (National Board of Health and Welfare 2003, Audit Commission 2004). For example, despite the considerable attention given to carers' needs in the UK over the last decade, a recent evaluation concluded that:

> 'The Government's aspirations for carers of older people are not being realised in practice for the majority of them. A clearly articulated and coordinated approach is needed from all concerned if this is to change.' (Audit Commission 2004)

Particular difficulties have been noted for several marginalised groups of carers such as those in rural areas, those from black and minority ethnic groups, and other minorities such as gay and lesbian carers (Scottish Executive 2005b).

Availability is in part an issue of resourcing, but things are unlikely to improve significantly until there is greater recognition of carers as individuals with rights of their own. Such formal recognition needs to permeate policy and practice throughput Europe.

2.10 Accessibility

There are several dimensions to accessibility, and perhaps the most obvious relates to the physical accessibility of services. Carers are often older people themselves and services that are geographically remote or do not provide disabled access have obvious limitations. Basic infrastructure such as adequate transport and a good built environment are therefore essential (Scottish Executive 2005a). Another key factor is knowledge and awareness of services, for even if services exist, carers cannot access them if they do not know about them. Despite living in the age of the 'information superhighway' one of the biggest single complaints from carers is a lack of information about available services and how to access them. For example in Germany the public are often unaware of the limited services that are available for carers (KDA 2003). Even in countries such as the UK where carers have certain statutory rights, for instance, to an assessment of their needs, most remain unaware of this (Audit Commission 2004, Scottish Executive 2005b). Certainly this is one area where immediate improvements could be made, and, as indicated earlier, ICT could have a major role to play.

However, greater knowledge is only the first step to increasing accessibility, and most carers still have to learn how to get into the 'system' and use it to their best advantage. Most formal services are accessed via some form of 'assessment' and it is here that difficulties often arise and barriers are constructed. A full and adequate assessment of need should be the foundation for an appropriate package of care and support (Nies 2004a, Audit Commission 2004, Scottish Executive 2005a, e), and several years ago Aneshensel et al. (1995) recommended that adequate support should be based on:

- a multidimensional assessment of the 'unique constellation' of issues in a particular caring situation, resulting in;

- goals for support that focus on a ‘particular configuration’ of issues at a ‘specific point’ in time;
- this requires a broad and comprehensive range of interventions and the use of;
- multiple evaluative criteria to judge success or otherwise (see later).

Consistent with the new policy rhetoric in several countries, assessment should also provide the opportunity to engage carers as ‘true partners’ (Audit Commission 2004, Nies 2004a). However, recent evaluations suggest that this is rarely the case and indicates that current assessment practice fails to involve carers fully. As such it represents a ‘lost opportunity’ to forge positive relationships (Audit Commission 2004). To compound difficulties, assessors often adopt a ‘gate-keeping’ role, and use assessment as an opportunity to ration existing resources rather than to think creatively about a range of possibly unconventional but innovative solutions (Audit Commission 2004, Scottish Executive 2005a). This is not to say that innovative services do not exist, several examples are provided in the PEUBARE, but that they are the exception rather than the rule. More usually carers see assessment as offering empty promises, with there often being a poor fit between carers’ and service providers’ views of the support required (Scottish Executive 2005c, e). The need for greater innovation is recognised in several countries. For example, in Italy there are calls for services to be tailored to carers’ specific needs rather than carers being ‘fitted into’ standardised services (Lippi 2002), but as noted in Germany, support for carers is usually ‘service shaped’ rather than being needs-led (Schaffer 1999).

Exacerbating the situation, eligibility for service is determined largely by the objective circumstances of carers. This is typical of the currently dominant approach to the assessment of carers’ needs in the UK, in which services are targeted primarily at carers providing ‘regular and substantial’ care, which is generally equated with more than 20 hours of care per week (Hirst 2001). Several recent studies in Canada and the USA have noted that carers’ needs are still not routinely considered by practitioners (Guberman 2005), and even when they are the dominant focus is on burden (Guberman 2005, Huyck 2005, Turner 2005). Eligibility criteria for services, usually in the form of an assessment of the activities of daily living that carers undertake for the cared-for person, remain prevalent (Albert 2005, Bedford 2005). Therefore whilst assessment should provide a ‘new lens’ through which better to understand carers’ needs (Fancey et al. 2005), resulting in customised support tailored to individual needs and priorities (Zank 2005) this is rarely the case.

Guberman (2005) has called for a move away from a service driven model towards one that provides carers with genuine choice. If such a shift is to occur it is suggested that:

> ‘Regardless of the type of service required, it is critical that carers receive a service that is tailored to their individual needs. To make this happen assessment processes need to be more interactive and holistic, giving carers the opportunity to determine more fully what they need.’ (Scottish Executive 2005a)

This is essential if services are to more appropriately address carers’ needs, and be acceptable to carers.

2.11 Appropriateness and acceptability

In carers’ eyes the appropriateness and acceptability of services are closely related attributes and therefore will be considered together. As noted earlier, the paradoxical situation often exists where, despite considerable need for support, carers do not always make full use of the limited help available. This is because they frequently do not see such services as appropriate to their needs, or of acceptable quality. Carers make subtle judgements about the relative 'costs and benefits' of support and reject help if the former outweigh the latter (Clarke 1999, Montgomery and Kosloski 2000). Essentially, carers want to be reassured that those providing support are 'up to the job' (Brereton and Nolan 2003, Brereton 2005), and if formal carers do not have the requisite knowledge, skills and attributes then help will be unacceptable.

If support is to be appropriate it must be 'meaningful' to carers (Beck 2001, Schulz 2001). Carers have the not unreasonable expectation that the support they are offered will be 'connected' with their concerns and 'congruent' with their expectations (Wuest and Stern 2001). Unfortunately services are often 'disconnected' and 'distant' (Wuest and Stern 2001) and 'disintegrated' rather than 'integrated' (Gilmour 2002). The acceptability of help often hinges on the quality of the personal relationship and rapport between professionals and carers (Scottish Executive 2005c), as this determines whether carers have 'confidence and trust' in the individuals involved (Brereton and Nolan 2003, Brereton 2005). It is therefore unfortunate that such relationships between carers and service providers are often fragmented or non-existent rather than close and supportive (Eframisson et al. 2001). Work in Italy suggests that formal services often still see families as barriers to getting the work done (Taccani 2004). The difficulties that can result are eloquently captured in the following quote:

> 'Thus the caregivers not only had to deal with the demands and stresses related to the care of the ill person, they also had to battle the health care system and the professionals who worked within it. Rather than becoming allies and partners, the health professionals were seen as a barrier to what the caregivers considered to be necessary care and the best interventions for the cared-for person.' (Jeon and Madjar 1998)

To make matters worse, professionals' interactions with carers are not always positive, with the Audit Commission (2004) reporting that the attitudes of some care managers was *'surprising'* and that the subsequent *'anger and frustration'* of carers was worrying. There is a need for services in general, and individual practitioners in particular, to be far more *'carer aware'* (Audit Commission 2004).

The acceptability of support is also linked to other factors such as socioeconomic status or carers' perceived role. So, for example, the German NASURE indicated that residential care is a less acceptable option to families from lower socioeconomic groups, who are consequently unwilling to see this as a viable alternative. The Italian NASURE suggested that carers often reject services because they see themselves as irreplaceable, and the reluctance of carers in Sweden to use services that they see as either too expensive or of inferior quality has recently become clear (National Board of Health and Welfare 2003). We need therefore more insights into the appropriateness and acceptability of support and how this is influenced by factors such as the social class and educational background of carers, or carers from the same or differing generations. This is an area where further research is needed. However, important lessons about the appropriateness and acceptability of support services can potentially be gained from the experience of countries that have a longer history of providing services to carers, for instance the UK.

In terms of the appropriateness and acceptability of support Nolan et al. (1996) argue that the best services are those in which there are overt, planned and systematic attempts by service providers to complement carers' efforts and to provide support that is sensitive and responsive to the caregiving dynamic and the 'expert' knowledge held by carers.

Recently Nolan et al. (2003a) have suggested that two factors are key in determining whether services are acceptable or not; these are the degree of symmetry and synchronicity that exists. Symmetry concerns the extent to which there is agreement between carer and service provider as to the intended goals and outcomes of the service, and when, where and by whom it will be provided. Synchronicity concerns the timing of support so that it is consistent with carers' needs at differing stages of their caring 'career' (see earlier discussion). When there is agreement about the intended goals and outcomes of services, and when support is delivered 'on time', then services are likely to be accepted readily. Conversely, when neither of these two criteria are met, then services are likely to be rejected. There is therefore a need to be far clearer about what carers themselves see as the goals of support.

A potentially very informative study was conducted by Nicholas (2001, 2003) who adopted an 'outcomes' focussed approach to the delivery of appropriate support for family carers. Underpinning this study was the belief that any appropriate support for carers has to *'understand the nature and complexities of caring and the relationships between unpaid carers and those who provide services to support them'*. Based on detailed work with carers she identified four broad domains of outcomes that carers see as essential to achieving appropriate and acceptable services. These are that services should:

- promote a good quality of life for the cared-for person;
- promote a good quality of life for the carer;
- give carers recognition and support in the caring role;
- provide support that is consistent with the carers' values, routines, expertise and so on, so called 'service process outcomes'. (Nicholas 2001)

Based on the existing literature, and her own work, Nicholas (2001, 2003) identified a number of key principles that should inform the development of future services for carers. These were:

- the definition and recording of outcomes should be carer-centred, specific and relevant to the individuals concerned;
- reaching a common understanding of the intended outcomes requires a thorough and sensitive assessment;
- the carer should be actively engaged as an 'expert' in the process of identifying and reviewing outcomes;
- the evaluation of outcomes should begin with clarity about the goals intended.

Nicholas' (2001, 2003) work adopted an action-orientated and user focussed design but the emphasis on outcomes is consistent with debates in the wider academic literature about the type of outcome measures that are used to judge the 'effectiveness' of carer support. As noted earlier, there is increasing recognition that in the past these have often been insensitive, inappropriate or unrelated to the intervention (Zarit et al. 1999), too global and grandiose (Zarit and Leitsch 2001), and too far removed or 'distal' from the intervention itself (Schulz 2001).

The similarities between Nicholas' practice-orientated study and the above theoretical and conceptual debates are striking and suggest that key to the appropriateness and acceptability of support for carers is the extent to which carers are actively engaged as 'partners', and seen as having important sources of 'expert' knowledge to contribute to negotiations about relevant services. The value of seeing carers as 'co-experts' was recognised some time ago (Triantafillou and Mestheneos 1993, Nolan et al. 1994, 1996) but has only recently permeated the policy rhetoric (Audit Commission 2004, Nies 2004a, Scottish Executive 2005a).

In considering the research literature on outcomes of carer support, one potentially interesting contribution is that of Schulz et al. (2002). Whilst their focus was on studies relating to the support of carers of people with dementia, the arguments advanced have much wider relevance. In 'taking stock' of the intervention literature Schulz et al. (2002) concluded that too much emphasis is placed on 'statistical significance' and too little attention given to 'clinical significance'.

In introducing the concept of clinical significance Schulz and colleagues draw upon Kadzin's (1999) work where clinical significance *'generally refers to the practical value of the effects of an intervention, or the extent to which an intervention makes a* ***'real'*** *difference (original emphasis) in the everyday life of the individual'* (Schulz et al. 2002). Subsequently, Schulz et al. (2002) suggest four dimensions of clinical significance that can be used to judge the appropriateness and effectiveness of carer support. These are:

- symptomatology - the extent to which support helps individuals return to normal functioning or experience an improvement in symptoms;
- quality of life - the extent to which interventions broadly improve an individual's quality of life;
- social significance - the extent to which interventions are important to society, as evidenced, for example, by their impact on service use, such as reducing admission to care;
- social validity - the extent to which treatment goals, procedures and outcomes are acceptable, as assessed by the client or expert ratings of the interventions and their effects on participants' lives. (Schulz et al. 2002, p. 590)

On the face of it such arguments appear to have a great deal to offer in terms of reconciling the differences between existing forms of support and the types of support that carers see as appropriate and acceptable. Unfortunately, the authors significantly limit the force of their conclusions by asserting that in order to be clinically significant results firstly have to be statistically significant, seemingly contradicting their earlier carefully made arguments. Moreover, they rely primarily on expert (as opposed to client) perceptions when defining social validity, and go on to state that of the dimensions of clinical significance:

> 'Researchers and policy makers would likely agree that social validity is important but that it is probably not the most valued indicator of clinical significance.' (Schulz et al. 2002)

It seems that within these few lines Schulz et al. (2002) reveal the Achilles heel within their own position, and also powerfully illustrate two of the major barriers to developing more effective support services for carers. The first is the widespread failure to grasp the fact that social validity is the single most important criterion; for if the goals, procedures and outcomes of services are not acceptable to carers then, unless they are in the most dire of circumstances, they will reject the support offered. Secondly, the continued emphasis on the views of *'researchers and policy makers'* reflects a professionalised view of the world in which the *'terms of engagement'* remain substantially defined by academics and professionals (Humphries 2003). This manifestly fails to recognise carers as partners and co-experts (Nolan et al. 2003, Audit Commission 2004, Scottish Executive 2005a), and is a situation that must be addressed if the appropriateness and acceptability of carer support is to improve. A specific section of the CAT questionnaire addressed the type of support carers would like and the quality criteria they apply (see chapter 3), and therefore EUROFAMCARE will be able to make an important contribution to informed debate in this area.

2.12 Affordability

Services cost money. In many countries the costs of services are (partly) covered by public authorities and/or health care/long term care/pension insurers. The financial public support is ranging within as well as between the countries. However, all in all the knowledge about the affordability of services – so far available – is small or even does not exist at all. Are the costs for service use a reason not to access a service or to stop the services use? Does private payment of a service influence the assessment of the relevant service? EUROFAMCARE tries to give answers both on the basis of the economic questions in the CAT questionnaire and the economic analysis in the ECO-report (deliverable 20).

2.13 Moving forward

As noted at the start of this chapter, the academic literature on family care has grown significantly over the last 30 years and more recently the attention of policy makers has been directed at supporting carers. However, most of the research and policy initiatives have been concentrated in North America, a small number of European countries and Australasia. As the NABARE's indicated, despite the rhetoric, family carers are not on the policy agendas of several European countries and others have only recently turned attention to their needs and circumstances.

The aim of this chapter has been to identify some key issues in relation to carer support and to consider areas where there is a need for further improvement or development. The project has adopted a multi-method, multi-phased approach involving:

- the production of 23 National Background Reports (NABARE's);
- a synthesis of the key points emerging from these reports in the form of a Pan-European Background Report (PEUBARE);
- the conduct of surveys of 1000 carers in each of six European countries (Germany, Greece, Italy, Poland, Sweden, United Kingdom) and analysis of the data to generate a Trans-European Survey Report (TEUSURE). It is these results that are the focus of this report.

The literature considered in this chapter has identified several key questions about carer support that remain 'unresolved' (Pearlin et al. 2001), including:

- WHY support family carers?
- WHO to support?

- WHAT do we mean by carer support?
- WHEN to provide support?
- HOW and WHERE is support best provided?

In addition it has been suggested that if better support services for carers are to emerge, then consideration will need to be given to the: availability; accessibility; appropriateness; acceptability and the affordability of current and future services.

Although EUROFAMCARE was not intended to address all of the above issues, it nevertheless sheds considerable light on many, and for the first time provides a genuinely pan-European perspective on policies relating to the support of family carers.

The PEUBARE represents an important addition to the literature by highlighting the diversity that characterises debates around family care. So, for example, the question of WHY support family carers simply does not arise in several countries as there is no formal recognition of family care as an issue. In several others greater interest in the needs and circumstances of family carers has emerged recently, whilst in a few there have been changes to legislation affording carers important, but still limited, statutory rights. Despite this it is apparent that in all countries most support is still directed at the older person, and that in many there are no formal services supporting family carers. Those services that do exist are frequently ad hoc and reactive, rather than proactive and carefully targeted.

Moreover, the motivation behind policies to support carers is largely instrumental, with services designed either to maintain existing carers in their role, and / or ensure a future supply of carers. There is, however, evidence of an emerging ‘rights’ based policy towards family carers, and a vision of carers as ‘partners’ and ‘co-experts’, working closely with formal systems of support.

Consequently support for carers should be based on a broad ranging and holistic assessment of their needs, with services being appropriate to their circumstances at the point they occupy in their caring history. The future vision is of a comprehensive, multi-component and flexible support package (Whittier et al. 2002, Scottish Executive 2005a). It is recognised that this will require a ‘paradigm’ shift in current relationships between carers and formal systems requiring changes in practice and culture, in particular the education and training of professional (Audit Commission 2004, Guberman 2005, Scottish Executive 2005a).

The analyses of the data from the six national surveys contained here will shed further light on a number of the issues raised above.

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3 The EUROFAMCARE Common Assessment Tool (CAT): Item and scale development and description

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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.

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 NASUREs.

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 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); 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 (Carers of Older People in Europe; 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 housewife / 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, no = 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), per month (2) or per 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 developed 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 (response format adapted from Krevers & Öberg, 2002).

A series of items were developed 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).

3.3 Item 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 2.

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. To this end a disability index was first derived, which took into account ADL, IADL, and the additional mobility item (see section 3.2.3.4). These items were first dichotomised 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) and then summed to produce the disability index, which had a theoretical range of 0 to 17. The dependency variable was then 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 disability index – where the median (50th percentile) of the distribution was used to distinguish elders with no / slight 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 disability' (0); 'cognitively able and more severe disability' (1); 'cognitively impaired and no / slight disability' (2) and 'cognitively impaired and more severe 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 disability' category was merged with the 'cognitively impaired and no / slight 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 section 3.2.5 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 for Elder-related scales are presented in Table 3, while descriptive statistics for Carer-related scales are presented in Table 4.

3.4.1 Elder disability and need

The three items of the BISID (Keady and Nolan, 1996; see 3.2.3.3) were used to develop a measure of behavioural problems. Participants' responses to these three items had a satisfactory internal consistency ($\alpha = .78$). 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.

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 ($\alpha = .78$), 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 = 4.27, SD = 1.74; 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 3.2.3.4) 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 ($\alpha = .92$). 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). There were a high number of missing values on this scale (N = 239, 4 %). Mean and median values were moderately high (M = 69.70, SD = 29.75; Median = 80.00), indicating that the majority of elders had a high level of independece on ADL activities.

To have available for analysis a more sensitive measure of functional impairment than ADL and IADL taken alone, the disability index was used (see section 3.2). The index had an excellent internal consistency ($\alpha = .93$). Due to the number of items comprising the scale, there was a high number of missing cases (n = 306, 5.2 %). The mean and median (M = 5.43, SD = 5.04; Median = 4.00) 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 3.2.3.1). 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 ($\alpha = .69$), 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 = 6.02, SD = 1,79; 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 ($\alpha = .87$) 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 = 13.89, SD = 5.99; Median = 15.00) were close to the scale mid-point.

3.4.2.2 Caregiving Indexes

Items assessing the Elder's need for support (see section 3.2.3.1) 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 ($\alpha = .70$) 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 ($\alpha = .84$) 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 ($\alpha = .82$), 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 = .86), 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 the internal structure of the instrument.

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. The analysis indicated the presence of three underlying components. Table 5 presents the item loadings and percent variance explained of the three components following varimax rotation. The first component (23.63 % of variance explained) consisted of items 2–7 and 14 and tapped a dimension of caregiving burden. In accordance with McKee et al. (2003), the component was named Negative Impact. The second component (13.96 % of variance explained) consisted of items 1, 9, 11, 13 and tapped aspects of value related to the caregiving role. Accordingly, this component was named Positive Value. A third component (13.61 % of variance explained) consisted of the remaining four items: 8, 10, 12 and 15, and tapped the perceived adequacy of social and professional support available. Again in accordance with McKee et al. (2003), this component was named Quality of Support.

In general terms the EUROFAMCARE analysis was consistent with that conducted by McKee et al. (2003), although the evidence for a third component in the earlier analysis was much weaker than in the latter. Additionally in the EUROFAMCARE analysis, item 6 (caregiving causes financial difficulties) loaded on the Negative Impact component, whereas in the McKee et al. (2003) analysis it failed to load on any component. Moreover, item 10 (feeling well supported by family) loaded on the Quality of Support component in the EUROFAMCARE analysis, whereas in McKee et al. (2003) it loaded on Positive Value.

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), and were summed to create the Negative Impact subscale with a theoretical range of 7 to 28 (highest impact of caregiving). The items comprising the Positive Value subscale had a low alpha ($\alpha = .65$), although Kline (1999) argues that for a psychological construct with relatively few items, an alpha of.6 to.7 is acceptable. Thus, the items were summed to produce the Positive Value scale with a theoretical range of 4 to 16 (highest positive value). Finally, the items on the Quality of Support component produced a similar level of internal consistency ($\alpha = .66$) and were therefore summed to give a subscale with a theoretical range of 4 to 16 (highest quality of support).

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, the same 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; Service use; Characteristics and quality of services*. 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 3.2.1). 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 3.2.6).

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 3.5.3.3.6) 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 3.2.2.1)

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 3.2.3.3) 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 3.2.3.4).

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 3.2.5.5): ‘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 3.2.5)

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 3.2.5.1): 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 3.2.5.3).

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 3.2.5.4).

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 3.2.7.2).

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).

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Table 2: 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 disability	0
	Cognitively able and more severe disability	1
	Suspected cognitive disorder and no / slight disability	2
	Suspected cognitive disorder and more severe disability	3
	Widowed, divorced / separated and single	1
	Married / cohabiting	0
	Partner	0
	Child	1
	Son / daughter in law	2
	Others	3
	None	0
	At least one	1
	Low	1
	Intermediate	2
	High	3
	Retired	0
	All other non-working (e.g., housewife / househusband)	1
	Working	2
	Cohabitant	1
	Non-cohabitant	0

Variable name	Categories / Levels	Values
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

Table 3: Elder-related scales

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Behavioural problems	5,894	29 (.50)	2.00 (2.56)	1.00	1.12 (.03)	.14 (.06)	0.00	9.00	.78
IADL	5,869	54 (.90)	4.27 (1.74)	5.00	-.63 (.03)	-.64 (.06)	0.00	6.00	.78
Barthel Index	5,684	239 (4.0)	69.70 (29.75)	80.00	-.99 (.03)	-.17 (.07)	0.00	100.00	.92
Disability index	5,617	306 (5.2)	5.43 (5.04)	4.00	.88 (.03)	-.30 (.07)	0.00	17.00	.93
Overall need for assistance	5,811	112 (1.9)	6.01 (1.79)	7.00	-.89 (.03)	.07 (.06)	0.00	8.00	.69

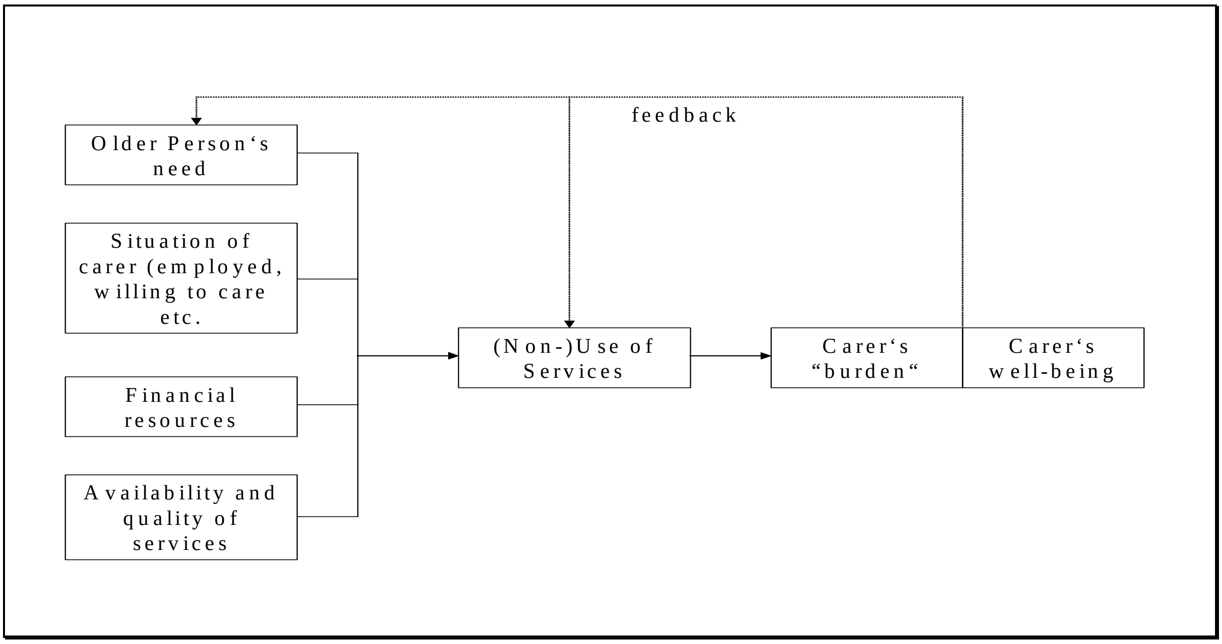
Table 4: Carer-related scales

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Negative impact of caregiving	5,847	76 (1.3)	11.89 (4.35)	11.0	1.07 (.03)	.78 (.06)	7.00	28.00	.83
Positive value of caregiving	5,783	140 (2.4)	13.45 (2.2)	14.0	-.74 (.03)	.01 (.06)	4.00	16.00	.65
Quality of support in caregiving	5,810	113 (1.90)	10.78 (3.01)	11.0	-.11 (.03)	-.69 (.06)	4.00	16.00	.66
Well-being index	5,880	43 (.70)	13.89 (5.99)	15.0	-.31 (.03)	-.65 (.06)	0.00	25.00	.87
Elder's needs covered by carer	5,830	93 (1.6)	5.31 (2.00)	6.00	-.54 (.03)	-.55 (.06)	0.00	8	.70
Elder's needs covered by informal support other than carer	5,829	94 (1.6)	1.82 (2.26)	1.00	1.12 (.03)	.14 (.06)	0.00	8	.82
Elder's needs covered by formal support	5,827	96 (1.6)	.85 (1.6)	0.00	2.06 (.03)	3.6 (0.6)	0.00	8	.86
Carer perceived need for more support	5,634	289 (4.9)	2.13 (2.46)	1.00	.98 (.03)	-.25 (.07)	0.00	8	.86

Table 5: The Cope Index: Items and factor loading

Cope Items	Negative Impact	Positive Value	Quality of Support
cope well as a caregiver?		0.51	
caregiving too demanding?	0.71		
caregiving cause difficulties in your relationships with friends?	0.73		
caregiving have a negative effect on your physical health?	0.76		
cause difficulties in your relationship with your family?	0.62		
caregiving cause you financial difficulties?	0.61		
feel trapped in your role as a caregiver?	0.70		
feel well supported by your friends and / or neighbours?			0.66
find caregiving worthwhile?		0.73	
feel well supported by your family?			0.60
have a good relationship with the person you care for?		0.74	
feel well supported by health and social services?			0.69
feel that anyone appreciates you as a caregiver?		0.59	
caregiving have a negative effect on your emotional well-being?	0.70		
feel well supported in your role of caregiver?			0.69
Variance Explained	**23.63 %**	**13.96 %**	**13.61 %**

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



Adapted from Aneshensel et al. (1995)

4 Sampling, recruitment and representativeness

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4.1 Aims of the Chapter

The aim of this chapter is to:

- present how the data was collected and which sampling strategies were used in the different countries within the project;
- to discuss the representativeness of the samples.

4.2 Method and sample

Data collection aimed to illuminate the most relevant care giving situations, to illustrate the plurality of possible care giving situations and to uncover the perspective of the carer. In the designing of the project a common strategy was built to ensure that samples from the different countries offered a good representation of carers and their situation and that these samples were comparable for the six countries. Therefore a standard evaluation protocol (STEP) for the national surveys (NASUR) was developed to make it possible to merge the data into a common database. This STEP for NASURE contained, among other things, guidelines on:

- questionnaires and guidelines for data collection;
- approaches for evaluating the percentage of family carers in the whole population and develop sampling strategies;
- training interviewers;
- the criteria of the sample unit (i.e. definition of “family carer of older people”).

To ensure a reasonable level of representativeness and comparability at a European level an agreement on a common definition of the elementary “sample unit”, to be used as the basis for the National Surveys, had to be found.

4.2.1 Sample units

This definition included any person who:

- perceived themselves to be a career;
- supported an older person 65+ for at least 4 hours a week and / or organised the care provided by others;
- provided care to an older person living at home or in residential care settings (nursing homes, sheltered housing, etc).

But excluded: those who only provide financial support or companionship.

In case a carer provides support to more than one elderly person, data collection was to be focused on the most relevant or primary care giving situation. Where more than one carer provided support to the same older person, data was to be collected from the person providing most care.

4.2.2 Sampling strategy

The common sampling strategy was formed based on the following steps:

- Sample sub-areas:
  The identification of at least three representative macro regions in each country.
- Sample regions:
  The identification of sample regions within the sub-areas based on urban / rural characteristics.
- Sample zones:
  One or more sub-areas representative of the region in term of socio-economic context and availability of services.

4.2.3 Recruitment procedure

Family carers were recruited through the agreed “saturation” ***method***, which involves contacting the population of caregivers living in the chosen sample communities through all the following potential recruitment channels:

- Contacts through volunteer, religious and private organisations, etc.;
- Door-to-door census;
- Advertisement in newspapers and on local radio;
- Letters sent by mail to residents;
- Phone calls to residents;
- Snowballing through contacts reached by any of the previous methods;
- Personal contacts of interviewers.

Number of planned participants

1,000

Type of sampling

Non-random sample, combination of judgemental and informed expert advice (Lonner and Berry, 1986: 87).

Sampling parameters

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

- Territorial parameter: a proportionate sampling was carried out according to the size of the population aged 65+ living at home in the sub-areas identified in each country.
- Urban-rural parameter: each of the sub-samples were subsequently divided according to the metropolitan, urban and rural population distribution.

- Availability of services; the regions and municipalities to be involved in the survey was chosen according to the level of supply of support services for elderly people, in order to assure that regions with high, medium and low availability of services were included.

The described strategy for sampling aimed to ensure that the sample would represent a variety of caring situations. However, in terms of the representativeness, each country has tried to compare the collected samples with existing descriptions of elderly people or carers in existing national data bases or from other studies. The comparisons used in each country are described below.

4.2.4 Distribution of the European sample based on the urban-rural parameter

Table 6 illustrates the distribution of the European sample by locality type and shows that the majority of the people recruited lived in urban and rural areas. The results must be considered in relation to the urban / rural characteristics within each country as presented later in the text.

Table 6: Distribution of sample by locality type in all countries. Number and % are presented

locality type	Greece		Italy		UK		Sweden		Poland		Germany		Total	
	Count	N %	Count	N %	Count	N %	Count	N %	Count	N %	Count	N %	Count	N %
Metro-politan	163	16.1 %	208	21.0 %	204	20.5 %	34	3.7 %	363	36.3 %	329	32.8 %	1,301	22.0 %
Urban	452	44.7 %	564	57.0 %	485	48.7 %	561	61.9 %	271	27.1 %	453	45.2 %	2,786	47.2 %
Rural	397	39.2 %	218	22.0 %	306	30.8 %	312	34.4 %	366	36.6 %	221	22.0 %	1,820	30.8 %
Total	1,012	100	990	100	995	100	907	100	1,000	100	1,003	100	5,907	100

4.2.5 Modes of recruitment in the different countries

Each country used the instructions from the step for NASUR and the different recruitment modes to achieve the agreed number of participants. Two countries, Germany and Sweden, experienced major problems in the recruitment of participants and therefore the strategy in these countries included contracting subcontractors to speed up the inclusion. This changed the initially agreed sampling strategy and details on this are presented further down in the text. The most common mode of recruitment in the study as a whole was the door-to-door approach; however, there was large variation in the methods used as successful ways of reaching family carers differed in each local area.

Table 7: The distribution of different modes of recruitment in each country (presented as numbers and %)

Mode of recruitment	Greece		Italy		UK		Sweden		Poland		Germany		Total	
	N	N %	N	N %	N	N %	N	N %	N	N %	N	N %	N	N %
health or social care professional (e.g. doctor or soc worker)	353	34.9 %	304	30.8 %	32	3.2 %	143	15.6 %	331	33.1 %	159	16.0 %	1,322	22.4 %
religious organisations	43	4.2 %	211	21.4 %	11	1.1 %	3	0.3 %	67	6.7 %	60	6.0 %	395	6.7 %
door to door	288	28.5 %	72	7.3 %	452	45.4 %	3	0.3 %	437	43.7 %	193	19.4 %	1,445	24.5 %
voluntary organisations	15	1.5 %	98	9.9 %	187	18.8 %	43	4.7 %	27	2.7 %	51	5.1 %	421	7.1 %
advertisement	2	0.2 %	0	0.0 %	58	5.8 %	59	6.4 %	15	1.5 %	118	11.8 %	252	4.3 %
lists (of older residents, or electoral roll, etc.)	8	0.8 %	0	0.0 %	39	3.9 %	480	52.3 %	66	6.6 %	13	1.3 %	606	10.3 %
personal contacts, neighbours, friends, relatives of int.	292	28.9 %	208	21.1 %	72	7.2 %	179	19.5 %	50	5.0 %	382	38.4 %	1,183	20.0 %
other	11	1.1 %	95	9,6 %	144	14.5 %	8	0.9 %	7	0.7 %	20	2.0 %	285	4.8 %
Total	1,012	100	988	100	995	100	918	100	1,000	100	1,003	100	5,916	100

4.3 Sampling strategy in each country

The sampling strategy for each country was chosen by the individual national research team, guided by the agreed procedures in the step for NASUR. The procedure for each partner is outlined below.

4.3.1 Germany

Sampling strategy

The German data collection was undertaken in four defined regions: north, south, west and east Germany. In each region certain metropolitan, urban and adjoining rural areas were chosen to define the area of recruitment. The final German sample consisted of n = 1,003 family carers of elderly people in need of care.

Sample distribution in the different regions

To prepare the sampling procedure, the population of each sampling region was evaluated and the number of older people (aged 65 years or more) determined. This relation between older people in need of care compared to the whole population was adopted for each region and resulted in different sample sizes in each region. In this way it was hoped to take into account an as broad a spectrum as possible of regional and site differences. However, following this strategy, for Germany, would have resulted in very unbalanced samples for each region. The aim of measuring regional and site differences may not have been achieved. In addition, there would have been fewer cases for meaningful and significant data analysis in some regions. Thus, the decision was taken to adopt four equal-sized sample areas.

According to this revised sampling strategy, 250 family carers of older people should have been interviewed in each region. Furthermore, the distribution of study participants, in relation to metropolitan, urban and rural areas, should have followed a certain, defined strategy, to take account of the influence of infrastructural criteria. In this way although the sample was not representative in a statistical sense, regional differences might be analysed in a much better way.

Sample distribution according to metropolitan and rural differences

In Germany not only regional differences, but also differences in metropolitan and rural structures were considered. The original distinction between metropolitan and rural populations was enhanced by the addition of a third category, “urban”, thus in each region the areas were distinguished according to their metropolitan, urban or rural characteristics.

In Germany 50 % of the population live in cities with less than 100,000 inhabitants. About one third live in cities with more than 100,000 inhabitants. The only available data from the Federal Statistical Office Germany in relation to the distribution of people aged 65 or older, between metropolitan, urban and rural areas shows, that it does not differ significantly from the distribution of older people in the whole population. Therefore in the German survey the distribution of older people in metropolitan, urban und rural areas was based on the statistics from the Federal Statistical Office Germany, i.e. based on the relation of older people in the whole population. This resulted in the following sample weighting (table 8):

Table 8: Germany: Distribution of interviews according to rural, urban and metropolitan areas

Region (coordination)	Rural	Urban	Metropolitan	Total
North (Hamburg)	50 (Kreis Herzogtum Lauenburg)	120	80 (Hamburg)	250
South (Freiburg)	50 (Breisgau-Hochschwarzwald)	120	80 (Freiburg)	250
West (Düsseldorf)	50 (Niederrhein, Wesel, Bergisches Land)	120	80 (Düsseldorf)	250
East (Halle)	50 (Saalkreis)	120	80 (Halle)	250
Total	200	480	320	1,000

Since Germany had no lists of family carers, nor national lists of dependent elderly people living at home, more intensive efforts using different means of recruitment had to be used to reflect the most common / most important care giving situations for Germany.

The recruitment of study participants in Germany was very difficult. One reason for these difficulties was the insufficient support from service providers. Due to the introduction of the health modernisation law (Gesundheitsmodernisierungsgesetzt, GMG) many service providers indicated they were experiencing a considerable additional workload. Thus, they did not have the time to support our project by helping to find family caregivers to participate. Other methods of recruitment proved relatively unsuccessful. Even with the use of many of the recruitment methods mentioned above and intense engagement by the coordination centres only a small number of the required interviews were made; since only few people who fulfilled the criteria of our definition of “family carer” volunteered. The most successful recruiting region was the North, primarily due to utilising the long standing contacts of the Hamburg research team as well as to the higher recruitment capacities. However, after four months of intensive recruitment only a quarter of all planned interviews had been undertaken in Germany.

Since the planned ways of recruiting family carers had not been successful in generating the required sample within the agreed time table, it was agreed by the consortium and the EC that a professional data collection organisation should be subcontracted to collect the remaining 730 interviews. The subcontractors were briefed to recruit study participants in the same areas, defined for data collection in the STEP for NASUR, using the same recruitment channels. However, the subcontractor also encountered problems in accessing family carers in this way. Thus it was decided that the only way to obtain the necessary number of interviews in time was to expand the sampling area to the whole of Germany. This new strategy made it possible to achieve a final sample size of 1,003 participant family carers. Expanding the sampling area to the whole of Germany allowed the subcontractor to deploy more interviewers who themselves had family carers as personal contacts. Although it was not our original intention to use these methods it did ensure that the German sample had a good mixture of low and high dependency among the older people referred to by participant family carers.

4.3.2 Greece

Sample strategy for family caregivers' survey

The sampling strategy used to recruit family carers for the Greek sample of the EUROFAMCARE project was undertaken in the following manner:

- **Sample units**: In accordance with the common research protocol, individuals living in Greece who cared-for dependent older persons aged 65+, for at least 4 hours per week (excluding those providing only financial support or companionship) were the target group to be recruited for interviewing. In Greece, however, a major difficulty in drawing up any accurate sampling strategy lies in the lack of systematic data and research in general, with the exception of the National Census. There are no nation-wide or regional statistical data on the family carers of dependent older people in Greece. The statistical sampling of the 1.000 carers to be interviewed could not be planned using any existing data base. The Census provides the only data on the distribution of older people aged 65+ living at home but is not a reliable basis for sampling since:
    - there is still a noticeable tendency for people to return to their villages of origin for the Census, though it might be argued that this is less likely amongst dependent older persons;
    - the dependent elderly from rural areas is more likely to have left their home and gone to live with children in urban areas with the onset of dependency;
    - there are still seasonal patterns of residence, with some dependent people going back to their village for extended periods in the summer months; this often involves their care by a different family carer.
- **Sample areas and municipalities**: 6 areas or regions of Greece were chosen as the sampling base following wider geographical regions and types of location (table 9). There are few noticeable regional differences except with respect to remoteness from the metropolitan regions (this includes mountainous areas an the islands) a feature that is combined with a low density of population; and with respect to income, with Thrace, Epirus and the Aegean Islands being the poorest areas. The main areas selected for sampling took into consideration the issues of population density, and remotes. Selected were:
    - Attiki including the metropolitan area of Athens-Piraeus and containing nearly 40 % of the whole population;
    - Macedonia including the metropolis of Thessaloniki contains over 20 % of the population;
    - the Peloponnesus (with over 10 % of the whole population) and including the cities of Patras and Corinth,
    - the largest island of Crete (with nearly 6 % of the population), including the city of Herakleion;
    - North West Greece (on the basis of its relative remoteness) including the towns of Corfu, Arta and Ioannina. The Regions of Epirus and the Ionian islands containing 4 % of the population. With over 70 inhabited islands in Greece it was felt important to include at least one small island, Corfu.;

- Mainland (central) Greece to ensure an adequate representation of rural and semi rural communities. 7 % of the population are in the area of Thessaly.

In all the six areas two types of municipality were chosen; in the two major cities the sample included central municipalities and peripheral urban areas; while in the other areas urban and rural municipalities were chosen.

The reason for maximising the number of areas chosen was to ensure that family carers in quite different regions and types of community were reached and thus any variations in support services would be noted. In addition it was felt that this would cover some of the regional and urban / rural differences in income levels.

Table 9: Greek Sampling Areas

Region	Locality	Site
1. Attica	Athens	Centre
		North Suburbs
		West Suburbs
		South Suburbs
		East Suburbs
	Piraeus	Centre
		Suburbs
2. Peloponnese	Achaia	Patra
		Patra Villages
	Corinthia	Corinth
		Corinth Villages
	Arcadia	Arcadia
		Arcadia Villages
3. Mainland Greece	Evoia	Chalkida
		Chalkida Villages
	Trikala	Trikala
		Trikala Villages
	Voiotea	Thebes
		Thebes Villages
4. Macedonia	Thessaloniki	Centre
		North Suburbs
		East Suburbs
		West Suburbs
		South Suburbs
	Imathia	Naousa
		Naoussa Villages
5. Crete	Irakleion	Irakleion (City)
		Irakleion Villages
	Chania	Chania (City)
		Chania Villages

Region	Locality	Site
6. NorthWestern Greece	Ioannina	Ioannina (City)
		Ioannina Villages
	Arta	Arta (City)
		Arta Villages
	Kerkyra	Kerkyra (City)
		Kerkyra North
		Kerkyra South

Sampling parameters

- **Territorial parameter**: The six different areas described above were selected to be geographically representative of the country.
- **Urban-rural parameter**: With the exception of the two metropolitan areas, in all other areas samples were taken from both rural and urban municipalities. It is worth noting that there is an intermediate category in the Greek census termed semi-urban which could also be termed semi-rural. The distinction between urban and rural municipalities is not always clear as towns expand outwards and this has been a strong trend in the past decades.
- **Availability of services**: there is no national register or record of the services available to older people. Despite attempts to record all municipal services by the Hellenic Association for the Developmental of Local Authorities (EETAA), this has not been completed. Services designed primarily for family carers hardly exist. Nonetheless, in planning the sampling procedure, the attempt was made to maximise the regions and communities in the survey in case there were significant regional or municipal differences in services.

The combined application of the territorial and urban-rural parameters described above ensured that the final sample was reasonably representative of the socio-economic differences existing throughout the country in terms of income, level of education, types of employment and economic activity. One should also note that as urban neighbourhoods vary in terms of their average income levels, a check was kept on the type of neighbourhood selected to ensure reasonable representativeness:

- **“Metropolitan”**: The two cities of Athens and Thessaloniki were defined as being metropolitan, with over 1,000,000 inhabitants in each.
- **“Urban”**: Urban municipalities were defined as having a population density higher than 100 inhabitants per Km^2 but excluded those areas considered “metropolitan”, however in the 2 metropolitan areas there were outlying municipalities which were counted as urban i.e. having a resident population higher than 5.000 inhabitants.
- **“Rural”**: municipalities were those with a population density lower than 100 inhabitants per Km^2, and those with less than 5.001 inhabitants. Villages throughout Greece have been organized into larger administrative municipalities most of which are now over 5000 inhabitants. However individual villages remain discrete (table 10).

Table 10: Population Distribution of the Greek Survey Sample by rural, urban and metropolitan areas

Typology of municipality	UN statistics 2003	Survey Sample	
		No.	%
rural	39 %	397	39.2
urban	61 %	452	44.7
metropolitan		163	16.1
total		1,012	100

Population Division of the United Nations Secretariat, 2003.

Identification of Greek regions and municipalities

The centralised nature of the Greek state and the relatively late development of services and power in local municipalities have the consequence that there are few variations in the availability and formal structure of services. More critically there is still no data on the distribution of all kinds of municipal services. Thus though some municipalities have been slightly more proactive in developing services such as Help at Home, by finding initial funding from the EU to run these, overall these differences are minimal.

Saturation zones

In each chosen municipality a “saturation zone” was identified by the interviewer, formed by one or more sub-areas representative of the municipality in term of socio-economic context. The necessary prerequisite to reach the population of caregivers living in the selected communities was that the area of each chosen community was as small as possible.

Recruitment of family caregivers

Family carers were recruited through the agreed saturation method, which consisted in identifying and contacting the population of caregivers living in the chosen sample communities through all the following potential recruitment channels:

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

In each municipality selected for recruitment, interviewers were asked to select an area and find an initial contact. This initial contact could be through a personal contact or family carers could be identified by asking local social workers and care professionals, After finding and making one or more initial contacts, the interviewer was instructed to try and “saturate” the specific area where the first contact lived by snowballing e.g. typically asking the original family carer who else was a family carer in the same block or neighbourhood or village. The **snow ball** method proved to be the most effective method of finding people to interview; the use of personal contacts and referrals is a particularly effective way of identifying people in Greece. However many interviewers classified this as door to door recruitment.

4.3.3 Italy

Sample distribution in the different regions

The first criteria for the recruitment of the Italian sample, established the demographic relevance of the main Italian geographical sub-areas. These four macro-territories, each including several of twenty regions compounding Italy, have been traditionally identified, according to their territorial location and socio-economic characteristics, as follows:

- **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, Piemonte, Liguria, Valle d'Aosta;
- **North East**: this area has in the last decade become the leading motor of economic development in the country, and is characterised by smaller cities (Bologna, Trieste, Venezia, Padova et.), widespread small industries and specialised agriculture. Regions: Emilia-Romagna, Trentino Alto Adige, Friuli Venezia Giulia, Veneto;
- **Centre**: smaller manufacturing industries, a less specialised agriculture and a widespread tourism industry are the main features of this sub-area. Major cities are Rome (the capital city) and Florence; regions are: Toscana, Umbria, Marche, and Lazio;
- **South and Islands**: this area – which in most studies is also subdivided into two, distinguishing the mainland South from the Islands of Sicily and Sardinia -, represents the economically least developed or urbanised part of the country, but also the youngest, in terms of population structure. Major cities are Naples, Bari, Palermo and Cagliari, while 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 65+ year old population living at home in the four Italian sub-areas (table 11).

Table 11: Italian Sampling Areas and number of subjects

North West (NW)	275 corresponding to	27.5 % of the sample
North East (NE)	198	19.8 %
Centre (C)	211	21.1 %
South and Islands (S)	316	31.6 %

Sample distribution according to metropolitan and rural differences

The four sub-samples identified above have been further subdivided according to the rural-urban-metropolitan dimension. To this purpose, following subdivisions have been used:

- **"Metropolitan"**: 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.
- **"Urban"**: For this study, urban municipalities have been considered both those with a population density higher than 100 inhabitants per Km^2 excluding those which are considered "metropolitan", and those with 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).

- **"Rural"**: Both municipalities with a population density lower than 100 inhabitants per km^2, and those with less than 5,001 inhabitants.

The number of interviews to be made in each macro-area was distributed between rural, urban and metropolitan municipalities using the proportion of people living in the respective type of locality, as above defined, in each macro-area (see table 12 calculations by INRCA on census data).

Table 12: Proportion of people living in rural / urban / metropolitan municipalities in each Italian macro-area

Type of municipality	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	100.00 %	100.00 %	100.00 %	100.00 %

Identification of Italy's regions and municipalities

Italian regions have been classified on the basis of the availability of services for elderly people and the results show that Lombardia, Liguria (located in the North West) and Emilia Romagna (located in the North East) are equipped with the best range of support services, Marche and Lazio (in the Centre) have an intermediate service supply, while Calabria, Sicilia and Campania (in the South) are the least well equipped. Generally the supply of services is higher in the North becoming increasingly less frequent as one move south. Consequently, taking at least one region from each macro area ensures the inclusion of regions with different availability levels.

In order to ensure that, following the above criteria, the recruited sample could be representative of the varied cultural and socio-economic, characteristics of the Italian population living in the different regions of the country (as described in several studies on territorial differences in Italy Censis 1998 and 2001; D'Alessio e Signorini 2000; Cadeo et al. 2001; Istituto Tagliacarne – Unioncamere 2001), and of the different service supply features, for each subarea (North West, North East, Centre, South and Islands) 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).

4.3.4 Poland

Sampling

When selecting sampling regions, we intended to select areas which would, taking into consideration regional differences, represent as far as possible the whole country. To select the most representative regions with regard care giving situations in Poland, twelve demographic, economic and social indicators were analyzed for each region: 1 – percentage of the

65-year and older people in the total number of inhabitants; 2 – percentage of inhabitants living in rural and urban areas; 3 – percentage of employed in agriculture; 4 – GDP per 1 inhabitant; 5 – investment expenditure per 1 inhabitant; 6 – income of municipalities per 1 inhabitant; 7 – average monthly gross wages and salaries; 8 – rate of registered unemployment; 9 – share of households with central heating at home in rural areas; 10 – numbers of telephones per 100 inhabitants; 11 – percentage of social welfare benefits users; 12 – percentage of social service users.

When identifying the indicators, we were aware that the national representativeness of the participants should be ensured with respect to urban and rural settings, as well as to the differences with regard to the availability of support services. However, we decided to extend the number of statistical characteristics (all related, directly or indirectly, to some extent to the „care giving situation" of the elderly) of the regions to twelve, for two reasons. Firstly, there were no data concerning the support service network for the family carers in Poland. Therefore we used other indicators (no 11 and 12) which indirectly described a given area in this respect. Secondly, in our opinion the use of more factors allowed for a more accurate characterization of each region and made the choice of the most representative "sample communities" for the country more readily apparent.

Sample distribution in the different regions

Based on the above indicators, and taking into account also historical, cultural and ethnic factors, three regions / voivodships were chosen as an area for sampling: Podlaskie, Małopolskie, Wielkopolskie. Each of them can be characterized as follows:

- **Podlaskie** (the less developed area): north-eastern part of Poland (so called „eastern wall"), demographically old (people 65+ constitute 13.7 % of the total population), the lowest level of urbanization, relatively high degree of poverty, the lowest rate of social service users, borderland with relatively multi-ethnic structure (which occurred during the partition of Poland under Russian government);
- **Małopolskie** (moderate developed area): southern Poland, a demographically younger population (people 65+ constitute 12.6 % of the total population), high rate of rurality, middling rich, moderate rate of unemployment, strong regional identity and family ties (formerly under Austrian government);
- **Wielkopolskie** (the most developed area): western Poland, relatively young population (people 65+ constitute 11.4 % of the total population), predominantly rich region, high standard of living conditions, low unemployment rate, higher indices of service users, lack of cultural distinctiveness of the region (formerly under German government).

We strongly believe that choosing the above three regions as the basis for sampling ensured a reasonable level of representativeness of the data collected. It is worth adding that the percentage of elderly people (65+) in the total population living in the selected area was very similar to the respective percentage in the whole country (accordingly 12.6 % and 12.8 %).

The second stage of the sample strategy was to identify concrete "sample communities" covering the variability of settlements, particularly in respect of family care giving situations, within each of the three regions. As a result, we selected 22 sample communities (6 in Podlaskie, 9 in Małopolskie and 7 in Wielkopolskie) comprising 10 rural and 12 urban settings. Among the urban areas there were 3 metropolitan settings (one in each region) of at least 200,000 inhabitants, which also took regard of the supposed availability of support services.

Sample distribution according to metropolitan and rural differences

In order to increase the representativeness of the sample further the size of the sub-samples in the three regions (voivodships) and the quantitative distributions of the samples among rural and urban areas reflected the demographic weight represented by the chosen regions (in terms of number of inhabitants 65 years and older).

According to statistical data 2002 about 960,000 inhabitants live in the chosen regions are 65 years and older. The distribution of the number and percentage of the elderly in the studied regions and in their rural and urban areas is shown in table 13.

Table 13: Distribution of the population 65 and older living in the studied regions

Region	Number of people 65+	Percentage (N = 959,900)	Percentage of people 65+ in rural area	Percentage of people 65+ in urban area
Podlaskie	167,400	17.44	56.68	44.32
Małopolskie	407,700	42.47	49.69	50.31
Wielkopolskie	384,800	40.09	42.20	57.80
Total	959,900	100.0	47.20	52.80

According to the sampling criteria and the suggested calculation by STEP for NASUR the regional distribution of the Polish national sample was constructed as can be seen in table 14. As a result, the percentage of people 65 and older in urban and rural areas in our sample reflects quite precisely the relevant percentage of the elderly living in these areas in the studies regions.

Table 14: Regional distribution of the constructed Polish sample

Region	Number of cases in urban area	Number of cases in rural area	Total number of cases
Podlaskie	**77** (= 1,000x44.32 % x17.44 %)	**97** (= 1,000x55.68 % x17,44 %)	**174** (= 1,000x17.44 %)
Małopolskie	**214** (= 1,000x50.31 % x42.47 %)	**211** (= 1,000x49.69 % x42,47 %)	**425** (= 1,000x42.47 %)
Wielkopolskie	**232** (= 1,000x57.80 % x40.09 %)	**169** (= 1,000x42.20 % x40.09 %)	**401** (= 1,000x40.09 %)
Total	**523** (52.3 %)	**417** (47.7 %)	**1,000** (100.0 %)

Table 15: Number of cases in urban and rural included in primary, modified and realized samples

Regions	Total number of cases (inter-views)	Number of cases in urban area in samples			Number of cases in rural area in samples:		
		primary	modified	realized	primary	modified	realized
Podlaskie	174	77	93	93	97	81	81
Małopolskie	425	214	251	248	211	174	177
Wielkopolskie	401	232	259	293	169	142	108
Total	1,000	523	603	634	477	397	366

4.3.5 Sweden

Sampling strategy in Sweden

The method and sample procedure for each country was chosen by the relevant partner guided by the agreed procedures in the step for NASUR.

A combination of national statistics of distribution of elderly people, known level of dependent elderly people and the expected number of carers in a population was used for planning of the sampling in Sweden.

In Sweden 17.2 % of the 8.9 million inhabitants was aged over 65 and 5.2 % were over 80 years in 2003 (National statistics). This was used as basic information for the sampling of participants in the survey. From the ULF-Study (Living conditions in Sweden) 2002 we know that some 13 % of elderly people 65+ living home need daily help, are helped by their families and the next of kin. A study performed in the east of Sweden has shown that among people aged over 45, 23 % are supported by a family member (Gustafsson, 2000). Based on these figures an estimation of the possible number of participants in each area was performed.

Sample distribution in the different regions

Three geographically different areas were chosen in Sweden based on urban and rural differences, geography and different models for service provision

The chosen areas were South West, Eastern and North of Sweden. In each region we calculated the expected number of family caregivers, based on the above reports, also taking into account the expected distribution of family carers in urban and rural areas. The calculated numbers are presented in table 16.

Table 16: The expected number of carer based on the population in each region

Region	Inhabitants ≥40 years (50 % of inhab.)	Family carers (10 % of ≥40 years)	Calculated interviews (with 75 % response frequency)		
			Number of interviews	% of inhab. ≥40	% of the study
Eastern					
Linköping	ca. 75,000	7,500	350	4.6	35
Urban			250		25
Rural			100		10
Norrköping	ca. 75,000	7,500	350	4.6	35
Urban			250		25
Rural			100		10
South West					
Varberg	ca. 15,000	1,500	200	13.3	20
Urban			100		10
Rural			100		10
North					
Nordanstig	ca. 7,500	750	100	13.3	10
Rural			100		10
Total			1,000		100
Urban					60
Rural					40

Recruitment procedure

The following recruitment procedure was used:

- **Territorial parameter**: A proportionate sampling was carried out according to the expected number of family carers.
- **Urban-rural parameter**: one area was chosen to represent a purely rural area, one represented urban and rural areas and one, urban rural and metropolitan The postal code was used for stratification urban / rural areas.
- **Availability of services**: the regions to be involved in the survey were chosen according to the criteria of different models of supply of support services for elderly people.

Recruitment of family carers to the survey

The first strategy for recruitment was based on sending out questionnaires to people older than 40 years of age to identify those who filled the criteria of providing at least 4 hours per week of care / support to any person over 65 year old living at home for any kind of need (excluding financial support only) using the postal code as the basis for stratification for urban and rural areas. The expected frequency of individuals in a caring situation was 10-15 % based on a previous study performed in one of the chosen municipalities (Gustafsson, 2000).

The distribution of the planned and accomplished cases in the different regions is presented below in table 17.

Table 17: Distribution of planned and accomplished cases in the different regions

Region	Planned %	Accomplished %
South West	20	15.4
East	70	75.0
North	10	9.6
Total	100	100

Recruitment channels

The first step in recruitment was sending out questionnaires to 3500 persons who were older than 40 years to identify family caregivers. In parallel to this strategy other recruitment modes were used:

- Advertisement in newspapers
- Flyers at places where the target group were likely to be found
- Contacts with voluntary and religious organisations
- Door to door approach
- Contacts with Health and social care.Primary care centres, geriatric elderly centres etc
- Snowballing making further contacts of potential participants through people already recruited
- Personal contacts of interviewers

Each site had a study coordinator and a between 5-20 interviewers who were given training in undertaking the interviews.

Introducing a subcontractor

After 5 months of using this recruitment strategy very few participants had been recruited to the study. Of the 3,500 questionnaire sent out to people of 40 year of age or older 1,400 responded out of these only 70 fulfilled the criteria for inclusion in the study and agreed to participate; and therefore it was decided to use an authorised telemarketing service as a subcontractor to achieve a higher number of participants.

It was agreed that the subcontractor should undertake 425 telephone interviews. The method used was based on the same assumption as in the first step by sending out a questionnaire to identify family care givers. The subcontractor referred to the public register and contacted people over 45 years old, who were caring for an older adult (within the criteria above), to invite them to participate in the study.

Sample distribution according to metropolitan and rural differences

The Swedish sample was based on the three geographically different areas. The North representing a rural only area; the Eastern area, which comprised both urban and rural neighbourhoods and the South west, in which were found urban rural and metropolitan districts. The postal code was used for stratification urban / rural areas. The distribution based on urban rural differences is presented in table 18. The sample overall was dominated by urban areas and included very few in metropolitan areas.

Table 18: Distribution in urban, rural and metropolitan areas in the different regions

Type of municipality	South / West		East		North		Total	
	n	%	n	%	n	%	n	%
Rural	47	15.2	179	57.9	83	26.9	309	33.9
Urban	71	51.4	481	71.4	3	0.5	555	60.9
Metropolitan	20	14.5	14	2.1	0	0	34	3.7
Total	138	15.4	674	75.1	86	9.6	898	100

4.3.6 UK

Sample distribution in the different regions

The identification of the sampling areas was based upon traditionally identified countries within the United Kingdom, with England having the largest population this was divided into North and South. The south of England, which includes London, has traditionally been considered more affluent society and its inhabitants are known to have better health and long term health prospects. The North of the country is seen as being much more industrial in nature, deprived socially and economically. Although some of these assumptions are erroneous it is certainly true that the health of the population declines for certain conditions such as coronary heart disease, the further north you travel (British Heart foundation 2005).

For the purposes of the EUROFAMCARE project, we first subdivided the 1,000 hypothetical survey participants according to the distribution of people 65 years + living at home in the five sub areas (table 19).

Table 19: Distribution of people 65 years+ living at home in the five sub areas.

Region	Total	% of the sample
Northern Ireland	40	4 %
Scotland	100	10 %
Wales	60	6 %
England North	275	27.5 %
England South	525	52.5 %
Total	1,000	100 %

Sample distribution according to metropolitan and rural differences

In 2001, the Office of the Deputy Prime Minister (ODPM) - then the Department of Transport, Local Government & the Regions (DTLR) - commissioned a consortium to undertake a review of the definitions of urban and rural areas in use for policy purposes and statistical reporting. The need for such a study had been recognised for some time. In particular there was a clear need for a more consistent approach to the use of definitions.

One of the main conclusions was that no single existing definition of urban and rural areas could meet the needs of all users. There was also a lack of clarity in the main central government departments around definitions in current use and around choosing a definition for particular policy and analysis purposes.

Therefore, whilst the research report recognised that more work needed to be done on spatial analysis to solve some of the problems of the existing definitions. The main report identifies a number of different types of definitions of urban and rural areas that could be said to be "core" in the sense that they meet a range of user needs and are more widely used than others. The definition of urban and rural areas used in this study was taken from that report and based on figures from the 1991 census. The definition of Urban and Rural areas adopted by the EUROFAMCARE study in the UK was as follows:

Urban Areas in the UK study are those built up settlements with a minimum population of 1,000 and a minimum land area of 20 hectares and all settlements of over 10,000 are treated as urban areas. All smaller settlements, together with all other land, are treated as rural areas (table 20).

Table 20: Urban and Rural populations in the UK

Definition Urban Settlements	Urban population (million)	Rural population (million)	Urban land area (hectares, million)	Rural land area (hectares, million)
Over 1,000+ population	42.4	4.6	1.1	2.0
Over 10,000+ population	37.8	9.2	0.9	12.1

N.B. Figures taken from the United Kingdom 1991 census

Although the UK census figures had no definition of a metropolitan area there were six areas England and Wales with populations of over 750,000 therefore we did classify these as metropolitan areas for the purposes of the EUROFAMCARE study.

The number of interviews to be made in each macro area were distributed between rural, urban and metropolitan areas using the proportion of people living in each type of locality as defined below in table 21.

Table 21: Number of participants sought from each metropolitan, urban and rural sample region

Region	Number of participants required by the sampling strategy			
	Metropolitan	Urban	Rural	Total
Northern Ireland	0	20	20	40
Scotland	0	60	40	100
Wales	0	26	34	60
England North	0	215	60	275
England South	200	147	178	525
Total	668		332	1,000

4.4 Representativeness

4.4.1 Germany

Representativeness

To give a better picture of the sample and the quality of the collected data, early results of certain frequencies will be compared with another study which claims to be representative for the situation of family carers of older people in Germany. As said before, the EUROFAMCARE sample is not representative for certain frequencies of family care situations in a strongly statistical sense, since the sampling strategy chosen did not fulfil the criteria which would of allowed us to talk about representativeness. However, the method of saturation chosen for the EUROFAMCARE sampling allows the assumption, that the different possible types of family care situations are well reflected in the German sample. The comparison between the EUROFAMCARE sample with another, representative study allows us to reflect on how well the sub samples of our German sample can be used to obtain significant results.

The choice of appropriate studies for data comparison

It was necessary to limit data comparison to one other study as many others refer to definitions of “cared-for person” which are too tight and exclude many family carers of dependent elderly people. This is true for cases where the older people are in need of some limited care, but not sufficient to be entitled to financial support and benefits from the Long Term Care Insurance (LTCI). A person is called “pflegebedürftig“ (i.e. the person is in *need of care* and has claims for special allowances, thus getting either cash, kind or combined kind and cash benefits), if they fulfil the definition of being in need of long-term care given in the law (SGB XI). In all other cases, a person is called “hilfebedürftig“ (in *need of help*), which means that she or he is in need of help to a lesser degree, i.e. not to such an extent that legal claims for allowances are given. So in Germany we distinguish between two different types of care dependency. However, most studies only take family cares of older persons into account, from the more dependent group who benefit from the LTCI (and are by definition “in need of care”).

Another reason for only choosing one study is the age range of dependent people who get benefits from the LTCI. Someone is “in need of care” (as defined by law), when she or he needs a certain amount of care, regardless of their age. Although most dependent people who are supported by the LTCI are aged 65 or older, many studies don’t distinguish their sample according to age, but only to care level. However, one study, the Infratest-Study, which was used for data comparison, made it possible to specifically compare older dependent people of age 65 and higher.

Each of the partners involved in the study had the opportunity to obtain additional data from family carers by adding certain “national specific” questions. These questions may not have necessarily been pertinent for other countries and have only been used for national data analysis. In the German survey questions about the Long Term Care Insurance were added to the questionnaire. Due to this supplement it is possible for the German data analysis to distinguish between persons in “need of help” as well as those in “need of care” as defined in law.

Comparison of the EUROFAMCARE data with results from the Infratest-Study "Möglichkeiten und Grenzen selbständiger Lebensführung in Privathaushalten III"

The research project "Möglichkeiten und Grenzen selbständiger Lebensführung III" (MuG III) (possibilities and boundaries of self-dependent lifestyle in private households) gives an overview of the situation of people living in their own household, who are in need of care. This study was carried out in 2002 and claims, due to the methodological approach and sample size, to be representative of the population of older people in need of help and care in Germany. As in the EUROFAMCARE study, the MuG III distinguishes between two types of independency which are very relevant for the German situation and are related to the system of the Long Term Care Insurance.

Although the main target of the EUROFAMCARE studies are main family carers, some of the following tables focus on the dependent older person. The reason for this is the fact that the relationship between family carer and cared-for person often has great impact on a care situation and care arrangements.

Considering the distinction of "need of help" / "need of car", the total number of people who are in "need of help" in the population outweigh the number of people who are in "need of care". However, this situation is reversed in the EUROFAMCARE sample (see table 22 and 23).

Table 22: Comparison between MuG III and EUROFAMCARE by "Need of help" / "Need of care" and by gender of the cared-for person in %

Need of help / care	Gender of cared-for person				Total	
	MuG III		EUROFAMCARE		MuG III	EFC
	Male	Female	Male	Female	Total	Total
Need of help	65.5	64.3	43.3	40.9	64.7	41.7
Need of care	34.5	35.7	56.7	59.1	35.3	58.3
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 23: Comparison between Mug III and EUROFAMCARE by gender and care level of the cared-for person in %

Need of care	Gender of cared-for person				Total	
	MuG III		EUROFAMCARE		MuG III	EFC
	Male	Female	Male	Female	Total	Total
Care level 1	52.9	59.5	29.2	35.2	57.5	33.3
Care level 2	37.9	32.7	43.8	40.4	34.2	41.5
Care level 3	9.3	7.8	27.0	24.4	8.2	25.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

A part of this deviation might be explained by recruitment effects of the EUROFAMCARE study. Considering the sub groups of "own" interviews done by the original recruited interviewers and those interviews made by the subcontracting survey institution, there was a huge variation in the distribution of people in "need of help" and those in "need of care" (see table 24).

Table 24: Distribution of older people in need of help and in need of care in the EUROFAMCARE sample by own interviews and interviews made by sub-contractor in row %

Interview "source"	Need of help	Need of care
"Own" interviews	12.8	87.2
Interviews from sub contractor	52.3	47.7
Total	41.8	58.2

Although the number of people who are in "need of care" in the EUROFAMCARE study is higher than the average of the whole population, the relation between male and female persons within each group corresponds to the actual distribution within the population as a whole (see table 25 and 26).

Table 25: Comparison between Mug III and EUROFAMCARE by gender of the cared-for person within the groups "Need of help" an "Need of care" in %

Gender of the cared-for person	Need of help / care				Total	
	MuG III		EUROFAMCARE		MuG III	EFC
	Need of help	Need of care	Need of help	Need of care	Total	Total
Male	31.0	29.9	32.9	30.7	30.7	31.6
Female	69.0	70.1	67.1	69.3	69.3	68.4
Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 26: Comparison between Mug III and EUROFAMCARE by gender and care level of the cared-for person in %

Gender of the cared-for person	Care level of Elder person						Total	
	MuG III			EUROFAMCARE			MuG III	EFC
	Level 1	Level 2	Level 3	Level 1	Level 2	Level 3	Total	Total
Male	27.5	33.1	33.8	26.9	32.5	32.9	29.9	30.7
Female	72.5	66.9	66.2	73.1	67.5	67.1	70.1	69.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

There are almost no significant differences between the results from MuG III and EUROFAMCARE with regards to age. That means that we can assume that we have a fairly well balanced sample (see table 27 and 28).

Table 27: Comparison between MuG III and EUROFAMCARE by gender of the cared-for person and grouped age according to “Need of help / care” in %

Need of help / care by age of cared-for person (grouped)		Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Need of help	65-69	22.7	13.6	23.5	14.6	16.5	17.6
	70-74	24.8	19.6	23.5	18.6	21.2	20.2
	75-79	22.0	20.8	25.7	21.2	21.1	22.7
	80-84	10.7	20.5	16.9	20.8	17.5	19.5
	85-89	8.8	15.3	6.6	16.1	13.3	12.9
	90+	10.9	10.3	3.6	8.8	10.5	7.1
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Need of care	65-69	18.6	7.0	21.7	7.6	10.5	11.9
	70-74	18.2	11.2	17.7	7.6	13.3	10.7
	75-79	19.3	14.7	20.6	15.9	16.1	17.4
	80-84	19.6	24.3	18.9	26.6	22.9	24.2
	85-89	11.8	21.4	12.0	19.7	18.5	17.4
	90+	12.5	21.4	9.1	22.5	18.7	18.5
	Total	100.0	100.0	100.0	100.0	100.0	100.0

Table 28: Comparison between MuG III and EUROFAMCARE by gender of the cared-for person and grouped age according to care level in %

Need of help / care by age of cared-for person (grouped)		Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Level 1	65-69	19.6	7.7	19.6	2.2	10.9	6.8
	70-74	15.5	11.5	17.6	8.6	12.6	11.1
	75-79	19.6	15.6	29.4	18.0	16.7	21.1
	80-84	20.9	24.6	19.6	28.1	23.6	25.8
	85-89	12.8	21.7	5.9	20.9	19.3	16.8
	90+	11.5	18.9	7.8	22.3	16.9	18.4
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Level 2	65-69	17.6	7.0	19.2	8.8	10.6	12.2
	70-74	20.4	10.7	15.4	8.2	14.0	10.5
	75-79	19.4	14.5	17.9	12.6	16.1	14.3
	80-84	20.4	21.0	19.2	25.8	20.8	23.6
	85-89	12.0	22.0	17.9	21.4	18.6	20.3
	90+	10.2	24.8	10.3	23.3	19.9	19.0
	Total	100.0	100.0	100.0	100.0	100.0	100.0

Need of help / care by age of cared-for person (grouped)		Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Level 3	65-69	16.0	3.8	28.3	13.4	7.8	18.2
	70-74	20.0	9.6	21.7	5.2	13.0	10.5
	75-79	16.0	9.6	15.2	18.6	11.7	17.5
	80-84	8.0	34.6	17.4	25.8	26.0	23.1
	85-89	8.0	17.3	8.7	15.5	14.3	13.3
	90+	32.0	25.0	8.7	21.6	27.3	17.5
	Total	100.0	100.0	100.0	100.0	100.0	100.0

Since the main target group of the EUROFAMCARE study are family caregivers, the following tables show data comparison according to the family carer aspects. First, results related to the gender criteria between primary carer and cared-for person are the focus. Looking at male persons who are in the role of the primary family carer, the EUROFAMCARE sample has noticeable variations compared to the representative Mug III study. Especially in the group of elderly in "need of care", this discrepancy is very pronounced (table 29 and 30).

Table 29: Comparison between MuG III and EUROFAMCARE by gender of main family carer and gender of cared-for person in %

Need of help / care	Gender of family carer	Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Need of help	Male	8.9	35.5	27.4	22.3	27.2	24.0
	Female	91.1	65.5	72.6	77.7	72.8	76.0
Need of care	Male	11.7	34.8	14.6	28.2	27.9	24.0
	Female	88.3	65.2	85.4	71.8	72.1	76.0

Table 30: Comparison between MuG III and EUROFAMCARE by gender of primary family carer and gender of cared-for person in %

Care level	Gender of family carer	Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Level 1	Male	16.2	33.3	15.4	27.7	28.6	24.4
	Female	83.8	66.7	84.6	72.3	71.4	75.6
Level 2	Male	6.6	34.1	16.7	27.8	25.0	24.2
	Female	93.4	65.9	83.3	72.2	75.0	75.8
Level 3	Male	7.7	48.1	10.4	29.6	34.6	23.3
	Female	92.3	51.9	89.6	70.4	65.4	76.7

Looking at the age of the primary carers, the EUROFAMCARE sample has on the average younger family carers than the MuG III study (table 31 and 32).

Table 31: Comparison between MuG III and EUROFAMCARE by age of main family carer and gender of cared-for person in %

Need of help / care by age of cared-for person (grouped)		Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Need of help	≤ 39	2.4	8.8	18.4	21.3	6.8	20.4
	40-44	4.5	11.0	16.2	12.6	9.0	13.8
	45-49	5.6	8.0	14.0	14.4	7.3	14.3
	50-54	7.7	10.9	7.4	16.2	9.9	13.3
	55-59	4.3	9.6	10.3	13.4	8.0	12.3
	65-69	12.6	10.4	9.6	10.8	11.1	10.4
	70-74	23.1	9.7	11.8	7.2	13.9	8.7
	75-79	16.7	9.8	9.6	2.2	12.0	4.6
	80-84	13.0	7.6	2.9	1.4	9.3	1.9
	85-89	3.9	5.6	-	0.4	5.1	0.2
	90+	2.4	8.8	18.4	21.3	6.8	20.4
	Total	4.5	11.0	16.2	12.6	9.0	13.8
Need of care	≤ 39	3.9	7.6	10.1	11.4	6.5	11.1
	40-44	3.6	5.3	6.7	7.7	4.8	7.4
	45-49	3.2	8.1	7.3	13.7	6.6	11.7
	50-54	5.4	16.6	9.6	13.2	13.3	12.1
	55-59	6.1	14.5	6.2	16.5	12.0	13.3
	65-69	16.8	16.2	19.1	16.7	16.4	17.4
	70-74	12.9	9.3	15.7	10.7	10.4	12.3
	75-79	17.6	7.5	9.6	3.2	10.5	5.2
	80-84	16.8	5.6	10.7	4.5	9.0	6.4
	85-89	12.9	7.8	5.1	2.2	9.3	3.1
	90+	3.9	7.6	10.1	11.4	6.5	11.1
	Total	3.6	5.3	6.7	7.7	4.8	7.4

Table 32: Comparison between MuG III and EUROFAMCARE by age of main family carer and gender of cared-for person in %

Need of help / care by age of cared-for person (grouped)		Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Level 1	≤ 39	6.1	10.5	11.5	10.6	9.3	10.9
	40-44	4.1	4.9	11.5	12.1	4.6	11.9
	45-49	3.4	8.4	5.8	14.9	7.1	12.4
	50-54	7.4	18.4	15.4	12.1	15.4	13.0
	55-59	4.7	15.1	7.7	17.0	12.2	14.5
	65-69	15.5	15.1	11.5	16.3	15.2	15.0
	70-74	8.8	8.7	11.5	9.2	8.7	9.8
	75-79	18.2	6.6	7.7	3.5	9.8	4.7
	80+	15.5	5.1	11.5	3.5	8.0	5.7
	Total	16.2	5.1	5.8	0.7	8.2	2.1
Level 2	≤ 39	0.9	3.8	15.4	14.8	2.8	15.0
	40-44	1.9	7.0	3.8	4.3	5.3	4.2
	45-49	3.8	8.0	12.8	13.6	6.6	13.3
	50-54	3.8	16.4	6.4	16.0	12.2	12.9
	55-59	10.4	15.0	5.1	14.8	13.5	11.7
	65-69	15.1	18.8	19.2	14.8	17.6	16.3
	70-74	15.1	8.5	15.4	13.0	10.7	13.8
	75-79	20.8	9.4	6.4	2.5	13.2	3.8
	80+	18.9	5.6	10.3	4.3	10.0	6.3
	Total	8.5	6.6	5.1	1.9	7.2	2.9
Level 3	≤ 39	4.0	1.9	0.0	7.1	2.6	4.8
	40-44	8.0	3.8	6.3	7.1	5.2	6.8
	45-49	0.0	5.8	0.0	12.2	3.9	8.2
	50-54	0.0	3.8	8.3	10.2	2.6	9.6
	55-59	0.0	9.6	6.3	18.4	6.5	14.4
	65-69	28.0	13.5	27.1	20.4	18.2	22.6
	70-74	28.0	17.3	20.8	9.2	20.8	13.0
	75-79	0.0	3.8	16.7	4.1	2.6	8.2
	80+	16.0	9.6	10.4	6.1	11.7	7.5
	Total	12.0	30.8	4.2	5.1	24.7	4.8

4.4.2 Greece

Representativeness

There are no national data on the carers of older people in Greece and therefore no basis for stating how far the carer sample is representative of Greek carers. However, comparisons with the NASUR data from the other five countries and from studies reported in the NABARES from other countries indicate that the Greek sample is within the expected parameters.

The proportion of female carers (80.9 %) was slightly higher than for the other five countries.

Carers had lower levels of education, compared with most of the other countries, in line with national statistics concerning the lower educational levels of older Greek people and especially women.

The relatively high numbers of working carers reflects the high rates of self employment in age groups over 45 years of age amongst men and women. This includes those working in agriculture, where many women still are employed in rural areas.

The relatively high numbers of situations where carers and the dependent older person cohabit reflect the lack of home care services and the social expectations of care; this also accounts for the slightly larger size of household found in Poland and Greece where coresidence is common.

As the first national survey of family carers, the non-random sample does not appear to be skewed in any obvious way and compares well with samples of carers from surveys in other countries. The variations in the sample between the 6 core countries are in line with the general trends in the populations including their patterns of residence and income. One of the possible biases in the Greek sample is in the large numbers of working family carers, which may be partly explained by:

- the higher numbers in the sample drawn from rural areas, where many people continue working unofficially in agriculture;
- the considerable numbers in self employment, which tends to permit a greater flexibility than permanent full time work;
- the slightly younger age of the Greek sample of family carers.

4.4.3 Italy

Representativeness

There are no national data on the carers of older people in Italy except for those who do not cohabit with the elder (Tomassini C., Principi A., 2005). Since it is known that a considerable proportion of Italian primary carers live with the elder these statistics are not suitable for testing the representativeness of the Italian sample of carers reached in the EFC survey.

The only data which approximates national coverage with regards to family carers and demographic characteristics of both carers and older people available for comparisons with the EFC data have been collected by INRCA in the ESAW Project. It is important to emphasise that this procedure does not pretend to lead to conclusions about statistical representativeness, but only to verify possible analogies or discrepancies between the two samples for having an indirect confirmation of the quality of the EFC sample.

Since the ESAW sample includes only adults aged 50 years and over, the EFC sample of carers has been restricted people of this age, for comparability reasons. It should be also understood that, differently from the EFC sample, the ESAW sample is not primary made up of carers (table 33).

Table 33: Illustration of the comparable data belonging to the two studies.

Characteristics	**EFC**	**ESAW**	**Compared to ESAW the EFC sample shows:**
Elder characteristics:			
Elder total Barthel score	M (SD) Median 58.6 (1.34) 70	M (SD) Median 64.2 (1.96) 70	a slightly higher level of dependency of elder
Carer characteristics:			
Carer age	M (SD) range 61.66 (0.36) 50-88	M (SD) range 61 (0.59) 50-88	no difference
Carer gender	N = 625	N = 219	an higher proportion of female carers
▪ Male	23.8 %	35.2 %	
▪ Female	76.2 %	64.8 %	
Carer marital status	N = 625	N = 219	no difference
▪ Married / with partner	73.0 %	75.3 %	
▪ Other	27.0 %	24.7 %	
Carer educational status	N = 624	N = 219	a lower proportion of graduated people
▪ Illiterate / no elementary school	5.4 %	0 %	
▪ Elementary school	26.0 %	26.0 %	
▪ Secondary school	24.5 %	21.5 %	
▪ High school	32.9 %	34.2 %	
▪ College / University and over	11.2 %	18.3 %	
Carer working status	N = 625	N = 219	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	N = 625	N = 218	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	N = 625	N = 218	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:			
Number of hours per week caring for the elder	M; Median 63.0; 40	M; Median 23.8; 15	an higher number of weekly hours of care provided

Carer age and marital status together with 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; people with graduate level education are under-represented as are workers. EFC carers live more frequently in the same house or in the same building as elderly people they care for and provide care for a much higher number of hours per week: both these tendencies could be related to the higher dependency of elders in the EFC study.

4.4.4 Poland

Representativeness

There is no evidence which could prove or disapprove directly and definitely the level of representativeness of our findings. In Poland, there is no statistical information concerning family carers, or the care giving situations of elderly people. Therefore, the only possible way of constructing sample and identifying the care giving cases was through the elderly, and not through the carers.

Moreover, in our research we used a particular definition of the elementary „sample unit", namely: the family caregiver is a person who provides at least 4 hours per week of help (excluding financial support only) to an over 65-year-old-relative. These criteria do not make comparison with findings of other existed studies easy. Nevertheless, we can try to compare some characteristics of the cared-for older people and of family carers from our study with finding from the others - which, unfortunately, used not only different definition of caregiver's situation but also different methodological approaches (therefore, such a comparison is of very limited value). There are two such studies which can be used in this comparison. First of them is a study done by the Polish Association of Gerontology (PAG study) on a wide national random sample of elderly people 65 and over the other is a study Bień conducted in the Podlaskie region on family carers of people 75 and older (table 34).

Table 34: Comparison of some demographic features of cared-for people 75+ in *metropolitan* area of Poland

Studies	Gender		Civil status		Mode of living	
	male	female	married	others	alone	with others
Bień study. ADL-depended on family carers inhabitants 75+ in metropolitan areas (N = 127)	48 37.8 %	79 62.2 %	53 41.7 %	74 58.3 %	30 23.6 %	97 76.4 %
PAG study. Sub-sample of cared-for people 75+ in metropolitan areas (N = 65)	19 29.2 %	46 70.8 %	21 32.3 %	44 67.7 %	14 21.5 %	51 78.5 %
EFC sub sample of 75+ cared-for people in metropolitan areas (N = 238)	55 23.1 %	183 76.9 %	54 22.7 %	184 77.3 %	53 22.3 %	185 77.7 %

Table 35: Comparison of some demographic features of cared-for people 75+ living in *rural* areas of Poland

Studies	Gender		Civil status		Mode of living	
	male	female	married	others	alone	with others
Bień study. ADL- depended on family carers inhabitants 75+ in rural areas (N = 127)	43 33.6 %	85 66.4 %	48 37.5 %	80 62.5 %	24 18.8 %	104 81.2 %
PAG study. Sub-sample of cared-for people 75+ in rural areas (N = 65)	52 28.4 %	131 71.6 %	47 25.7 %	136 74.3 %	47 25.7 %	136 74.3 %
EFC sub sample of 75+ cared-for people in rural areas (N = 238)	52 22.2 %	182 77.8 %	46 19.7 %	188 80.3 %	35 15.0 %	199 85.0 %

Table 36: Family relationship of carers in EFC and PAG studies

Studies	Spouse	Children	Son / daughter-in-law	Siblings	Other family members
PAG study. ADL-depended on family carers people 65+ (N = 1,017)	243 24.0 %	481 47.4 %	121 11.9 %	14 1.4 %	158 15.3 %
EFC study (N = 1,000)	182 18.2 %	512 51.2 %	134 13.4 %	9 0.9 %	161 16.1 %

When comparing basic demographic features (gender, civic status and mode of living) of cared-for people 75 and older in metropolitan and rural areas in the three studies (see table 35 and 36), we can see some similarities (in spite of the use of different methodology and criteria). But, again, the characteristics concern the cared-for, not the caregivers.

When we compare the family relationship (the family structure) of the carers of elderly people in our study with the relevant features of people caring for their relatives of 65 years and older in the PAG study, we see much greater similarities. In place takes a spouse, then son or daughter-in-law and other family members (siblings in both the studies constitute about 1 % only).

Unfortunately, no other research or statistical data is available in Poland which could be used for estimating representativeness of our sample. It should be noted that our data are the first information concerning the family care giving situation

4.4.5 Sweden

Representativeness

The sampling in Sweden was hard to perform in the way that was agreed but even though this might influence the representativeness it seems that a comparison with exiting data shows that the characteristics are reasonable good with the exception of distribution between male and females. This does not mean that we can ensure any statistically proven representativeness but we can expect that the sample represents a good variety of caring situations.

One draw back in the Swedish sample is the territorial distribution. The sample is dominated by the eastern region which was driven by a choice of areas where different models for service provision was used and the introduction of a subcontractor. The distribution between urban and rural areas, however, is reasonable.

Two different studies Busch-Zetterberg and Living conditions in Sweden (ULF study) by the Social welfare and Health Board were used as a comparison to the Swedish EFC sample.

In the first instance some of the characteristics of the older person and the carer were compared and secondly a sub sample of those of 55 years and the frequency of caring situations were compared: The question used in the ULF study was “Do you on a regular basis help someone old, sick or handicapped that lives in your household or somewhere?”.

Tables 37 and 38 show that in most areas the distribution is similar. However, there is one exception in that in the Swedish EFC sample a lower proportion of older people are cared for by men. In the characteristics of the carer more women are married, and more people are providing daily help as shown the EFC sample is characterised by a high number of couples living together.

Table 37: Elders' characteristics – comparison between the Swedish EFC sample and selected data from reference studies*

Elder ≥65 characteristics		Reference studies* %	EFC sample %
Living	lives in their own home	92	83
	lives in institutional living and sheltered housing	20	17
Married	those who are married and needs help	48	56
Needs	women who needs help	65	58
	those who are > 75 years and cared by men	81	68
	those who are > 75 years and cared by women	88	79
Health in age 65-74	men who are in bad health	8	4
	women who are in bad health	9	5
Cognitive status	those who have dementia at 70 years of age	5	22
	those who have dementia at 90 years of age	40	6

* The ULF study (2002) and Busch-Zetterberg (1996).

Table 38: Family carers' characteristics – comparison between the Swedish EFC sample and selected data from reference studies*

Carer characteristics		Reference studies* %	EFC sample %
Married	men	81	83
	women	53	84
Health	excellent or very good	20	39
	good	36	34
	fairly good	36	31
	bad	8	5
Help giving	women who give help once a week	15	2
	men who give help once a week	9	4
	those who give help every day	40	64
Working life	those who work in age 45-54	90	85
	those who work in age 55-64	70	68
Carers > 75 year	men	60	46
	women	40	54
	those who are married	82	93
	men who are married	90	97
	women who are married	72	89
	those who are widow	17	8
	those who are widower	4	3

* The ULF study (2002) and Busch-Zetterberg (1996).

Table 39 shows the result divided into groups related to frequency of care giving for those over 55 years of age in the EFC sample. It shows that the EFC sample has a higher proportion of those with daily care giving responsibilities especially women and a lower proportion of those caring a few times a week. In both the studies about half of the carers are children of the cared-for. The numbers in the EFC sample caring only a few times a week makes the comparison difficult.

Table 39: The frequency of care giving - Comparison between the ULF study and the EFC study

Carer 55+	Frequency	Study	Spouse / partner in the same household		Spouse / partner at institution		Family member / relative in the same household		Family member / relative in different household		Other person		Total	
			n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Male	Daily	EFC	124	(32.6)	9	(19.1)	6	(31.6)	12	(4.3)	3	(16.7)	154	(20.7)
		ULF	27,616	(40.5)	0	(0.0)	6,310	(25.8)	9,354	(4.6)	6,368	(5.2)	49,648	(11.9)
	Several times a week	EFC	3	(0.8)	7	(14.9)	0	(0.0	20	(7.2)	0	(0.0)	30	(4.0)
		ULF	3,769	(5.5)	660	(25.7)	2,100	(8.6)	28,944	(14.3)	13,012	(10.7)	48,485	(11.6)
	A few times a week	EFC	0	(0.0)	3	(6.4)	0	(0.0)	23	(8.2)	1	(5.6)	27	(3.6)
		ULF	2,050	(3.0)	794	(30.9)	1,521	(6.2)	54,191	(26.8)	34,847	(28.7)	93,403	(22.3)
Female	Daily	EFC	247	(65.0)	10	(21.3)	12	(63.2)	81	(29.0)	6	(33.3)	356	(47.9)
		ULF	31,191	(45.8)	0	(0.0)	7,831	(32.0)	12,321	(6.1)	14,072	(11.6)	65,415	(15.6)
	Several times a week	EFC	5	(1.3)	15	(31.9)	1	(5.3)	105	(37.6)	4	(22.2)	130	(17.5)
		ULF	1,991	(2.9)	1,117	(43.4)	2,463	(10.1)	38,427	(19.0)	20,550	(16.9)	64,548	(15.4)
	A few times a week	EFC	1	(0.3)	3	(6.4)	0	(0.0)	38	(13.6)	4	(22.2)	46	(6.2)
		ULF	1,508	(2.2)	0	(0.0)	4,266	(17.4)	58,733	(29.1)	32,679	(26.9)	97,186	(23.2)
Total		EFC	380	(100.0)	47	(100.0)	19	(100.0)	279	(100.0)	18	(100.0)	743	(100.0)
		ULF	68,125	(100.0)	2,571	(100.0)	24,491	(100.0)	201,970	(100.0)	121,528	(100.0)	418,685	(100.0)

According to the above presented comparison the Swedish sample is reasonably representative.

4.4.6 UK

Representativeness

Unfortunately there is no national data on family carers of older people in the UK and so it is impossible to compare the EUROFAMCARE sample of carers with that of carers of older people in the UK as a whole. The census 2001, covering England and Wales, for the first time, did ask a question about whether people provided unpaid care for a family member or friend and for how many hours, but provided no information on the age of the cared-for person and so the following information includes family carers of both adults and children with special needs. However, the resulting picture overall was one of a considerable amount of care being provided. In April 2001, 5.2 million people were providing unpaid care in England and Wales, including over a million providing more than 50 hours a week.

There are however, estimates for the population of older people in the UK. In the EUROFAMCARE sample 26.2 % of the cared-for people (all of whom were 65 years of more) were over 85 years (table 40), this is a considerably higher proportion than in the general population where 11.6 % of people over 65 years were 85 years old or over in 2003 (ONS 2004 annual abstract, ONS 2003 population estimates).

Table 40: Frequency of cared-for people 65-84 and 85+years old in the UK EUROFAMCARE study

Age group	Frequency	Percent	Valid Percent	Cumulative Percent
65-84 years	734	73.8	73.8	73.8
85+ years	261	26.2	26.2	100.0
Total	995	100.0	100.0	

4.5 Discussion on the total EFC sampling and representativeness

The strategy in this project was to access people in a large variety of caring situations and to form a basis for a common sampling strategy. All countries agreed to use a combined application of geographical, and urban / rural parameters to ensure that the sample should be representative in a demographic, cultural and socioeconomic sense. The use of small zones, saturation recruitment and a variety of sampling modes ensures that partner countries have captured the large variety of caring situations. To our knowledge this is the first European data that exists based on the description from the carer themselves.

After the data collection, each country performed compared their data to known descriptions of elder and if possible descriptions of carers in order to be able to comment on the representativeness of the sample. Most countries have used studies based on demographics of older people and some have studies on carers to refer to. The problem with these comparisons is that different questions and definitions are used in different studies and moreover in Greece and Poland this is the first survey that has been performed.

In most of the countries comparisons with available data supported the premise that the characteristics of both the carer and the older person in the EFC sample are similar and not particularly skewed in any major aspect as judged by the involved researchers. Again this does not mean that we can assure statistical representiveness but we can expect that we have a sample that illustrates a variation of different caring situation in the different countries which is useful for further analysis.

Other support for the quality of the EFC sample is provided by the extent to which the characteristics of the carer and the older person seems to be in line with expected general trends in the populations of each country.

The saturation method has been more or less successful although some countries have not been able to fulfil these criteria. The sampling in Sweden and Germany was very much influenced by the low number that was achieved using the initial sampling methods and subcontractors was used. This might have influenced the possibility of reaching representative samples. Germany reported improvement participant recruitment by broadening the geographical distribution, however the contrary is found in Sweden where one area dominated the sample.

The aim was to get a large variation of situations covering the plurality of these and also to reflect the different situation in relation to existing services. There was a large variation in the availability of services between countries where UK, Sweden and Germany have existing services and others such as Greece and Poland have very few services. This has meant that the subsequent variation between countries is probably larger than the variation within each country.

Conclusion

The sampling procedure has helped to get a unique dataset with a variety of caring situation which allows for further analysis. The dataset will be useful for comparison between situations rather than comparison between countries. In most countries the sample is in line with existing data available and variation between countries is in line with the expected variation in the cultural, demographic and socioeconomic situations in the six core countries. This strengthens the argument that the sample can be valuable for the analysis of caring situations and can also serve as a basis for policy making.

4.6 References

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5 Main characteristics of The sample: the cared-for ELDERLY people and their Primary family carers

Piotr Czekanowski, Eva Mnich, Kevin McKee, Birgitta Öberg, Costis Prouskas, Sabrina Quattrini

5.1 Aims of the chapter

The aim of this chapter is to present the profile of the two groups involved in a caring situation: the old family members needing support / care and their main family carers.

Variables such as age, gender, civil status, family or financial situation are generally considered by the public as “important factors influencing the caring process”. This research confirms such statements in many aspects and the findings presented here contribute in the description of a variety of caring situations within the sample.

The present chapter attempts to provide answers to the question: who are the older persons needing support / care and who are their main family carers?

5.2 Data Collection Methods

Concerning details connected with the methodology and tools used to collect data – see the previous chapters no. 3: *The EUROFAMCARE questionnaire: contents & psychometrics* and the chapter no. 4: *Sampling, recruitment and representativeness*.

5.3 Main findings

5.3.1 Cared-for elderly people’s profile

All data describing the cared-for elderly people (OP) were reported by the family carers (FC), not by the elders themselves, and are, therefore, subjective. That is, they reflect the opinion and attitudes of the family carers.

5.3.1.1 Socio-demographic characteristics of the cared-for elderly people

Our research includes family carers of elderly people over the age of 65. The mean age of the cared-for people of the whole sample is 79.8 years (table 41).

Table 41: Mean age of the cared-for elderly people

Age	Total N = 5,893	Germany N = 990	Greece N = 1,014	Italy N = 988	Poland N = 999	Sweden N = 910	UK N = 992
Mean	79.8	79.7	79.5	82.0	78.6	81.3	78.0

The mean age of the Italian sample is the highest, whereas that of the U.K. sample is the lowest.

When dividing the total sample of elderly people into two age subgroups, those between the ages of 65 and 79 and those over the age of 80, a higher percentage of elderly people belonging in the second group is observed in the Italian and the Swedish sample. On the contrary, the Polish sample consists of a higher percentage of "younger" elderly people (table 42).

Table 42: Age groups of the cared-for elderly people (in %)

Age groups	Total N = 5,893	Germany N = 990	Greece N = 1,014	Italy N = 988	Poland N = 999	Sweden N = 910	UK N = 992
65-79	47.5	48.6	49.8	36.4	55.3	39.6	54.7
80+	52.5	51.4	50.2	63.6	44.7	60.4	45.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

The proportion of the cared-for elderly women in the total sample, is bigger than the proportion of the cared-for elderly men (see table 43). In addition, in all countries more women were interviewed than men. The Polish and the Italian samples have the highest percentages of cared-for women, whereas the Swedish sample is more balanced in that respect.

Table 43: Gender of the cared-for elderly people (in %)

Gender	Total N = 5,919	Germany N = 1,002	Greece N = 1,014	Italy N = 990	Poland N = 1,000	Sweden N = 920	UK N = 993
Female	67.5	68.5	64.5	71.2	72.8	57.7	69.5
Male	32.5	31.5	35.5	28.8	27.2	42.3	30.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

A high proportion of widowhood was expected in the samples of the elderly people. The research findings confirm this. As seen in table 44, more than half of the cared-for elderly of the total sample are widowed. The percentage of elderly people still married or cohabiting is much smaller. Among the national samples, only the Swedish consists of more married / cohabiting OP's than widowed.

Table 44: Marital status of the cared-for elderly people (in %)

Marital status	Total N = 5,911	Germany N = 999	Greece N = 1,007	Italy N = 990	Poland N = 1,000	Sweden N = 92	UK N = 994
Widowed	56.0	63.5	56.7	60.2	63.7	38.7	52.3
Married / cohabiting	37.1	28.5	38.3	32.6	31.3	55.9	36.6
Divorced / separated	2.9	5.0	1.8	0.8	1.2	2.6	6.1
Single	4.0	3.0	3.2	6.4	3.8	2.8	5.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Five national samples seem more homogeneous with at least 95.9 % of the elderly have the same ethnic origin and nationality (Italian, Greek, Polish, German and Swedish). There is a wider variation within the British sample where almost every fifth older person (19.5 %) has an ethnic origin other than British. In addition, over 97.8 % of the above mentioned five national samples have the nationality of the state they live in, with the exemption of the UK sample which consists of 9.3 % non-British citizens.

5.3.1.2 Financial situation[1] of the cared-for elderly people

The data collected shows that a very high percentage of the cared-for elderly people receive state funded pension or some other kind of financial support (table 45). There are differences among the national samples. For example, in the Swedish and Polish sample everyone, or almost everyone receives pensions and / or financial support as opposed to the Italian and Greek samples, where the percentage of elderly people receiving such support is lower.

Table 45: State funded pension or financial support (of any kind) received by the cared-for elderly people (in %)

Type of answer	Total N = 5,740	Germany N = 959	Greece N = 997	Italy N = 987	Poland N = 995	Sweden N = 864	UK N = 938
Yes	95.5	94.7	92.1	92.9	98.2	100.0	95.4

5.3.1.3 Place of living and the household composition of the cared-for elderly people

As shown in table 46, the biggest proportion of the elderly people of all national samples live at home.

Other place of living include care homes which seem to be more popular among the Swedish and German samples (every tenth older person lives in such institutions).

A small percentage of elderly people in the samples live in sheltered housing (around 2 %). This kind of residence is more common within the Swedish (5.7 %) and the UK's (4.0 %) sample and it is almost absent in the Polish, Greek and Italian samples.

Table 46: Place of living of the cared-for elderly people (in %)

Type	Total N = 5,917	Germany N = 1,000	Greece N = 1,013	Italy N = 990	Poland N = 1,000	Sweden N = 919	UK N = 995
At home	92.9	87.7	98.7	95.8	99.8	83.0	91.4
In other place	7.1	12.3	1.3	4.2	0.2	17.0	8.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

table 47 shows that in the whole sample over two thirds of all cared-for elderly people live with someone else. The highest percentage of cohabitating elderly people appears in the Polish and in the Italian sample and the lowest in the German sample.

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[1] For further details concerning the financial situation of the elderly see the ECO analysis and the Background reports (NABAREs) concerning the 6 studied countries.

Table 47: Cared-for elderly people living alone or with others (in %)

Type of answer	Total N = 5,922	Germany N = 1,003	Greece N = 1,014	Italy N = 990	Poland N = 1,000	Sweden N = 920	UK N = 995
With someone else	68.7	55.5	75.2	78.9	80.1	61.0	60.7
Alone	31.3	44.5	24.8	21.1	19.9	39.0	39.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

According to table 48, most of the elderly cared-for people of the Swedish, UK and German sample, who cohabitate, live with their partners. Some live with their children. The reverse is observed in Poland, Greece and Italy. When comparing the extremes, 4 / 5 of those elderly people who live with someone in the Swedish sample live with their partners while in the Polish sample the proportion is two times smaller. Furthermore, 12 times more Poles than Swedes live with their children. Another difference is observed when examining the number of the elderly cared-for people living with their grandchildren: the Polish percentage is over 100 times bigger than the Swedish.

Finally, in the Italian and Greek sample, almost 13 % and 8 % respectively of cared-for elderly people live with a paid carer. This percentage is much smaller in the other four country samples.

Table 48: Household composition of the cared-for elderly people (in %)*

Co-tenants	Total N = 4,067	Germany N = 557	Greece N = 763	Italy N = 781	Poland N = 801	Sweden N = 561	UK N = 604
With partner	50.6	48.5	47.8	40.3	38.8	80.9	57.0
With children	43.7	35.9	51.9	47.6	70.4	5.5	35.4
With grandchildren	13.6	5.7	4.3	15.1	44.9	0.4	1.7
With children in law	10.9	3.2	0.5	16.4	35.7	0.2	0.8
With other relative	2.5	2.2	1.6	4.7	3.1	0.4	2.5
With siblings	2.2	2.0	1.4	5.0	1.5	0.5	2.2
With paid carers	4.7	1.6	9.3	12.8	0.2	1.1	0.3
With others	1.2	0.2	1.7	1.5	0.7	0.4	2.3
In residential care settings	5.8	11.1	1.4	4.9	0.2	14.3	7.0

* Multiple answers possible – percentages do not sum up to 100 %.

In table 49, the size of the household of cared-for elderly people who do not live with the main carer or in a care home is presented. Almost 2 / 3 of the households are one person households. In the Swedish sample the proportion of the one person's households is the largest in the whole sample. The difference between the percentages of one versus two person's households is much smaller in other country samples (i.e. Greek sample). Only in the Italian sample there are more two persons' households than households including only one person.

Table 49: Total number of people in the households of the cared-for elderly people who do not live with the main carer nor in an institution (in %)

Number of people	Total N = 2,769	Germany N = 535	Greece N = 473	Italy N = 501	Poland N = 304	Sweden N = 400	UK N = 556
1	64.7	76.6	53.1	41.7	65.5	83.6	69.5
2	29.0	20.7	40.8	46.9	22.0	15.3	24.3
3	4.3	1.7	5.3	9.6	6.3	0.8	2.9
4 and more	2.0	1.0	0.8	1.8	6.2	0.3	3.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

5.3.1.4 Health situation and the need of support of the cared-for elderly people

According to responses collected through the open-ended question regarding the main reason of care (see table 50), carers in four country samples (Poland, Sweden, Greece and in the UK) report that physical illness / physical disability is the most frequent reason for caring. In the Italian and German samples, the most frequent reason for providing care / support is the mobility problem of the cared-for elderly person. With the exception of the Polish sample, mobility problems is the second most often reported reason of support / care. Despite differences among the samples, carers reported next three main reasons for providing care: age-related decline, memory or cognitive problems and difficulties in self-caring. Other reasons, such as the lack of security or the need for company (or loneliness), were not reported often as main reason.

Table 50: The main reason for providing support / care to the elderly people reported by carers (in %)

Type of answer	Total N = 5,912	Germany N = 1,000	Greece N = 1,012	Italy N = 989	Poland N = 999	Sweden N = 917	UK N = 995
Physical illness / disabilities	30.9	24.8	30.7	18.6	43.7	38.8	29.4
Mobility problems	20.5	27.9	24.4	29.6	10.4	9.7	20.4
Age-related decline; old age	17.5	12.1	15.9	15.0	28.0	23.9	10.7
Memory / cognitive problems / impairments	10.6	14.9	5.6	9.0	4.9	19.0	11.1
Non self-caring	6.9	10.0	5.5	9.9	3.5	0.7	11.1
Sensory problems	3.8	3.8	3.2	4.3	2.6	3.9	4.9
Social reasons; loneliness; need for company	3.5	2.2	5.7	2.3	4.3	0.4	5.4
Safety / feeling of insecurity	3.2	1.7	6.4	7.8	0.3	0.5	2.3
Psychological / psychiatric illness / problems	1.8	1.5	1.9	1.7	1.0	2.2	2.5
Other reason	1.3	1.1	0.7	1.8	1.3	0.9	2.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Asking about OP memory problems we were interested in difficulties which affect carers life such as elder's difficulties in remembering what day it is, or problems with recognising friends or neighbours.

Although memory or cognitive problems were not among the three primary reasons for providing care in the total sample, in the German and the UK samples they were more often reported. Apparently, these problems influence the carer's and the cared-for elderly people relationship in many situations. Almost half of the cared-for elderly people in the total sample appear to suffer from memory problems (see table 51). More specifically, the German sample contains the highest percentage of elderly people with memory problems, whereas the Greek sample contains the lowest.

According to our respondents, in 66 % of elder's memory problem cases, doctors gave a cause of such problems (in 64 % of the explained by doctors situations, dementia was reported as a reason of the OP memory problems).

Table 51: Memory problems of the cared-for elderly people (in %)

Type of answer	Total N = 5,918	Germany N = 1,001	Greece N = 1,013	Italy N = 990	Poland N = 1,000	Sweden N = 920	UK N = 994
No	53.7	44.2	64.2	50.9	57.6	48.8	56.1
Yes	48.3	55.8	35.8	49.1	42.4	51.2	43.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

A relatively large proportion (¼) of the total sample of elderly cared-for people seem to suffer from behavioural problems such as wandering, constantly repeating what has been said, shouting inappropriately, etc. As seen in table 52, there are differences between country samples. Again, the highest proportion of elderly people suffering from behavioural problems is in the German sample and the lowest is in the Greek sample. This result may be associated to the fact that more people in the German sample have a dementia diagnosis.

Table 52: Behavioural problems of the cared-for elderly people (in %)

Type of answer	Total N = 5,842	Germany N = 998	Greece N = 982	Italy N = 990	Poland N = 1,000	Sweden N = 909	UK N = 963
No	72.4	64.0	76.2	69.4	71.8	73.7	79.4
Yes	27.6	36.0	23.8	30.6	28.2	26.3	20.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

The 10-item Barthel scale, an additional item on mobility and a 6-item scale derived from the OARS assessment[2] were used to measure the dependency of the elderly cared-for people.

As shown in table 53, when dichotomizing the IADL scale[3] into two groups ("low or moderate IADL dependency" and "more severe IADL dependency"), approximately especially ¾ of the older people in the Italian, Swedish and German samples have a high degree of impairments on these kind of activities. The lowest percentage of older people with more severe IADL dependency is in the polish sample.

Table 53: IADL dependency of the cared-for older people (dichotomized)

Type of answer	Total N = 5,869	Germany N = 1,001	Greece N = 999	Italy N = 985	Poland N = 993	Sweden N = 908	UK N = 983
Low to moderate IADL dependency	33.9	28.3	37.2	25.3	43.2	28.6	40.1
More severe IADL dependency	66.1	71.7	62.8	74.7	56.8	71.4	59.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

As far as the Barthel-Index is concerned, in table 54 it is shown that the elderly people in the polish sample show the highest mean, an indication that a large proportion has a high level of independency on ADL activities. Elderly people in the German and the Italian sample have the lowest mean. This result corresponds to the IADL dependency shown in the table before.

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[2] For References, the single items and a detailed description of scale construction see chapter 3.

[3] The IADL scale has a theoretical range of 0 to 6 (highest number of activities for which elder needed help) and the Barthel Index has a theoretical range of 0 to 100 (totally independent on activities of daily living).

Table 54: Barthel-Index of the cared-for older people

Barthel_Index (0-100)	Total N = 5,684	Germany N = 983	Greece N = 942	Italy N = 978	Poland N = 995	Sweden N = 883	UK N = 903
Mean	69.7	61.6	70.0	63.0	79.3	70.7	73.9

Respondents were asked to assess the degree of dependency of the elderly people using a dependency scale[4]. Nearly 2/3 of the elderly people in the total sample was assessed as moderately or severely dependent.

More specifically, as seen in table 55, three samples (German, Italian and Greek) have higher percentages of severely dependent cared-for elderly persons, whereas, the UK and the Swedish sample have a higher percentage of moderately dependent cared-for elderly people. In the Polish sample, slight dependency is higher and severe dependency lower - the lowest of the whole sample.

Table 55: The level of dependency of the cared-for elderly people (in %)

Type of answer	Total N = 5,921	Germany N = 1,002	Greece N = 1,014	Italy N = 990	Poland N = 1,000	Sweden N = 920	UK N = 995
Moderately dependent	33.8	32.5	31.3	30.0	31.3	38.7	39.4
Severely dependent	30.6	37.9	31.5	37.3	19.4	34.6	23.1
Slightly dependent	25.7	22.9	24.3	23.8	34.4	23.4	25.1
Independent	9.9	6.7	12.9	8.9	14.9	3.3	12.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Elderly people have the need for help in various types of activities. In many cases, they rely – partially or completely – on others to manage these activities. Taking into account these cared-for elderly people who completely rely on others (see table 56), it is clear that over a half of the cared-for elderly have to rely on others trying to manage their financial affairs, their domestic activities including housework or the organization of their care. This data make us conscious that a big group of the cared-for elderly could not function at their homes at all without the support of others (mainly family members).

As table 56 shows, all national samples share some common characteristics (i.e. domestic needs), but there are also differences among country samples. For example, 69 % of the Italian, 60 % of the Greek and 57 % of the German samples are reported to be in need of financial management, as opposed to only 15 % of the Swedish sample. Also, the Polish and the UK sample have lower health needs than the rest of the samples, and the Italian and German samples have higher mobility needs.

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[4] 1) Independent – able to carry out most activities of daily living, but may need some help occasionally.
2) Slightly dependent – able to carry out most activities of daily living, but requires help with some instrumental activities (e.g., shopping, cooking, housework, etc.).
3) Moderately dependent – able to carry out some basic activities of daily living (for example, bathing, feeding, dressing) but unable without help to carry out most instrumental activities of daily living (e.g. shopping, cooking, housework).
4) Severely dependent – unable to carry out most activities of daily living, without help (e.g. feeding ourselves or going to the toilet).

Table 56: Cared-for elderly people who rely completely on others in meeting their needs (in %)*

Type of need	Total N = 5,864-5,920	Germany N = 997-1,003	Greece N = 1,012-1,014	Italy N = 982-990	Poland N = 999-1,000	Sweden N = 892-920	UK N = 979-995
Financial management	58.3	57.1	58.9	69.1	47.9	15.1	47.7
Domestic needs	55.8	60.2	55.7	63.4	48.2	53.9	53.3
Organising and managing care and support	54.6	52.8	47.1	71.1	45.5	65.3	46.7
Emotional / psychological / social needs	43.9	45.5	54.0	51.9	32.3	30.1	48.5
Health needs	42.8	44.2	51.4	46.1	31.3	50.1	33.9
Mobility needs	35.2	45.2	31.0	47.7	29.8	22.3	34.3
Physical / personal needs	28.0	35.5	32.9	32.3	17.9	25.6	23.9
Financial support	13.6	16.0	21.1	12.3	6.2	6.3	18.9

* Multiple answers possible – percentages do not sum up to 100 %.

In the following table, the proportion of elderly cared-for people who rely on others completely or partially in meeting their needs is presented. As reported by their carers, most elderly cared-for people rely on their family members, neighbours and / or available services in meeting their daily needs (see table 57).

Table 57: Cared-for elderly people who rely partially or completely on others in meeting their needs (in %)*

Type of need	Total N = 5,864-5,920	Germany N = 997-1,003	Greece N = 1,012-1,014	Italy N = 982-990	Poland N = 999-1,000	Sweden N = 892-920	UK N = 979-995
Domestic needs	92.0	94.3	86.3	95.4	92.9	92.9	90.1
Emotional / psychological / social needs	89.4	90.1	90.0	95.5	88.3	84.6	87.7
Mobility needs	82.1	92.0	71.8	94.5	80.3	73.3	80.3
Financial management	79.9	78.3	79.2	91.7	77.8	85.1	67.4
Organising and managing care and support	78.8	72.9	73.0	94.2	75.4	87.4	70.5
Health needs	78.5	81.4	88.3	86.4	72.3	76.7	65.6
Physical / personal needs	66.0	77.3	65.9	78.3	46.2	68.6	60.3
Financial support	35.6	34.4	52.5	41.6	37.7	12.9	31.9

* Multiple answers possible – percentages do not sum up to 100 %.

5.3.2 Main family carers' profile

5.3.2.1 Socio – demographic characteristics of the family cares

For the purposes of this research, adult family members caring for an elderly family member for more than four hours a week were interviewed. The mean family carers' age in the total sample is 55 years (see table 58). The highest mean age of the carers is in the Swedish sample (65 years) and the lowest is in the Polish sample (51 years).

Table 58: Mean age of family carers

Age	Total N = 5,898	Germany N = 1,002	Greece N = 1,003	Italy N = 989	Poland N = 997	Sweden N = 919	UK N = 988
Mean	54.8	53.8	51.7	53.5	51.0	65.4	54.5
Minimum	15	18	18	18	18	25	15
Maximum	96	89	95	88	87	96	88

Table 59 shows the variety of the possible family relations between the carers and the cared-for elderly people. Almost every second carer is a child of the cared-for person, followed by the spouse / partner of the elderly. In the Swedish sample, spouses / partners of the old persons play the role of the family carers more often than children. The third most often cited family carer is a daughter / son in law. These three categories of carers are most equally spread in the UK sample.

Table 59: Carer's family relationship with the cared-for elderly people (in %)

Kind of relationship	Total N = 5,920	Germany N = 1,002	Greece N = 1,013	Italy N = 990	Poland N = 999	Sweden N = 921	UK N = 995
Child	48.9	53.3	55.4	60.9	51.1	40.5	31.6
Spouse / partner	22.2	18.4	17.1	10.9	18.2	48.1	22.8
Daughter / son-in-law	11.0	9.0	13.9	9.7	13.4	4.5	15.3
Other *	17.9	19.3	13.6	18.5	17.3	6.9	30.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

* "Other" category includes: nephews / nieces, siblings, uncles / aunts, cousins, grandchildren, close neighbours, etc.

The percentage of female family carers is on average 3 times bigger than the percentage of the male carers in the whole sample (see table 60), a pattern that exists also in all six national samples. The Swedish sample has a higher proportion of male carers compared to the other samples.

Table 60: Gender of family carers (in %)

Gender	Total N = 5,911	Germany N = 1,002	Greece N = 1,009	Italy N = 990	Poland N = 1,000	Sweden N = 918	UK N = 992
Female	76.3	76.1	80.9	77.1	76.0	72.0	75.4
Male	23.7	23.9	19.1	22.9	24.0	28.0	24.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Five out of the six samples are to a big extent homogeneous (at least 96.1 % of the carers have the same ethnic origin as the main nation) In the UK sample, almost every fifth carer (19.7 %) has an ethnic origin other than British. In addition, the Italian, Greek, German, Swedish and Polish samples are homogeneous, as far as their nationality is concerned (98.4 % of all carers have the nationality of the country they live in). 8.8 % of the family carers in the UK sample are non-British citizens.

In an attempt to identify cultural factors influence caring and caring relationship, the carer's religious denomination was recorded (see table 61).

Almost ¾ of the total number of the carers belong to mainstream religions or religion denominations. There are big differences in the proportion of carers who belong to a religion / religious denomination and those who do not belong to any religion / religious denomination. For example, 95 % of the carers in the Polish sample belong to a religious denomination, as opposed to only 50 % of the Swedish sample.

Table 61: Religion / religious denomination of family carers (in %)

Type of answer	Total N = 5,905	Germany N = 1,003	Greece N = 1,003	Italy N = 990	Poland N = 999	Sweden N = 918	UK N = 992
Yes	73.6	58.4	85.3	87.8	95.9	50.5	61.9
No	26.4	41.6	14.7	12.2	4.1	49.5	38.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

In table 62, the percentages of people belonging to religious faiths are presented. Apparently, religious orientation is associated with national history and culture. In all country samples denominations of Christianity are more dominant. The UK and the German sample contain also members of other religions (14.3 % and 4.7 % respectively).

Table 62: Type of religion / religious denomination of the family carers (in %)

Type of denomination	Total N = 4,291	Germany N = 578	Greece N = 858	Italy N = 847	Poland N = 954	Sweden N = 459	UK N = 595
Roman catholic	48.1	34.9	0.7	99.3	98.2	0.9	12.3
Protestant	28.8	60.1	0.1	0.1	0.0	98.2	73.4
Orthodox (Russian, Greek)	20.0	0.3	99.0	0	0.8	0	0
Jewish + Muslim + Hindu + Buddhist + other	3.1	4.7	0.2	0.6	1.0	0.9	14.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

The reported degree of religiosity of the family carers is presented in table 63. Most carers characterised themselves as *"Quite religious"*. Relatively high percentages of *"Very religious"* respondents exist in the Greek sample and the Italian samples followed by the UK and the Polish samples. *"Not religious at all"* respondents' percentages are higher in the Swedish, UK and German samples.

Table 63: Degree of religiosity of family carers (in %)

Type of answer	Total N = 5,812	Germany N = 1,000	Greece N = 1,006	Italy N = 972	Poland N = 997	Sweden N = 866	UK N = 971
Quite religious	59.7	57.7	50.9	67.9	84.6	46.2	49.0
Not religious at all	24.9	37.0	12.8	11.3	5.2	47.9	38.3
Very religious	15.4	5.3	36.3	20.8	10.2	5.9	12.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

5.3.2.2 Level of education and employment status of the family carers.

For comparability purposes national levels of education, were grouped in three more general categories: the low level, the intermediate level and the high level of education[5] (see Table 64). Most family carers have completed an intermediate level of education. There are some differences at a national level (e.g. 41 % in the Greek and 69 % in the UK sample). Almost ¼ of the family carers has had low or no education, and a small proportion has had high level of education (see table 64). Greeks and Swedes have the highest percentages of family carers with low level of education. On the other hand, these two country samples have the biggest percentages of the highly educated people.

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[5] In order to obtain comparable level of education across countries, national categories of education that have been asked to carers have been allocated by national teams into the ISCED categories. These categories have been recoded in three following levels of education: Low (primary education and lower secondary education: ISCED 0-2), Intermediate (upper secondary and post secondary education, without university degree: ISCED 3-4), High (first and second stage of tertiary level: ISCED 5-6).

The percentage of the carers who are currently pursuing education is not large – 4.8 % in the whole sample (2.6 % in the German sample, 6.2 % in the Polish sample and 6.3 % in the Italian sample).

Table 64: Level of education of family carers (in %)

Level of education	Total N = 5,768	Germany N = 940	Greece N = 979	Italy N = 989	Poland N = 999	Sweden N = 899	UK N = 962
Intermediate	57.4	59.8	40.5	63.4	67.7	42.1	69.4
Low	24.3	21.2	37.4	21.5	17.1	32.6	16.8
High	18.3	19.0	22.1	15.1	15.2	25.3	13.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

The employment status of the family carers was also investigated (see table 65). In general, the percentage of employed carers is smaller than the percentage of non-working carers. The biggest group of working carers is in the Greek sample and the smallest is in the Swedish sample.

Table 65: Employment status of the family carers (in %)

Employment status	Total N = 5,906	Germany N = 1,003	Greece N = 1,009	Italy N = 989	Poland N = 1,000	Sweden N = 919	UK N = 986
Non-working	59.0	57.7	53.2	56.6	60.3	66.1	60.4
Employed	41.0	42.3	46.8	43.4	39.7	33.9	39.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Four categories of employment sector were used to categorise the carers' jobs: the private sector, the public sector, the self-employment sector and the sector including other types of work. The differences among country samples are shown in table 66. In the total sample, most carers are occupied in the public sector (4 out of 6 national samples). The private sector follows second. The private sector employees are mostly represented in the German and in the UK's samples, although in the latter country the percentage of the public sectors' employees is almost the same as in the private sector.

High percentages of self employment exist within the Greek sample, followed by the Polish, Italian and the UK samples.

Table 66: Sector of work of family carers (in %)

Sector	Total N = ,2374	Germany N = 423	Greece N = 461	Italy N = 421	Poland N = 394	Sweden N = 293	UK N = 382
Private	37.1	51.7	34.7	31.8	33.5	25.6	41.9
Public	41.8	26.5	36.2	46.8	46.5	61.5	40.6
Self-employment	17.4	12.1	26.9	16.9	18.5	10.2	16.5
Other types of work	3.7	9.7	2.2	4.5	1.5	2.7	1.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Quite a large proportion of carers (15.3 % of the total sample) had to reduce the amount of their working hours because of caring for elder relatives (see table 67). This is more common in the German, and less common in the Polish, sample. Among these carers, most of them (93.9 %) have experienced the negative income effect because of the reduction of hours. More specifically, the reduction of the working hours causes a negative income effect in the total Polish (100 %) and Italian (100 %) samples and in a very high proportion of the Greek (98.6 %), German (93.0 %), UK (90.4 %) and Swedish sample (81.8 %).

Table 67: Necessity to reduce the working hours of the working carers (in %)

Type of answer	Total N = 2,399	Germany N = 423	Greece N = 473	Italy N = 425	Poland N = 393	Sweden N = 302	UK N = 383
No	84.7	79.4	80.8	86.4	93.9	85.8	83.3
Yes	15.3	20.6	19.2	13.6	6.1	14.2	16.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Table 68 presents the status of carers who are not in the labour market. Most of the non-working carers in the total sample are retired. This percentage ranges from 35 % in the Greek sample to 91 % in the Swedish one. Over ¼ of non-working carers described themselves as housewives / househusbands. There are differences among national samples. The Greek sample has the highest proportion of housewives' carers whereas this proportion is very small in the Swedish sample (only 1.4 %).

Every eleventh carer in this research is unemployed and seeking work, although this percentage in the Polish and German samples is much higher than in the rest of the national samples.

Table 68: Status of the non-working family carers (in %)

Type of situation	Total N = 3,742	Germany N = 571	Greece N = 529	Italy N = 558	Poland N = 600	Sweden N = 621	UK N = 593
Retired	60.1	54.5	35.2	52.0	62.4	91.0	60.7
Housewife / househusband	26.2	29.9	54.0	39.4	17.3	1.4	19.9
Unemployed and seeking work	9.0	14.2	9.5	7.2	14.5	3.7	5.4
On long term seek leave but intending to return to work	2.3	1.2	1.3	0.7	0.3	3.4	6.6
Other	2.4	0.2	0.0	0.7	5.5	0.5	7.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

In table 69 the working life restrictions of the non-working family carers are reported. In the total sample, every tenth family carer can not work at all, and every twelfth carer has had to give up his / her work because of caring for the elderly. In the Swedish sample, only 2 % of the carers could not work at all. This proportion increases in the UK and the Greek sample (15 % and 18 % respectively). The second restriction – the necessity to give-up work – characterises mainly the carers of the British sample, followed by those from the German and the Greek sample.

Table 69: Restrictions to the working life or career of the non-working family carers due to caring for the elderly (in %)

Type of restriction	Total N = 3,445	Germany N = 560	Greece N = 525	Italy N = 543	Poland N = 602	Sweden N = 618	UK N = 597
I can not work at all	10.0	9.5	17.7	8.7	8.1	1.9	15.4
I have had to give up work	8.4	11.8	10.3	7.4	4.7	1.9	14.7

In an attempt to summarise findings regarding restrictions to the working life of both - working and non-working family carers, table 70 has been produced. The difficulties with the development of the carer's professional career or studies, and the necessity to work only occasionally are restrictions that appear almost to the same extend. Once again, the Greek sample has the largest percentage of family carers who meet such working life restrictions, followed by the UK sample. Apparently, the situation is better for the Swedish and the Polish samples.

Table 70: Restrictions to the working life or career of working and non-working family carers (in %)

Type of restriction	Total N = 5,862	Germany N = 992	Greece N = 997	Italy N = 987	Poland N = 994	Sweden N = 913	UK N = 979
I can / could not develop my professional career or studies	7.7	8.0	12.6	5.3	3.6	6.0	10.3
I can / could work only occasionally	7.4	9.6	12.2	4.9	5.2	2.3	10.0
Other restrictions	3.7	6.6	3.8	3.2	0.4	3.3	4.6

As it results from the above findings, working carers seem to be in a better position with bigger income that enables them to buy services. On the other hand however, they may face difficulties in caring and supporting their family members because of the time they have to spend at their workplace.

5.3.2.3 Financial situation of family carers

The economic analysis of the overall carers' financial situation is examined in depth at the ECO section. Only "additional financial costs because of the caring situation" will be reported here (see table 71).

According to the data presented in the following table, every second carer of the total sample is burdened by the costs of buying medicine for the elderly cared-for person. An additional expense covered by the carers is the cost of travelling. These types of expenditures vary from country to country due to differences in social security systems etc. For example, in the UK sample, the percentage of people spending money for medicine as additional cost of caring is only 6.1 %. In the rest of the national samples the percentage is much higher, particularly in the Greek and the Polish samples (73.3 % and 71.9 % respectively). Finally, there is a difference between countries as far as the adaptation of the home environment and / or furniture is concerned. More specifically, 5.2 % of the carers in the Swedish sample, as opposed to 31 % of carers in the German sample, mention such type of additional costs.

Table 71: Type of additional financial costs as a result of the caring situation (in %)*

Type of costs	Total N = 5,904	Germany N = 1,002	Greece N = 1,008	Italy N = 989	Poland N = 1,000	Sweden N = 910	UK N = 995
Medicines	48.2	60.6	73.3	47.4	71.9	27.4	6.1
Travel costs	30.4	41.6	23.7	26.6	26.1	34.6	30.1
Adaptation of the home environment and / or furniture	18.4	31.0	17.9	17.3	12.1	5.2	25.7
Special food	16.3	19.3	34.3	9.5	16.0	5.9	11.6
Other costs	12.4	18.6	13.5	14.3	9.9	9.0	8.7

* Multiple answers possible – percentages do not sum up to 100 %.

In an attempt to investigate the amount, if any, of financial support a carer receives, carers were asked whether they received any financial aid or allowances “because of their caring situation”. According to findings, carers rarely received such help (3.6 % of the total sample). Furthermore, in most of the six countries, such support does not exist. The percentage of people receiving financial aid or allowances “because of their caring situation” is almost null for the Greek, the Italian, the German and the Swedish samples (0.1 %, 0.6 %, 1.1 %, 1.1 % respectively). In the UK sample, every tenth carer receives financial support because of the caring situation. In Poland, 8.3 % of the carers receive such kind of the support.

5.3.2.4 Family situation of family carers

The marital status of the carers is reported in table 72. Most carers are married / cohabiting. The percentage of single carers in the national samples varies from 8 % in the Swedish sample to 18 % in the Italian one. There is an apparent differentiation between national samples in the proportion of divorced / separated carers.

Table 72: Marital status of family carers (in %)

Marital status	Total N = 5,885	Germany N = 1,002	Greece N = 987	Italy N = 989	Poland N = 1,000	Sweden N = 913	UK N = 994
Married / cohabiting	74.0	71.1	76.3	71.0	72.8	83.6	69.6
Single	13.2	11.7	12.0	17.9	15.2	8.0	14.3
Divorced / separated	7.0	12.0	5.7	3.9	5.5	5.1	9.7
Widowed	5.8	5.2	6.0	7.2	6.5	3.3	6.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

There is also a high percentage of carers with children (see table 73). Eighty percent of the carers in the total sample have children. Looking into it at a national level, carers with children amount for almost 75 percent of the Italian and 87 percent of the Swedish sample. The average number of children per carer in 5 out of the six national samples is 2, with the exception of the Italian sample where the average number of children is smaller – one child per carer.

Finally, in the total sample, 48 % of carers having children, have a grandchild or grandchildren. At a national level, the Italian and the Greek samples consist of 33 – 34 % of carers who have grandchildren, whilst in the Swedish sample the percentage of carers having grandchildren rises up to 74 %.

Table 73: Family carers having children (in %)

Type of answer	Total N = 5,913	Germany N = 1,003	Greece N = 1,012	Italy N = 990	Poland N = 999	Sweden N = 920	UK N = 989
Yes	80.0	79.0	79.8	74.4	80.3	87.3	79.9
No	20.0	21.0	20.2	25.6	19.7	12.7	20.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Last, the size of the carers’ household will be reported. As shown in Table 74, the average size of the carers’ household including the carer himself / herself is three people. The smallest households are observed in the Swedish sample and the biggest households in the Polish sample. Lack of housing may be the cause for this.

Table 74: Number of people in carer's household (carer included)

Number of people	Total N = 5,900	Germany N = 1,002	Greece N = 1,000	Italy N = 988	Poland N = 998	Sweden N = 919	UK N = 993
Mean	2.94	2.51	3.38	3.20	3.75	2.02	2.70
Maximum	12	7	10	12	11	8	9

5.3.2.5 Caring situation

In describing the caring situation in 6 European countries, it is necessary to make a distinction between objective and subjective measurement. Objective measurement consists of facts such as number of cared-for people in household, duration of caregiving, etc. Subjective measurement consists of the carers personal opinion about things such as principal reason for caring, carers willingness to continue caring etc.

Starting with some information obtained from the objective measurements, table 75 shows that 14 % of the family carers care for more than one older person. Almost one fifth of the Greek and the Italian sample care for more than one elderly people.

Table 75: Percentages of cared-for 65+ elderly people per one family carer

Number	Total N = 5,911	Germany N = 1,000	Greece N = 1,013	Italy N = 990	Poland N = 1,000	Sweden N = 920	UK N = 988
1	86.0	93.0	80.9	81.5	85.3	90.0	85.3
2+	14.0	7.0	19.1	18.5	14.7	10.0	14.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Family carers tend undertake multiple caring roles for many people including care of the younger people (children or grandchildren for example). Considering the number of the cared-for non-elderly people (see table 76), it seems that over one third of all carers care for at least one younger person. However there are differences among samples. For example, 60 percent of the carers in the Greek sample not only care for an elderly person, but also for someone younger.

Table 76: Number of cared-for non-elderly people per family carer (in %)

Number	Total N = 5,830	Germany N = 996	Greece N = 1,009	Italy N = 972	Poland N = 999	Sweden N = 884	UK N = 995
0	64.3	74.6	40.6	56.6	60.9	91.0	65.6
1+	35.7	25.4	59.4	43.4	39.1	9.0	34.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

The distance between a carer's place of living and a cared-for older person's place of living is presented in table 77. More specifically, over half of the carers live in the same household or in the same building as the cared-for person. Over 74 % of the Polish and 66 % of the

Greek sample belong in this category. Fewer are the carers that live in the same household or in the same building as the cared-for person in the rest of the national samples.

When combining the first three categories into one, namely living with or within walking distance to the elderly, this includes 74 % of the total sample of carers.

Every fourth carer of the total sample live in a bigger distance and need at least 10 minutes by car, bus or train to get to the cared-for person. The percentage of these carers is the lowest in the Polish and in the Greek sample and the highest in the UK's sample, followed by the German and the Swedish sample.

Table 77: Distance between the carer's and the cared-for person's residence (in %)

Type of situation	**Total N = 5,921**	**Germany N = 1,003**	**Greece N = 1,013**	**Italy N = 990**	**Poland N = 1,000**	**Sweden N = 921**	**UK N = 994**
In the same household	47.8	36.6	50.7	45.3	68.5	45.6	39.2
In the different households, but in the same building	8.5	13.9	15.4	10.2	5.9	2.1	2.9
Within walking distance	18.1	17.7	15.6	20.0	11.1	21.5	23.0
Within 10 minutes drive / bus or train journey	12.6	14.0	7.8	16.3	7.2	14.4	16.5
Within 30 minutes drive / bus or train journey	9.0	12.6	7.0	4.8	5.3	12.3	12.3
Over 30 minutes drive / bus or train journey	4.0	5.2	3.5	3.4	2.0	4.1	6.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Carers' burden can be associated with the period of caring for the older persons. The average duration of a caring period in months is presented in table 78 below. The mean caring period for the cared-for elderly people was 60 in the total sample, and varied from 47 months in the German sample to 70 months in the Polish sample.

Two general types of caring periods were created: the short period (up to two years of care) and the long period (more than two years of caring). Over 2/3 of all carers provide care for more than two years, a relatively long time period.

There are differences in the national samples: the highest percentage of carers, caring for more than two years for their elderly people, is in the Polish sample (74.1 %) and in the Swedish sample (70.3 %). The lowest percentage of carers, caring for longer time, is in the German sample (54.8 %), followed by the UK sample (60.6 %).

Table 78: Average duration of a caring period (in months)

Duration	Total N = 5,848	Germany N = 991	Greece N = 986	Italy N = 981	Poland N = 997	Sweden N = 910	UK N = 983
Mean	59.8	46.6	59.8	57.2	70.0	64.1	61.5
Median	36	30	36	36	52	48	36

Also place of living, that is the type of the locality, is of key significance in service access and service provision for elderly people and their carers (see Chapter 4.2.2: Sample strategy for family caregivers survey).

A number of subjective questions were included in the survey. They will be presented hereon.

Table 79 shows that, according to most of the carers, *"Emotional bonds"* (i.e. love or affection) is the principle reason for caring. However, there are differences within national samples.

"Sense of duty" is the second most often declared principle reason for caring (apart from the German sample, where this reason stands third). The proportion of carers stating "sense of duty" as the principle reason for caring is almost three times bigger in the Polish than in the Swedish sample.

"Personal sense of obligation" was the third reason, most often mentioned by carers as the principle reason for caring. The percentage of carers, who has given this answer varies from 7 % in the Italian sample up to 21 % in the Polish sample (total sample: 13 %). Only in the German sample, this principle reason of caring stands in the second position of the list of reasons (18 %).

A small number of carers *"Had no other alternative"* than to care for the elder. The lowest percentage of such carers is in the Swedish sample, much higher in the Greek sample and the highest in the German sample.

Table 79: Principle reason for caring (in %)

Type of reason	Total N = 5,855	Germany N = 994	Greece N = 1,012	Italy N = 986	Poland N = 1,000	Sweden N = 882	UK N = 981
Emotional bonds	57.3	45.2	57.1	71.2	47.5	72.0	52.8
A sense of duty	14.7	16.6	15.8	11.2	22.0	8.3	13.3
A personal sense of obligation	13.4	17.9	14.4	6.5	21.1	6.9	12.9
Caring makes me feel good	3.5	3.6	2.6	3.3	1.8	4.9	5.0
There was no alternative	3.1	6.1	4.7	1.7	2.1	1.1	2.5
Elder would not wish any one else to care for them	2.1	2.9	1.9	1.3	1.4	1.8	3.3
I found caring by chance	2.1	1.9	2.1	1.7	1.1	1.6	4.4
Religious beliefs	0.7	0.5	0.7	0.8	1.3	0.2	0.7
The cost of professional care too high	0.6	1.7	0.6	0.5	0.2	0.1	0.3
Economic benefits for both	0.4	0.6	0.1	0.1	0.8	0.0	0.6
Other	2.1	3.0	0.0	1.7	0.7	3.1	4.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

As shown in table 80, a large group of carers is willing to increase the level of care when asked whether they were willing to continue to provide care in the next year (69 % of the total sample – two first categories combined). However, while in 4 out of 6 national samples (Greek, UK, Polish and Italian), a big amount of carers (71-76 %) are willing to consider increasing the amount of care, in the Swedish and in the German sample only 62 % and 57 % of the carers are willing to continue care in this way.

The second group of carers (24 % in total) chose the answers *"Yes, I am prepared to continue care if the situation remains the same"*. The percentage of carers, who make such a choice, differs from country to country. In 4 national samples, (Italian, UK, Greek and Polish) the percentage of carers who are willing to provide care to such extend, reaches almost the same level (19-21 %), but in the Swedish sample it rises to 29 % and in the German sample up to 36 %.

The third and smallest group of carers wish to decrease the level of care (answers *"Yes, but only with more support"* and *"No, no matter what extra support I receive"* combined) and do not exceed 7 % of the total sample (5 % in the Italian sample, 9 % in the German sample).

Table 80: Carer's willingness to continue to provide care in the next year (in %)

Type of answer	Total N = 5,890	Germany N = 997	Greece N = 1,008	Italy N = 984	Poland N = 1,000	Sweden N = 914	UK N = 987
Yes, and I would even consider increasing the care I give if necessary	60.9	41.0	68.5	70.0	65.6	51.6	68.5
Yes, and I would increase for a limited time	8.3	15.8	2.8	6.2	9.3	10.0	6.0
Yes, if the situation remains the same	24.0	35.7	19.8	18.8	21.4	29.2	19.4
Yes, but only with more support	5.8	6.3	8.2	4.2	2.8	8.1	5.1
No, no matter what extra support I receive	1.0	1.2	0.7	0.8	0.9	1.1	1.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Considering the elder's placement in a care home may be a sign of carer's burden. In the total sample, almost 59 % of the interviewed carers would never consider their cared-for elderly placement in a care home, regardless of circumstances (see table 81). There are huge differences in the carers' attitude to that question since most carers think in this way in the Polish and in the Greek samples, whereas only 13 % of carers reject this option in the Swedish sample.

Also, a large percentage of carers consider senior's placement in a care home, if senior's condition get worse (37 %). Most carers in the Swedish and in the German sample responded in this way.

Table 81: Carer's consideration of the placement of the cared-for older person in a care home (in %)

Type of answer	Total N = 5,567	Germany N = 898	Greece N = 994	Italy N = 943	Poland N = 997	Sweden N = 816	UK N = 919
No	58.7	43.4	81.0	67.1	86.9	13.2	50.6
Yes, but only if elder's condition gets worse	36.9	53.7	17.7	31.6	11.6	70.3	44.6
Yes, even if elder's condition remains the same	4.4	2.9	1.3	1.3	1.5	16.5	4.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

5.3.2.6 Health status and quality of life of family carers

Carers' health status was assessed by using a self-evaluation 5 points scale (see table 82). Generally, carers most often reported their health status as being *"Good"* followed by the *"Fair"* category. Carers who estimate their health as *"Excellent"* or *"Very good"* combined represent over one fourth of the sample, while carers with a *"Poor"* health status are fewer.

Again, there is large variation between national samples. For example, the "healthiest" carers, i.e. who answered *"Excellent"* or *"Very good"*, are more likely to be found in the UK sample (42 %), in the Greek sample (32 %) or in the Swedish sample (29 %). This category of carers is the smallest in the Polish and in the Italian samples (15 % and 16 % respectively). As a consequence higher percentages of carers whose health status is not good (the categories *"Fair"* and *"Poor"* taken together) are to be found especially in the Polish and in the Italian sample (51 % and 43 %).

Table 82: Health status of carers (in %)

Health status	**Total N = 5,870**	**Germany N = 992**	**Greece N = 1,002**	**Italy N = 988**	**Poland N = 995**	**Sweden N = 918**	**UK N = 975**
Excellent	6.8	4.2	6.8	2.7	2.7	10.7	13.9
Very good	19.1	18.3	25.0	13.0	11.9	18.4	28.2
Good	38.6	53.0	35.9	41.5	34.8	34.3	31.4
Fair	29.4	21.5	26.4	37.4	39.2	31.3	20.7
Poor	6.1	3.0	5.9	5.4	11.4	5.3	5.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Finally, the quality of life of carers was assessed and is described in table 83 below.

The most frequent response in the total sample was *"Good"* quality of life. When combining the two categories ("Very good" and "Good") in the national samples, most British and Swedish carers (67 % and 65 % respectively) report good or very good quality of life. On the other hand, there are fewer responses in this combined category in the Mediterranean country samples.

The second most often chosen answer is the *"Neither good nor poor"* answer. The percentage of carers who chose this answer varies from 24 % in the UK sample to 40 % in the Greek and the Italian sample.

Fewer people (8 % of the total sample) report "poor" and "very poor" quality of life (ranges form 6 % in the Polish sample to 10 % in the Greek sample).

Table 83: Quality of life of carers in the last two weeks preceding the interview (in %)

Quality of life	**Total N = 5,911**	**Germany N = 1,002**	**Greece N = 1,012**	**Italy N = 988**	**Poland N = 999**	**Sweden N = 915**	**UK N = 995**
Very good	10.8	6.4	11.1	5.9	6.8	16.6	18.6
Good	46.8	49.2	39.1	45.5	51.0	48.2	48.1
Neither good nor poor	34.2	37.9	39.8	40.4	35.8	26.7	23.8
Poor	6.8	5.5	8.4	7.0	5.2	7.7	6.9
Very poor	1.4	1.0	1.6	1.2	1.2	0.8	2.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Information on carers' psychological well being was gathered using the World Health Organisation-5 Well-being Index[6]. This Index was dichotomised to produce two groups, one of them consisting of carers reporting worse quality of life and the other of carers reporting better quality of life. The results are shown in table 84 below.

The Greek and Italian sample have the highest percentage of carers reporting worse quality of life. In the other countries, carers report better quality of life, with the highest proportion observed in the Swedish sample (62.1 percent). These results are highly correlated with the overall quality of life that is described above.

Table 84: WHO-5 Well-being Index (dichotomized)

WHO-5	Total N = 5,880	Germany N = 997	Greece N = 1,011	Italy N = 985	Poland N = 994	Sweden N = 904	UK N = 989
Worse quality of life	49.8	44.3	64.8	62.8	47.2	37.9	40.3
Better quality of life	50.2	55.7	35.2	37.2	52.8	62.1	59.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

The Cope Index is an instrument that can measure the impact in carers of older people. 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 care-giving relationship. Therefore seven items like "…care-giving cause difficulties in your relationships with friends" or "…feel trapped in your role as a caregiver" were summed up to build the "negative impact"-scale and four items like "…cope well as a caregiver" or "…find care-giving worthwhile" were summed up to build the "positive values"-scale[7].

In the following table 85 the two scales were dichotomized by median-split. In the total sample more than half of the carers reported a higher burden while approximately 40 % also mentioned the positive value of care-giving. In the Greek sample the percentages of those carers with higher negative impact (73.3 %) is clearly higher than in the other national samples. On the other side, the Polish sample has the lowest proportion (30.2 %). Looking at the positive value scale, the German sample had the lowest percentages (22.2 %) with higher positive value followed by the Italian sample (32.5 %). All other countries come up to more than 40 % in this category. It is interesting to see that in the Greek and in the Swedish sample, higher negative impact corresponds with higher proportions on the positive value scale.

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[6] The well-being Index is a five item scale in which each item addresses an aspect of psychological health over the previous two weeks like "… I have felt calm and relaxed" or "… I woke up feeling fresh and rested". The participant were asked to record how they have felt on a six-point scale, anchored by "all of the time" (6) and "at no time" (0). The five items were summed to produce the Well-being Index with a theoretical range of 0 to 25 (highest well-being). For References, the single items and a detailed description of scale construction see chapter 3.

[7] For References, the single items and a detailed description of scale construction see chapter 3.

Table 85: **COPE-Index: negative impact and positive value for carers (dichotomized)**

Negative impact	Total N = 5,847	Germany N = 993	Greece N = 995	Italy N = 981	Poland N = 993	Sweden N = 908	UK N = 977
Lower impact (7 to 10)	46.0	44.8	26.7	40.6	69.8	38.9	54.7
Higher impact (11 to 28)	54.0	55.2	73.3	59.4	30.2	61.1	45.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Positive value	**Total N = 5,783**	**Germany N = 980**	**Greece N = 998**	**Italy N = 957**	**Poland N = 991**	**Sweden N = 884**	**UK N = 973**
Lower (4 to 14)	60.8	77.8	55.3	67.5	52.1	53.7	58.3
Higher (15 to 16)	39.2	22.2	44.7	32.5	47.9	46.3	41.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

5.4 Summary of Findings

This chapter aimed in presenting the profiles of the two groups involved in the caring situation: the old family members needing support / care as well as their main family carers.

Cared-for elderly people

The cared-for elderly people of the sample, are on average almost 80 years old and are mostly females. They are mainly widowed (apart from the Swedish sample where the group of married / cohabiting is the biggest). Up to a large extent every national sample is homogenous as far as the elderly people's ethnic origin and nationality are concerned, with the exception of the UK sample. The vast majority of the cared-for elderly people receive a pension or some other kind of state funded financial support. Almost 93 % of the elderly people live at home, over two third of the elderly people do not live alone (usually they live with their partners or / and with their children).

Physical illness / physical disability is the most often declared main reason for care towards the elderly people. Almost half of the elderly people have memory problems and over one fourth suffers from some behavioural problems. Only every tenth elder is independent in carrying out most activities of their daily living. Therefore, most elderly people are dependent on their family members, neighbours and available services for carrying out daily activities.

Family carers

The mean age of carers is 55. Almost every second carer is a child of the cared-for person, followed by the spouse / partner of the cared-for person (22 %). In the Swedish sample the spouses / partners of the cared-for elderly people are more often family carers than their children. The amount of female family carers is on an average 3 times bigger than that of male carers.

Carers constitute homogeneous groups in each national sample as far as their ethnic origin and their nationality is concerned (with the exception of the UK sample where about 9 % are from different nationality and ethnic origin)

Almost ¾ of the total number of carers belong to main stream religions or religious denominations (from 51 % in the Swedish sample to 96 % in the Polish sample). The degree of religiosity varies in the total sample as well as in the national samples.

In the total sample, the biggest group of family carers attained intermediate level of education (57 %), even though there are differences within the national samples (e.g. in the Greek sample: 41 % and the UK: 69 %).

The percentage of the employed carers is 41 %. The main sector of the carers' employment is the public sector, followed by the private sector. Quite a large number of carers (in total 15 %) had to reduce the amount of their working hours because of caring for elder relatives (the vast majority of them experience the negative income effect because of such reduction)

Most of the non-working carers are retired, yet this percentage ranges from 35 % in the Greek sample up to 91 % in the Swedish sample. Over ¼ of non-working carers perceived themselves as housewives / househusbands with variations between national samples (54 % in the Greek sample and only 1.4 % in the Swedish sample). Many carers bear some additional costs because of the caring process, for example the cost of medicines or costs due to additional travelling.

Almost 75 % of carers are married / cohabiting, and 80 % of them have children.

The average size of the carers' household including the carer himself / herself is, on average, approximately 3 people per household; the largest households are in the Polish sample (nearly 4 people) and the smallest are in the Swedish sample (2 people).

Objective and subjective questions were used to describe the general caring situation and the possibilities of care.

Apparently, over 1/3 of carers in the total sample not only care for an elderly person, but also for someone younger. This proportion reaches 60 % for the carers of the Greek sample and is limited to 9 % in the Swedish sample.

Over half of the carers live in the same household or in the same building as the cared-for persons. Every fourth carer in the whole sample live in longer distance and need at least 10 minutes by car, bus or train to get to the cared-for person.

The average duration of the caring period is 60 months in the total sample, and varies from 47 months in the German sample up to 70 months in the Polish sample.

"Emotional bonds" (i.e. love and affection) is reported as the principle reason for caring by most carers in the total sample (57 %). There are some differences within national samples. Less often mentioned reasons are the *"Sense of duty"* (15 %) and the *"Personal sense of obligation"* (13 %). Only a small percentage of carers *"Had no other alternative"* than to care for the elder (3 %).

Approximately 70 % of the carers respond as willing to increase the level of care for the cared-for older person in the next year. Also, 59 % of the interviewed carers in the total sample would never consider placement of their cared-for elderly people in a care home, irrespective of circumstances. Looking into findings from the national perspective, most carers think as above in the Polish and in the Greek samples, while in the Swedish sample only 13 % of carers reject the option of care home placement.

When carers report on their health status, *"Good"* health level is mentioned most often, followed by the *"Fair"* category. The "healthiest" carers, i.e. who answered *"Excellent"* or *"Very good"*, are more likely to be found in the UK sample (42 %), and in the Greek (32 %) and the Swedish (29 %) samples. There seem to be less carers of this category in the Polish (15 %) and the Italian (16 %) sample.

Finally, as far as carers' quality of life in the last two weeks preceding the interview is concerned, the highest reported level of quality of life is found among the samples of the British and the Swedish carers (67 % and 65 % respectively), and the lowest in the Mediterranean country samples: in Greece (50 %) and in Italy (51 %).

6 Typology of care giving situations in Europe: a cluster analysis approach

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6.1 Aims of the chapter

Each interview conducted with a caregiver represents a specific relationship to the cared-for that is embedded in further relevant informal and formal social relationships. If you want to abstract from each individual case and combine comparable cases into groups that, in turn, each represent different possible constellations, you require a listing of characteristics. Here, you have to be modest regarding the number of characteristics, their degree of differentiation, and the dimension of time. Thus, what we have here at the moment is a snapshot of the care-giving situation at the specific time of the interview.

The catalogue of variables we use for our subsequent analysis consists of characteristics which were assumed, when designing the survey instruments, to be critical to the definition of a care-giving situation. Then and today the list of characteristics can surely be expanded, but there were and are limitations with respect to both the surveys and the analysis.

The following general aspects may be suitable to define care situations:

- Does the situation result in a significant burden on the caregiver's well-being?
  The burden experienced by the caregiver is an important aspect to be assessed. Research in the area of care-giving outcomes has repeatedly reported the clinically relevant consequences of giving care, in terms of both the caregiver's anxiety and depression (Barinaga, 1998; Macdonald & Dening, 2002; Marshall, 2001; Pinquart & Sorensen, 2003; Schulz et al., 1995; Vitaliano, 1997) and there is also evidence that care-giving may be an independent risk factor for mortality (Schulz & Beach, 1999).

- Is there an increased demand of financial / material support for the cared-for?
  This is another crucial aspect to be taken into consideration in evaluating a care-giving situation, since care-giving may have profound consequences on the available material resources of the carer (e.g. Covinsky, 1994), placing on him / her considerable additional burden.

- Can the caring be assumed by others if needed (sickness, downtime)?
  This aspect aimed at obtaining an indication of the caregiver's available social support, which is an important protective factor for keeping psychological balance / mental health (e.g. Zunzunegui et al., 2002).

- Is the caregiver working or not?
  This fact could be taken as a measure of involvement in extra-caring activities in combination with the correspondingly increased demands of care (incl. organizational demands). The demands of care can only be combined with work with great difficulty and it can be presumed that such a double burden affects both the physical and mental well-being of the caregiver. If caregivers work, they are often faced with a necessary reduction of working hours which brings about less chance of advancement and loss of income (Dallinger, 1997).

- Does the caregiver form a household with the elder?
  Many family caregivers, often together with the person they care for, are confined indoors because they have to be available around the clock. Consequently, they can rarely take part in social activities outside the home and thus do not have the opportunity of relaxing by taking part in leisure activities or talking to friends. They get more and more socially isolated and this could also be a factor that will increase the strain on the caregivers.
- Are caregivers and cared-for of the same generation or does the caring take place across generations?
  With different generations, diverging experiences have to be assumed (Mannheim, 1964; Höpflinger, 2004) that may manifest as a potential conflict in the relationship between caregivers und cared-for.
- Degree of impairment of elder?
  Studies show that the degree of impairment influences the caregivers' burden. In particular caring for individuals suffering from dementia leads to extreme physical and mental burden (Infratest 2003).
- How the caregiver perceives her / his own well-being?
  Perceived well-being will be related to a number of different factors, but it can be assumed that the caregiver perceived well-being will be influenced by the care-situation.
- For how long has this caring situation existed?
  The early stages of care giving (less than 2 years) can be a difficult period as the carer adapts to his / her role. Research evidence suggests that taking up the care role is a more burdensome period for a carer than the period when the care role is established.
- Do elder and caregivers live in an urban or a rural area?
  The carer's place of residence will influence not only the services and resources that can be accessed, but also the extensiveness of the informal social support network.

From this, we can develop a typology of care-giving situations that is to be understood as an explorative, simplified description that identifies cluster of similar care giving situations which differ as much as possible. Distributions are not aspired but rather a “control" variable for important differences of individually definable care-giving situations is created. Against this background, further questions can be analyzed, as, e.g., whether motivations to assume the care-giving role vary by care giving situations or with other variables.

Lastly, the typology of care situations can be helpful to solve or at least to control two problems which are relevant for all country comparison studies:

- there could be a bias because of different recruitment strategies in the countries (selection distortion) or / and
- country specific care structures could also affect the observed phenomenon, for example if in one country there is more intra-generational care or a higher occupation rate of caring women.

Both effects should be controlled if possible and could be managed different ways, depending on the research question and the variables that should be controlled. In our case we use a cluster analysis approach.

6.2 Methodology used to analyse the data

For clustering care-giving situations we took into consideration the following caregiver related variables (see also chapter 3): caregivers demographics as indicated by caregivers gender, educational level, working status and generation with respect to elder, and the characteristics of caregivers place of residence (i.e., location). We also took into consideration variables more strictly related to the care giving situation, namely duration of care, availability of help if ill and availability of help if in need of break.

As for the caregivers well-being, we included the perceived burden associated with care giving as indicated by the Cope Index's negative impact subscale (McKee et al., 2003, see also chapter 3), and measures of caregivers reported state of health and quality of life (World Health Organization, 1998).

As for the elder-related variables, we took into consideration elder's age and gender, elder / caregivers cohabitation status and whether the elder had a need for financial support. Measures of elder's functional disability were elder's cognitive status and IADL abilities.

Here, we have to take into consideration that some aspects should not be weighted more than others because they are included multiple times by the variables used. We have collected, e.g. for elder's functional impairment, several measures (IADL, Barthel-index), but only used one of them. Such multiple measurements may also occur with other characteristics that we could use.

A **dimension analysis** (factor) performed beforehand can offer insight in to the extent to which correlations between the selected characteristics exist, suggesting overlapping constructs. This applies to the reported state of health and the subjectively perceived quality of life of the caregiver. In this case, we have dropped reported state of health as an indicator and used the more general concept of quality of life for the cluster analysis. In other cases correlations also occur, e.g. between the fact that caregiver and the cared-for belong to the same generation and live in the same household. However, this correlation does not reflect a single underlying construct, and so both characteristics are used to create the care-giving situation. The same is true for measuring cognitive and functional limitations of the cared-for, as subgroups exist in which both characteristics do not co-occur.

Altogether 15 characteristics (see table 86) remain after this selection that reflect both metric and nominal scales. In such cases of “mixed" variables three strategies can be followed:

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

We have decided to use variant c) for this analysis, as we aspire a simultaneous typing for all characteristics, 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 cluster very intricate (and possibly difficult to interpret). However, we have to accept that variant c) leads to loss of information, as with the selection of the cutting points for 0 and 1 other – possible – differentiations are lost. In return we gain a much simpler model in which the selected characteristics with the same weights for the cluster separations are entered. The following table 86 shows the variables that are included in the analysis:

Table 86: Variables for the cluster analysis

ELDER	
Elder’s age	0 = 65-79 1 = 80-highest
Elder’s sex	0 = male 1 = female
Cohabitation status	0 = different houses 1 = same house
Cognitive status	0 = no cogn disorder or age assoc memory impairment 1 = behavioural disorder or probable dementia
IADL	0 = low to moderate iadl dependency 1 = more severe iadl dependency
Financial support	0 = no need 1 = need
CARER	
Carers educational level	0 = higher level 1 = lower level
Duration of care-giving	0 = up to two years 1 = more than two years
Working conditions	0 = non working 1 = working
Negative impact of caregiving	0 = lower impact_7 to 10 1 = higher impact_11 to 28
Quality of life	0 = worse qual of life_0 to 14 1 = better qual of life_15 to 25
Carers sex	0 = male 1 = female
Help if ill?	0 = Yes I could find someone 1 = I could find someone with difficulties or no
Generation	0 = not the same generation as elder 1 = same generation as elder
Place of residence	0 = rural 1 = urban
Not included (because of high correlations with “help if ill”)	
Help if break needed	0 = Yes I could find someone 1 = I could find someone with difficulties or no
Not included (because of high correlations with “quality of life”)	
Self-perceived health	0 = better health_1 to 3 1 = worse health_4 to 5

6.3 Main findings

6.3.1 Number of cluster

We have to take into consideration that with the 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 care-giving arrangements that are homogenous. To achieve this we have selected a cluster fusion procedure (Ward procedure) to provide information about the possible number of cluster first.

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

The inspection of the fusion table shows that with the change from six to five cluster 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 cluster are fused and form a new – comparatively heterogeneous – cluster. Thus, a solution with 6 cluster is to be seen as the limit of simplification possibilities (see table 87).

Table 87: Agglomeration schedule

Number of cluster	Heterogeneity in all cluster	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 cluster, a **discriminant-analysis** is used. It takes our 15 variables for separation of the six subgroups (cluster) and then tries to reproduce the individual group membership only on the basis of the 15 original characteristics. The degree to which this is successful can be interpreted as a quality factor for the cluster solution. The present cluster solution results in a rate of 81 % correctly classified cases. This relatively low value can be traced to the fact that in two of the six cluster only two out of three cases can be assigned to the “correct” (from the cluster solution) subgroup. The fusion procedure used here does provide good criteria for the number of possible cluster. Its disadvantages, however, are that objects (care-giving situations) that are assigned once cannot be “moved” to different cluster, even if after one cluster was enlarged an alternative assignment would make sense.

The necessary flexibility can be provided by adding a **non-hierarchical cluster-approach** (quick cluster in SPSS) in order to use the possibility of "re-sorting" this offers. The optimizing algorithm of quick cluster checks for each case whether the previous assignment from the hierarchical analysis is really best or whether with another assignment the homogeneity of the new target cluster is less affected than with the previous one.

Our newly arranged cluster now deliver 92 % correctly classified cases with the discriminant analysis based on the new classification, and the corresponding value in each individual cluster now reaches at least 85 %.

6.3.3 Description of cluster

The description of the different care giving situations is at first performed with few characteristics and then, step by step, with the entire listing of characteristics used for this clustering, to determine the characteristics that best define the cluster. In the first step, a sorting is performed that at first shows the impairments of the cared-for (measured by functional IADL abilities and cognitive status of the cared-for) and in the second column (table 88) the subjective impairments (measured by negative impact of care giving and quality of life) of the caregiver in a sequence from “relatively high" to “relatively low" burden.

Table 88: Main characteristics of cluster

Cluster	Objective burden	Subjective burden	Generation	Working
1 (n = 946)	high	high		
2 (n = 937)	high	high		yes
3 (n = 838)	high	high	same	
4 (n = 436)	high	high	same	
5 (n = 943)	high	low		
6 (n = 1,266)	low	low		

In cluster 1 and 2 the reported objective impairment of the cared-for, as well as the subjectively perceived burden of the caregiver, dominate (table 89). As compared to cluster 1, in cluster 2 most care-giving women are working and they mostly have a higher education. Cluster 3 and 4 mainly include couples, but cluster 4 consists primarily of men caring for a female partner, while cluster 3 consists of women giving care to their male partners. Here, the relevant actors are members of the same generation and live in the same household.

Cluster 5 displays the special characteristic that the subjective burden strain is perceived as comparatively minor, with a very small proportion of caregivers reporting high negative impact from care-giving, while most report a good quality of life. This appears in contrast with the higher functional – but only average cognitive – disability showed by elders in this cluster. The relatively large group 6 includes those care giving situations in which the cared-for does not show severe IADL impairment and in the lowest percent of cases report a cognitive impairment. Only a minority of caregivers in this cluster show a higher negative impact from care-giving while the majority reports a better quality of life. In this group, most of the caregivers are able to combine care giving with work.

The need for additional financial support for elder generally varies with the subjectively perceived burden of the caregiver. A closer look at the fusion steps has shown, however, that the second group before the last combination existed of two cluster that could only be differentiated with this variable. Thus, it has to be taken into consideration when characterizing this care-giving situation that the additional financial need was only voiced by a subgroup.

In groups 3 and 4 the cared-for are usually relatively younger. Older cared-for persons can be found more often in the care-giving situations formed by the first two cluster, and to some extent in cluster 5.

In general, alternatives for support in case of sickness of the care-giving person are only reported by caregivers from the last two care-giving situations. In all other care-giving cluster the majority of caregivers (from 57 % to 73 %) does not have such possibilities.

To summarize: We found two situations (cluster 1 and 2) where the caregivers have high objective and subjective burdens and the two cluster differ in so far as the caregivers are not working in the first cluster; both cluster are about the same size. Then we have two situations where “spouses” care for each other and they also have subjective and objective higher strain (cluster 3 and 4), and differ only in the fact that one cluster consists of caring women (cluster 3) and the other one of caring men (cluster 4). The latter is also the smallest cluster in our sample. In our final two cluster support is available to caregivers if they need it (cluster 5 and 6). The cluster differ in the fact that cluster 5 has objective burden but no subjective burden, while cluster 6 has relatively little subjective and objective burden; this last cluster is also the largest in our analysis.

Table 89: Characteristics of cluster

Cluster	Carer related variables									Elder related variables					
	Gender: % female	Education: % lower	Working status: % working	Generation: % same	Place of residence: % urban	Caregiving duration: % > 2 years	Help if ill: % only with difficulties or no	Negative impact: % higher	Quality of life: % better	Gender: % female	Age: % 80+	Cohabitation status: % same house	Financial support: % needed	Cognitive status: % higher impairment	IADL abilities: % higher impairment
1 (n = 964)	89.9	34.7	0.6	3.4	63.9	70.9	69.4	92.4	22.7	85.0	82.7	52.0	50.1	74.3	90.4
2 (n = 937)	81.2	**9.8**	**99.2**	2.0	75.4	62.7	56.9	95.4	32.9	77.4	55.6	35.3	49.1	71.7	81.9
3 (n = 838)	99.3	47.7	5.7	97.3	67.8	71.8	72.9	71.0	35.8	1.9	30.7	91.5	35.6	58.7	78.8
4 (n = 436)	**3.4**	35.1	3.9	**86.9**	75.7	73.2	72.7	57.3	53.2	**96.6**	23.4	92.4	47.0	44.5	69.3
5 (n = 943)	76.5	14.7	50.9	4.4	64.6	62.7	26.5	5.2*	77.3*	74.1	67.9	29.8	28.2	48.3*	99.8*
6 (n = 1,266)	72.9	14.5	60.2	8.0	69.6	53.1	**28.9**	**14.7**	**73.0**	77.1	40.8	21.1	15.8	**17.5**	**0.0**

Highlighted in bold: main characteristics.

* Contrast: lower subjective burden and higher objective burden.

6.3.4 Distribution of cluster in the six countries

If you look at the distribution[8] of cluster in the six countries it becomes apparent that care-giving couples occur almost twice as often in Sweden than in the other countries (cluster 3: SW = 30.7 % vs. GR = 13.8 %, I = 9.2 %, UK = 14.5 %, Pl = 12.8 %, GE = 14.8 %; cluster 4: SW = 16 % vs. GR = 5.0 %, I = 5.3 %, UK = 10.0 %, Pl = 7.2 %, GE = 6.2 %), which is, at the same time, the biggest country-specific characteristic. In Poland, a focus lies on those two care-giving situations that feature the least subjectively perceived burdens (i.e. cluster 5 = 24.5 % and cluster 6 = 32.2 %). The distribution in the UK looks more or less like the Polish one and the cluster with relatively low subjective and objective burdens occurs most often (cluster 6 = 30.7 %).

Southern Europe, represented here by Greece and Italy, shows a high percentage in the first two groups in which both the objective and the subjective burdens are above average (cluster 1: GR = 24.4 %, I = 25.4 % vs. UK = 14.6 %, SW = 8.2 %, Pl = 13.9 %, GE = 19.7 %; cluster 2: GR = 26.5 %, I = 21.9 % vs. UK = 11.9 %, SE = 15.3 %, Pl = 9.5 %, GE = 19.5 %). Germany displays all types of situations at a relatively equal magnitude.

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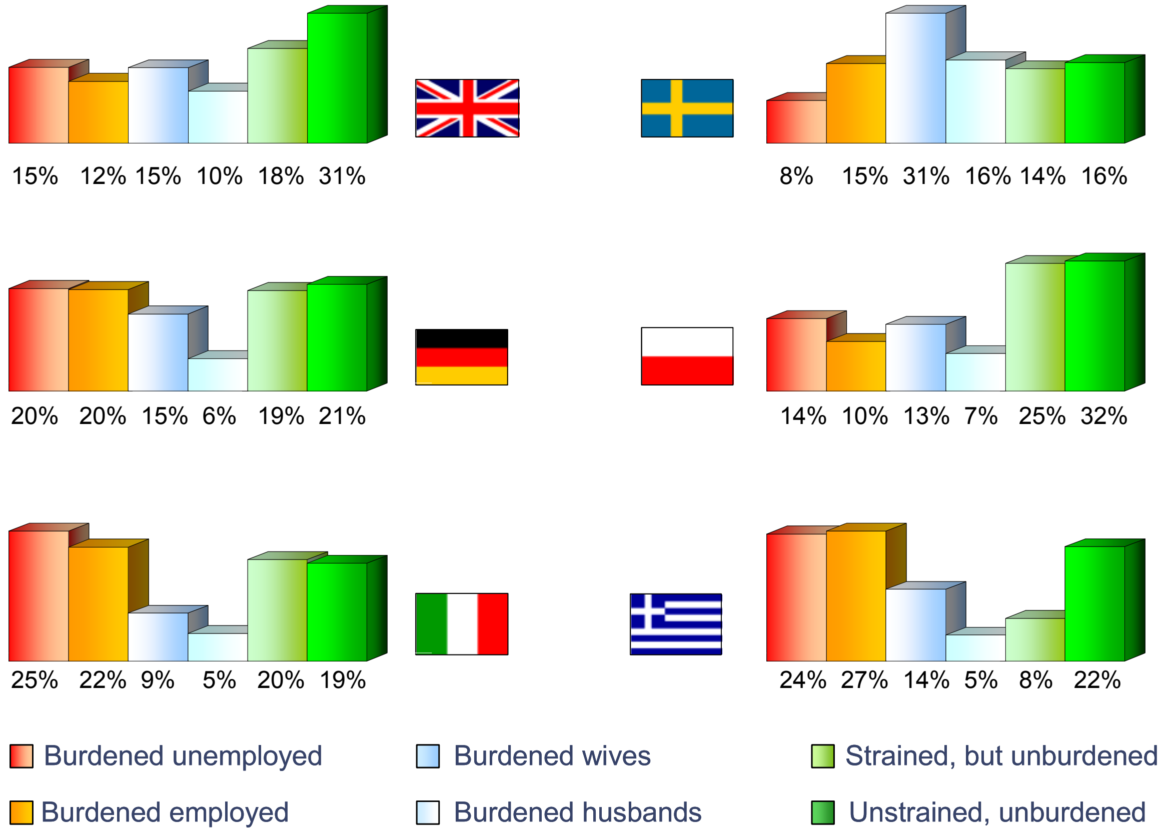
[8] Again, it is to be noted that the distribution of the individual cluster in the countries does not necessarily represent the actual distributions in these countries due to different recruiting strategies and representativeness. However, these cluster allow – independent of the marginal distribution – the comparison of countries.

Figure 2: Care situations in the six countries



These country-specific differences in care-giving situations first of all display the structure of local opportunities and chance events. Beyond this, however, they could be attributed to differences in the survey designs, sampling and recruitment strategies. The magnitude of these two possible effects cannot be separated. They can however be simultaneously controlled within country comparisons on other variables, e.g., we are able to view other care-relevant variables or system differences between the countries independently of local chance structures or country-specific requirements for the survey. Examples of this approach follow.

6.4 Care situations and motivations for caring and future care

6.4.1 Motivations

To show how the cluster could work in a country comparison we used the question about motivation for care-giving. In table 90 we see the distribution of the motives by country. Emotional bonds or a sense of duty are mentioned in all countries from a high number of carers. In general, the intrinsic motives like “emotional ties” (94.5 %), “a sense of duty” (81.4 %), “personal sense of obligation” (80.6 %) and “caring for elder makes me feel good” (74 %) dominate and more extrinsic motives are less mentioned. As most intrinsic motives are, generally speaking, positive statements one has to expect a considerable effect of social desirability contributing to the dominance of intrinsic motives over possible extrinsic motives. To avoid this problem or “bias” (social desirability) countries’ relative position on each motive dimension can be established, i.e., the distinctiveness of each country's motive to care relative to other countries can be determined within comparable care giving situations (cluster).

Table 90: Motivations for care giving

Motivation	Greece	Italy	UK	Sweden	Poland	Germany	All
emotional bonds (love, affection)	96.8	96.3	90.5	96.6	94.1	92.6	94.5
a sense of duty	89.3	73.3	79.5	67.7	91.6	85.8	81.4
personal sense of obligation towards elder as a family member	91.4	57.4	75.6	73.6	93.7	90.9	80.6
caring for elder makes me feel good	81.5	56.4	61.9	83.4	77.2	84.2	74.0
elder would not wish anyone else to care for them	43.5	45.4	62.9	46.1	53.6	62.1	52.3
there was no alternative	53.2	30.3	46.0	45.5	45.4	64.4	47.6
I found myself caring by chance without making a decision	37.8	31.5	61.5	65.3	32.3	29.5	42.7
my religious beliefs	40.0	38.0	22.6	8.2	67.7	24.7	33.9
cost of professional care too high	43.8	31.1	30.2	14.8	34.4	45.1	33.5
economic benefits for both caregiver and elder	8.0	4.3	8.7	13.2	8.1	12.3	9.1

With help of a dimension (factor) analysis we combined original 10 care motivations into the following five (independent) dimensions (table 91). Doing so we can identify on a European level five different groups of motives that have caused the caregiver to assume the care role:

Table 91: Factor analysis for motivations of care[9]

A sense of duty	▪ A sense of duty ▪ Personal sense of obligation towards elder as a family member
Externally determined	▪ Elder would not wish anyone else to care for him ▪ There was no alternative ▪ I found myself in these circumstances almost by chance without making a decision
Strong emotional ties	▪ Emotional bonds (love, affection) ▪ Caring for elder makes me feel good
Religious beliefs	My religious beliefs
Financial advantages and / or prevention of financial disadvantages	There were economic benefits for me (carer) and / or elder

In the different care situations (cluster), the motivations based on religious beliefs or finances do not differ in a noteworthy way.[10] For emotional ties and duty you find a trend in which the sense of duty increases with the degree of the caregivers' subjective burdens, in contrast, the emotional ties tend to lose importance. The greatest differences between the six cluster arise when the care does not require additional motivation because the situation simply demanded it ("no alternative solution"). Such constellations occur more often in care-giving situations accompanied with higher objective and subjective burdens.

Countries can now be compared on the five care motivation dimensions within comparable care situations (cluster). The meaning of a motive is emphasized below, if it is more pronounced in one country than in others across a number of care giving situations. We then speak of country specifics or motive structures. Thus, in this case we are not concerned with the motives that are stated most often in absolute terms, but those stated more often in comparison with other countries.

Religion plays a prominent role in Poland, whereas sense of duty is also stated more often (see table 92). As these patterns can be noticed in all care situations it constitutes a Polish characteristic. Duty is the strongest motivation in Greece, while there the religious background is not especially pronounced.. In Italy we found no relatively dominant motive. That doesn't mean that there is no motive for care. It means only that there is no motive relatively more mentioned in comparison with the other countries.

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[9] The motive for care "The cost of professional care would be too high" was not assignable because we chose a statistical approach. Theoretically, one could argue to assign this motive either to "financial" or to "no alternative" (ext. determined). But from a statistical point of view, this item had only low value (weights) for the factor "financial" as well as for "ext. determined". Due to this (statistical) reason, the low impact of this item to none of the factors, we chose to exclude the item "The cost of professional care would be too high" from the assignment to one of the dimensions.

[10] For the comparison we use the means of the factor scores.

Table 92: Care situations and motivation for care

Care situation	Poland	Greece	Italy	UK	Sweden	Germany
Subjective and objective high burden	▪ religion ▪ duty	▪ duty ▪ externally determined ▪ religion	–	▪ externally determined	▪ emotional bonds	▪ religion financial
Subjective and objective high burden, working	▪ religion ▪ duty	▪ duty	–	▪ externally determined	▪ externally determined	▪ externally determined ▪ financial
wives (women) with subjective a. objective high burden	▪ religion ▪ duty	▪ duty ▪ externally determined ▪ religion	–	▪ externally determined	▪ emotional bonds ▪ financial	▪ externally determined
Husbands (men) with subjective a. objective high burden	▪ religion ▪ duty	▪ duty ▪ externally determined ▪ financial	–	▪ externally determined	▪ emotional bonds ▪ externally determined ▪ financial	▪ duty ▪ religion
Subjective low and objective high burden	▪ religion ▪ duty	▪ duty ▪ emotional bonds	–	–	▪ emotional onds	–
Subjective and objective low burden	▪ religion ▪ duty	▪ emotional bonds	–	–	▪ emotional bonds	▪ financial

Typical for the UK compared with all other countries, the motive “externally determined” was pronounced in the four cluster with higher subjective burden, perhaps expected in a country with weaker familiar ties than in some of our other countries, and where the welfare states does not provided their enquired level of support. We found the motive “financial” (economic benefits) relatively prevalent in Sweden, especially for caring spouses. Germany shows mixed motives but as in Sweden here the “financial” motive plays a special role. It is interesting that in Sweden and Germany, both relatively wealthy countries, financial reasons are stated more often than in other countries. Sweden is the country where “emotional bonds” is most pronounced across care situations, it should be recalled, however, that in this country very many care-giving situations were found with couples from the same generation, a situation in which it is to be expected that emotional ties will often be the motivation to assume care. For this reason, it is advisable to perform country comparisons within the different care-giving situations to see that not only couples stress this motive.

- **Care situations 1 and 2 (higher objective and subjective burden)**
  No alternative solutions (“externally determined”), because the cared-for does not want anyone else to care for him / her or because the caregiver him / herself was suddenly in a position to require care, seem to have occurred as a motive for care more often in the UK. In Poland and Greece, a perceived duty to care is a comparably strong motive. The

care motivation "finances" for Germany, which seems to be relatively important in these care situations and is possibly an effect from the material transfers of the German compulsory long term care insurance, is especially pronounced.

- **Care situations 3 and 4 (Couples from the same generation)**
  As was to be expected due to the dominance of caring spouses in the Swedish sample, “strong emotional ties” as a pronounced care motivation in Sweden is not only restricted to these cluster, but is also emphasized in other care situations. This is specific to this country. In addition, the financial motivation to care is stated in Sweden as well, this, however, is pronounced only in these cluster, representative of care-giving couples. In the other countries we found for these cluster more often were notable for the dominance of the care motives “sense of duty” and “externally determined”. Remember that the item “elder would not wish anyone else to care for them” loaded on this dimension It may be understandable that especially couples endorsed that item as a principal care motive.
- **Care situation 5 (higher objective but lower subjective burden)**
  ”Externally determined” is, for this and the following care situation, no longer a pronounced care motivation in the UK. Caregivers with a religious motivation to care are most pronounced in Poland in this care arrangement, while a sense of duty as a care motivation is less emphasized. In Greece, the care motivation “strong emotional ties” is at the same level of dominance as in Sweden in this care situation.
- **Care situation 6 (lower objective and subjective burden)**
  “Strong emotional ties" as a care motivation is again pronounced in Greece and Sweden. As in the first two care arrangements (cluster 1 & 2) with higher burdens, financial motivation is emphasised as the care motivation in Germany in this care situation.

As for care motives in general we found that intrinsic motives are the most frequently mentioned motives across all countries. But there also appear to be trends related mostly to countries rather than care situations. So three of our countries are rather homogenous in their country-specific motive-structures: Poland with “religion” and “duty”, Sweden with “emotional bonds “ and the UK with “externally determined” – the latter at least in the four care situations defined by higher burden. In Germany and Greece rather heterogeneous care motive patterns emerge as, depending on the care situation, different motives are relatively pronounced. It seems that strong cultural values regarding care giving exist in countries like Poland, Sweden and the UK (and to some extent Greece) which influence all care giving situations, whereas it is only marked in Germany that aspects of specific care situations have great influence on the motivation to provide care.

6.4.2 Future care

Which prospects do family caregivers see for their future care work? We gathered answers for this question under 2 possible development scenarios (see table 93 with selected answer options): a) in the next year the caregiver is willing to provide care to the elder and b) the carer is prepared to consider elder’s placement in a care home.

The willingness to expand care if necessary is of importance because in many cases this may be necessary in the future. The majority of family caregivers are willing to do this, the corresponding percentage in care situations with low subjective burden is at 70 % (cluster 5 und 6) and for caregivers that care for a relative of the same generation it lies between 60 % and 70 % (see table 93). If you add those that state their willingness to expand care for a restricted period, than in the first two cluster, those that are characterised by higher burdens and intergenerational relationships, approximately 60 % of caregivers are willing to do so.

Table 93: Future care: % of answers

Care situation	a) In the next year, are you willing to continue to provide care to ELDER?* b) Would you be prepared to consider ELDERS placement in a care home?**	Total	Greece	Poland	Italy	UK	Germany	Sweden
1	a) Yes, and I would even increase	53	61	53	61	55	37	35
	a) Yes, I would increase for a limited time	9	3	8	9	6	14	17
	b) Yes, despite from elder’s condition	40	19	22	32	65	56	90
2	a) Yes, and I would even increase	49	57	58	63	48	26	37
	a) Yes, I would increase for a limited time	11	2	13	5	17	22	13
	b) Yes, despite from elder’s condition	51	29	23	45	71	67	95
3	a) Yes, and I would even increase	60	79	60	70	73	43	49
	a) Yes, I would increase for a limited time	7	2	7	6	3	12	10
	b) Yes, despite from elder’s condition	43	13	15	28	43	48	79
4	a) Yes, and I would even increase	67	59	61	76	80	46	69
	a) Yes, I would increase for a limited time	5	5	7	2	2	13	4
	b) Yes, despite from elder’s condition	44	9	17	29	46	44	79
5	a) Yes, and I would even increase	68	81	72	76	73	51	58
	a) Yes, I would increase for a limited time	9	0	10	6	5	13	13
	b) Yes, despite from elder’s condition	36	12	7	35	44	56	95
6	a) Yes, and I would even increase	71	78	73	84	75	45	63
	a) Yes, I would increase for a limited time	8	4	10	5	4	18	9
	b) Yes, despite from elder’s condition	34	17	8	22	43	56	94

* The complete answer categories are: Yes, and I would even consider increasing the care I give if necessary / Yes, and I would consider increasing the care I give for a limited time / Yes, I am prepared to continue to provide care if the situation remains the same / Yes, I am prepared to continue to provide care to elder but only if I have some more support (from services, family, friends etc.) / No, I am not prepared to continue to provide care to elder, no matter what extra support I receive.

** The complete answer categories are: No, not under any circumstances / Yes, but only if elder’s condition gets worse / Yes, even if elder’s condition remains the same as it is now. The two latter categories are added to the category “yes, despite fro elder’s condition” in this table.

Both Germany and Sweden diverge from this general pattern. In Germany, the willingness to expand the care tends to be stated less often, but a short-term expansion of the care effort is stated more often. This is especially the case for care situations with increased burdens and working caregivers (cluster 2). In Sweden as well, the possibility to continue care is seen by a below average number of caregivers in five of the six care situation types (exception: caring husbands from cluster 4).

The nursing home is an option for 30 % to 50 % of carers independently of the condition of the elder. This percentage varies, depending on the care situation. It is approx. 40 % with married couples and about 50 % if the carer is working (cluster 2). The most pronounced differences can then be found when comparing countries. In Sweden, it is an option that is considered often in all types of caring situations, in the UK more often in the first two caring situations (cluster 1 and 2) with increased objective and subjective burdens, and in Italy it is group 2 with the higher burdened working carers. As an overall picture, a structure is found in which only 7 % and a maximum of 45 % consider the option of a nursing home in Greece, Poland and Italy. In UK, Germany and Sweden across all types of care situations a minimum of 43 % and up to 95 % consider that option – the latter is found especially in Sweden with the carers of group 2 (high objective und subjective burden, working) but also with carers of group 5 and 6 where the well-being of the carers is relatively higher than in the other cluster.

6.5 Discussion

We have selected a method of analysis that identified a care giving typology consisting of a relatively low number of care situations derived from comparatively detailed information regarding individual care circumstances. Using this information, we display at the core burden differences for the individual caregiver and are able to differentiate intra and intergenerational care relationships. As another interesting cluster a care giving situation forms that – even though the elder is functionally more impaired – the caregiver perceives the care as less burdensome. At the same time, this situation is characterised by the fact that the caregiver can more easily find help for the cared-for (in the sense of replacement when they cannot do it themselves) than in other care situations.

The use of this typology allows for the "control" (as a statistical strategy) of the different distribution to these groups in country comparisons, e.g. more low burdened caregivers in Poland and the UK, more intra-generational care in Sweden and a greater number of high burdened caregivers in Greece and Italy. This is done by performing country comparisons within the individual cluster. Country-specific structures regarding the motivations, for example, are taken more seriously if they not only occur in one type of care situation that occurs often in one country and are the sole reason this country differs from others. Vice versa, this allows for specifics of a subgroup in a country to be emphasised that were not discovered in the overall view.

As might have been expected, the religious motive to care (in combination with a more pronounced "sense of duty") plays a more important part in Poland in comparison to other countries, but it is also important in Greece with wives who are in an intra-generational care situation and in the care situation of women with a low level of education (as in Germany, although there it is more pronounced with caring husbands). In the UK, assuming the care role is comparatively more often motivated by "externally determined" factors in care situations where stated burden is high. Swedish caregivers comparison to caregivers in other countries are more often motivated to care by "strong emotional ties", also the case for subjectively low burdened caregivers in Greece. Italy does not show specific structures in this country comparison, while in Germany a financial motivation to care is more pronounced than in other countries in three out of the four intergenerational care situations. All in all the country comparison shows that in case of motives for providing care cultural specific aspects of the countries have a greater impact than care situations in the majority of our countries.

With regard to caregivers' willingness to continue their caring role and to prevent institutionalisation of the cared-for, patterns of response in our countries fall into two distinct categories. If the burden due to the care situation increases for the carer because the health of the cared-for deteriorates only a small number of carers in Greece, Poland and Italy would consider a nursing home. In other countries, a higher number – in some a considerably higher number – of carers would do this. Whether this is due to the different availability of these institutions in the different countries or due to cultural norms for providing care is unclear.

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7 Experiences and Preferences of Family Carers in the Use of Care and Support Services

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7.1 Aims of chapter

This chapter describes the use of support services by family carers of older people in the six EUROFAMCARE countries. The information provided indicate **what kind of services are mainly used** by family carers and cared-for older persons detailing their experiences in using them, and also whether they receive **care allowances** and quantifying their amount. This includes an analysis of the **frequency** of service use, whether any **costs** have to be met by caregivers in order to use them, and, when used, the extent and degree of general **satisfaction** with them. A further section of this chapter focuses on the **types of support** that family carers identify as most "important", and investigates which of them are actually received. This information is integrated with data revealing the most useful **characteristics of services** in the carers' eyes, and whether these are currently met. **Services accessibility**, including their territorial availability, is a further key factor tackled in this chapter, differentiating between what carers experience both as the main obstacles and as the greatest help in accessing services, reasons for not using (needed) services (at all) or for stopping using still needed services. A final issue examines **service effectiveness**, in order to understand whether the use of a service really makes a "measurable" difference for family carers.

7.2 Methodology

The questionnaire used for the EUROFAMCARE survey, termed the Carers' Assessment Tool (CAT), included a section aimed at collecting detailed data on service use by the family carer and the older person cared-for by him / her (for details see section 2.8 in chapter 3). Specifically, a first group of questions collected information on the services used in the 6 months preceding the interview, asking the following: "what services have you / elder used?"; "does this service meet your own / elder's needs?"; "do you / does elder pay for this service?"; "how much do you pay per each service unit?"; "how often have you used it?". All these questions have been asked in each country using a national list of health and social care services likely to be used by older people as well as of support services for family carers, a list that has been explicitly developed for the project by all involved research teams (cf. National Survey Reports for further details). For comparative reasons, the "national" services (including care allowances, also based on national categories) were then re-classified into a **European classification** (see table 94 below), allowing comparisons of the cross-national data, discussed later in this chapter. This re-classification allowed the creation of **a first level** grouping of the services based mainly on the **care needs** covered by the different services (e.g. health care needs, personal care needs etc.); this criterion was revealed to be particularly useful in categorising the several care services addressing older people, while a simple distinction between "generic" and "specific" support services was sufficient for the (far less numerous) services addressing the needs of family caregivers.

Table 94: Categories of care services and allowances in the EUROFAMCARE countries

SERVICES USED BY FAMILY CARERS		
1. Specific support services for family carers	1.1 Socio-emotional support (counselling, social work, family support or self help groups, crisis management)	
	1.2 Respite care (including supervision of elder)	
	1.3 Information (about the disease, caring, available services and benefits, Help lines, Internet services etc.)	
	1.4 Training for caring	
	1.5 Assessment of caring situation	
	1.6 Other specific services for carers	
2. Generic services used by family carers	2.1 General hospital (acute care)	
	2.2 General Practitioner (GP)	
	2.3 Specialist doctor	
	2.4 Other generic services used by carers	
SERVICES USED BY ELDER (classified accordingly to the needs covered)		
3. Health care needs	3.1 General hospital (acute care)	
	3.2 Temporary residential health (not acute) care (Rehabilitation, Medical, Nursing)	
	3.3. Medical and nursing services	3.3.1 Ambulatory services (nurse, GP, medical specialists, diagnostic tests; day hospital; integrated assessment of elderly people etc.)
		3.3.2 Home based services (doctor at home, medical specialists at home, nurse at home, diagnostic tests at home, chiropodist, palliative care at home etc.)
	3.4 Rehabilitation services	3.4.1 Ambulatory services (physiotherapy, occupational therapy)
		3.4.2 Home based services (physiotherapy at home, occupational therapy at home etc.)
4. Physical or personal care needs	4.1 Home based personal care (bathing, toileting, hairdressing, nail care etc.)	
	4.2 Cohabiting / co-resident non-family (paid) carer	
	4.3 Privately paid non-family carer in temporary residential settings or in hospital	
5. Mobility needs	5.1 Transport services	
6. Emotional, psychological or social needs	6.1 Emotional, psychological or social support service	6.1.1 Ambulatory services (counselling, psychologist, recreational social centre etc.)
		6.1.2 Home based services (companionship, care attendant, respite care at home, counselling, help lines etc.)
7. Organizing and managing care and support	7.1 Organizational support services	7.1.1 Ambulatory social work (help in organising care etc.)
		7.1.2. Home based social work (visits at home etc.)
8. Domestic care	8.1. Home based services: Domestic (help with cooking, cleaning, shopping, laundry, meals on wheels etc)	

SERVICES USED BY ELDER (classified accordingly to the needs covered) (cntd.)		
9. Residential and semi-residential care	9.1 Permanent Residential Care (nursing homes, sheltered housing, old people's home, psycho-geriatric residences, palliative care hospices etc.)	
	9.2 Temporary residential care of social kind only (respite care etc.)	
	9.3 Day care centre with either health and social care purposes or both	
10. Other kinds of care	10.1 Technical equipment / aids / home environment adaptation (telemedicine, stair lifts, security systems etc.)	
	10.2 Other services used by elderly people	
CARE ALLOWANCES		
11. Financial support to older person	11.1 Disability-related allowance to older person	
	11.2 Care allowances to elder	11.2.1 Care allowance to older person from national state / social insurance
		11.2.2 Care allowance to older person from local authorities
	11.3 Other financial (fiscal etc.) benefits to older person	
12. Financial support to carer	11.4 Care allowances to carer	11.4.1 Care allowance to carer from a national, state, or social insurance scheme
		11.4.2 Care allowance to carer from local authorities
	11.5 Other financial (fiscal etc.) benefits to carer	

A **second, more detailed grouping level** was created on the basis of **which and how specific care needs were addressed** by the considered services. This level is particularly relevant in distinguishing between different kinds of health care (i.e. hospital, medical, nursing and rehabilitation care, including temporary residential care of this kind), personal care (differentiating organised assistance of "formal" services from the private care provided on an individual basis – at home or even in residential settings – by single care workers) and residential care (subdivided into permanent, temporary – of social kind only, to differentiate it from the health-based one – and semi-residential). A **third grouping level** was introduced to indicate, wherever possible, whether services are **delivered at home or on an ambulatory basis**, a distinction which has been especially relevant for health, socio-psychological and organisational care services.

With regard to **care allowances**, a primary level of distinction concerns the beneficiary (i.e. the dependent older person or the family carer), followed by a secondary level differentiating monetary transfers aimed at covering directly the disability risk itself (disability-related allowances) from those addressing the care needs deriving from it (care allowances) or other kinds of financial benefits (of fiscal or similar nature). A third, further classification criterion distinguishes care allowances provided by local authorities from those provided by the State (or a nationally relevant legislation scheme). In the following paragraph, however, analysis will be limited to the first level only (beneficiary of the allowances), in order to simplify the overall interpretation of the data collected with respect to care allowances.

It should be noted that services used by carers were collected separately from those used by older people, and interviewers were trained to ask carers explicitly to list only those "support" services which were relevant to them in their role as caregivers. This did not prevent some carers from indicating as relevant also "generic" health and social care services (i.e. "usual" services for the general population, e.g. GPs), especially when specific support services for carers were absent (which "normal", generic services compensated for). As a result, since it was not always possible to distinguish between a “care-related” and a “health or social related” use of generic services by family carers, a possible overestimation of the carers’ use of “generic services” might have occurred (since these might have been used simply for the carer’s personal health, with no direct relation with the caring situation).

Finally, it should be underlined once again that **comparative data in the field of care service provisions should always be interpreted with caution**, since the contents and meaning of single services are very much nationally defined, thus not always completely comparable across countries and within different care systems.

7.3 Main findings

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

The data collected through the EUROFAMCARE national surveys in the six involved countries permit one to build a comparative picture of the use of support services by family caregivers in Europe. Since however the presence and usage of such services throughout the different countries is not always widespread, these data are integrated with information on the use of “usual” health and social care services by the older people they care for. This is useful also in the light of the high interconnection existing between the two kinds of services, in terms of both users’ characteristics and their impact on the family carers’ condition, thus contributing to a better understanding of the overall situation. A further paragraph on this topic is finally dedicated to the care allowances available to both dependent older persons and their caregivers.

7.3.1.1 Services used by family carers

Initial information emerging from the EUROFAMCARE survey is that, on average, less than a third (30.2 %) of all family carers throughout Europe benefited, in relation to his / her caregiving experience, from at least one support service in the last six months (table 95). This corresponds to a mean value of almost 0.5 services per carer, thus revealing on the whole a quite **low rate of service usage** in the interviewed national samples. In a cross-national perspective, British carers seem to be able to count on a more diffuse service network, since over 40 % of them have used at least one support service in the last half a year, a value which is followed by that reached by their Polish and Greek colleagues, while all other countries show percentages just above 20 %.

Table 95: Which services do carers use? (by country, % values)*

Services used by family carers	Greece (N = 1,014)	Italy (N = 990)	UK (N = 995)	Sweden (N = 921)	Poland (N = 1,000)	Germany (N = 1,003)	All (N = 5,923)
Total % of carers using at least one service	34.6	21.4	41.6	22.3	38.2	22.2	30.2
Mean number of services used by carers	0.5	0.3	0.7	0.4	0.5	0.4	0.5
Specific support services for carers							
Socio-emotional support (counselling, social work, support or self help groups etc.)	0.2	1.2	7.9	10.7	0.9	8.1	4.8
Information (about disease, caring, available services and benefits, help lines, internet)	0.1	0.2	5.9	0.1	2.5	16.2	4.1
Respite care (including supervision of elder)	0.3	0.1	2.3	6.1	0.7	1.0	1.7
Training for caring	-	0.5	1.8	0.5	0.4	2.1	0.9
Assessment of caring situation	-	0.1	2.0	0.4	-	-	0.4
Other specific services for carers	0.1	0.4	1.1	2.5	2.6	-	1.1
Generic services used by family carers							
General practitioner (GP)	17.8	16.4	25.7	5.9	35.1^	0.8	11.1
Specialist doctor	13.3	4.5	3.1	2.0	^	0.5	4.0
General hospital	6.0	0.7	7.2	0.1	^	0.1	2.4
Other generic services used by carers	7.5	3.9	7.2	5.8	5.9	0.9	4.2

* The cross-national categories of services are based on the national lists of services (reclassified); service use is referred to the last six months.

^ In Poland all forms of counselling provided by doctors (as GPs, specialist or in hospital) are computed under “GP”.

Once we analyse what kind of support services family carers mainly use, it can be observed that the “core” is represented by **socio-emotional support services**, which comprise all forms of counselling, social work, self-help groups and similar initiatives explicitly addressing the pragmatic and / or psychological support needs of family carers. These services generally reach less than 5 % of all carers, but represent the most used service in Sweden (where they are delivered to over one carer out of ten), as in the UK and Germany (in the latter country they come second to information services), while on the contrary they remain quite rare (if not almost absent) in Italy, Poland and Greece.

Information services – which can in a sense be considered “instrumental” to other core support services – include all kinds of services aimed at providing information on the disease suffered by the cared-for persons, on which care services are available in the local area as well as on relevant care benefits and allowances, but also help-lines, internet services etc. This kind of service had been used on average by about one carer in 25 (4.1 %), a situation where cross-national differences are strongly present, Germany revealing a quite widespread diffusion of such services, in contrast to Greece and Italy, where they are quite absent (while in Sweden they often do not appear since they are often included in other types of health and social care services).

Respite care (in the project’s acceptation this included services that supervised the dependent older person as well as any other form of relief granted to the family carer) constitutes a further category of service belonging to the “core” of a support system for family caregivers. Its diffusion throughout Europe seems to be systematic only in Sweden (where over 6 % of carers benefit from it) and to some groups in the UK (2.3 %), while in all other countries no more than 1 % of the sample has the chance to profit from this kind of support.

Even less widespread appear to be programs and initiatives aimed at providing **training** opportunities for caregivers (to promote their ability to better tackle care-related difficulties and tasks) as well as at granting a systematic **assessment** of the caregiving situation (through the use of standardized, validated tools able to monitor and map the existence of possible support needs by the carers of dependent older people): both kinds of services are a “perceptible” reality only in the UK (for less than 2 % of cases) and in Germany (but only with regard to training).

A final remark in this regard has be granted to services that, although not being specifically addressed to the support needs of family caregivers, end up however to play this role in an indirect way. This is the case, in many countries, or the **general practitioner** (GP), who is felt by many carers as a real “support service” – in terms of counselling, information and, even if only partly, also emotional and psychological support – with percentages which reach particularly high levels in the case of Poland, the UK, Greece as well as Italy. This “substituting function” provided by generic services seems to be more widespread, with the only exception being the UK, in countries where specific support services for carers are mostly unavailable, and regards also further services such as different kinds of **specialist doctors** (especially in Greece) and **general hospitals** (where hospital stays might sometimes exert a possible “respite” effect on carers).

Through an analysis of the **frequency of service use** (table 96), it is possible to buttress the above remarks (although only partially, due to the low numbers for many items, and taking into account specific support services for carers only). In this respect, **socio-emotional** support services are on the whole more frequently used than **information services** (the percentage of carers using the first on a weekly basis embracing one fifth of the whole sample, compared to one tenth for the latter), but less often than **respite services** (which are used weekly in half of cases). In a cross-national comparison, the percentage of family carers using information and respite care services at least weekly is higher in the UK than elsewhere, Sweden reaching high frequency of use for respite care as well and Germany and Italy for socio-emotional supports. In this regard it should be finally mentioned that “generic” services – such as for instance the GP – are taken advantage of only very rarely by carers, who on average refer to it on a weekly basis in less than 2 % of cases (non reported data).

Table 96: How frequently are specific support services used by family carers? (Percentage of carers using services at least weekly, by country)*

Specific support services for carers	Greece	Italy	UK	Sweden	Poland	Germany	All
Socio-emotional support (counselling, social work, support or self help groups etc.)	*	33.3	20.0	12.3	*	23.3	20.2
Information (about disease, caring, available services and benefits, help lines, internet)	*	*	38.2	*	4.2	10.2	10.2
Respite care (including supervision of elder)	*	*	63.1	50.0	*	*	49.5
Training for caring	*	*	6.7	*	*	*	18.0
Assessment of caring situation	*	*	0.0	*	*	*	0.0
Other specific services for carers	*	*	*	21.1	30.8	*	30.6

* Percentages are indicated only if more than 10 cases are reported per service per country, and calculated on the total number of carers using that service in that country (cf. Table 95).

7.3.1.2 Services used by older people

As mentioned above, due to both the low availability / use of specific support services for caregivers and the strong interconnection between the situation of family carers and the use of care services addressing the dependent older person, it is appropriate to analyse the latter too in order to gain a comprehensive picture of support for family carers.

The information contained in table 97 shows that almost all older people (94.3 %) cared for by the family carers included in the EUROFAMCARE sample have used at least one care service in the last six months. This is true in particular for Italy, while almost one out of ten older persons in the UK and Germany have used no services at all. On average, this situation corresponds to a mean of 3.5 services used by each elder, with higher amounts (over four) in Sweden and Germany, and a much lower percentage in Greece.

With regard to the kind of **services** mostly used by older persons, and starting with those **addressing health care needs**, a central role is clearly played by **primary care services**, i.e. medical and nursing services delivered on an ambulatory basis or at home. With over 86 % of older persons receiving them, they represent the bulk of the care network available in all the studied countries, and seem particularly widespread in Italy and Poland (93-98 %) though a little less in the UK, Sweden and Greece (around 80 %). Although they are mainly provided on an ambulatory basis, in Poland and Germany, but also in the UK, there are significant proportions that are also home based delivered.. Acute care provided by **general hospitals** is a second “pillar” in this area, from which on average just under a fourth of the sample had used in the previous six months, with higher levels, up to one third of respondents, in Greece and the UK, with lower levels in Sweden and Germany. The latter two countries in contrast are particularly advanced in the provision of **rehabilitation services, while** in Germany, **temporary residential health care** is more used, a mainly post-acute form of care that is much less diffused in the Mediterranean and Eastern European countries.

Compared to the above services, in particular primary care, all other kinds of services do not have the same level of diffusion, although thee is a remarkable concentration in some of the countries studied. **Home based personal care services,** mainly provided or funded through public agencies, are given to about one sixth of the whole sample. However, higher percentages are recorded for Germany and the UK, and much lower ones in Poland. **Privately paid solutions to address personal care needs** are much less widespread in the six countries, but have a peculiar concentration in Italy – where almost one tenth of the national sample of older persons were cohabiting with a (usually migrant) care worker providing them with almost 24-hour daily supervision, and Greece, where this type of personal care assistant is also present in the home (as in Italy, though to a lesser extent) and also in hospitals and other temporary residential care settings, to support the (apparently not sufficiently "personalised") care provided by these institutions to the older person.

Table 97: Which services do elder use? (by country, % values)*

Used service	**Greece (N = 1,014)**	**Italy (N = 990)**	**UK (N = 995)**	**Sweden (N = 921)**	**Poland (N = 1,000)**	**Germany (N = 1,003)**	**All (N = 5,923)**
Total % of elders using at least one service	93.4	99.8	90.6	96.1	94.8	91.6	94.3
Mean number of services used by elders	2.3	3.7	3.5	4.2	3.3	4.1	3.5
Services addressing health care needs							
Medical and nursing services^	81.2	97.6	79.1	80.3	92.6	87.7	86.5
▪ ambulatory	80.3	64.4	72.5	-	71.9	85.2	63.3
▪ home based	11.1	21.3	30.4	-	55.7	44.8	27.8
General hospital	35.2	19.3	33.2	12.5	21.2	14.2	22.7
Rehabilitation services^	4.6	9.8	14.9	28.7	10.4	22.8	15.0
▪ ambulatory	0.9	3.2	-	-	7.0	18.2	5.3
▪ home based	3.9	6.6	-	-	3.8	5.3	3.4
Temporary residential health care	-	1.3	0.6	-	0.7	6.7	1.6
Services addressing personal care needs							
Home based personal care services	13.8	16.5	20.3	16.9	8.1	23.4	16.5
Cohabiting / co-resident non-family paid care	3.0	10.0	1.3	0.1	0.2	1.0	2.6
Privately paid non-family carer in temporary residential setting or in hospital	2.3	0.9	-	-	-	-	0.5

Used service (cntd.)	**Greece (N = 1,014)**	**Italy (N = 990)**	**UK (N = 995)**	**Sweden (N = 921)**	**Poland (N = 1,000)**	**Germany (N = 1,003)**	**All (N = 5,923)**
Home based (domestic) care services	10.7	13.4	17.0	23.7	6.5	26.1	16.1
Emotional / psychological / social services^	8.1	5.1	18.7	5.2	20.5	15.3	12.2
▪ ambulatory	6.6	2.6	7.6	-	0.7	2.1	3.4
▪ home based	1.7	2.3	12.0	-	19.8	14.0	8.6
Transport services	1.0	5.3	11.1	38.0	2.6	8.2	10.6
Organisational support (social work)^	-	6.8	16.5	3.3	4.3	13.8	7.5
▪ ambulatory	-	0.5	-	-	0.6	10.2	1.9
▪ home based	-	-	-	-	4.0	4.6	1.5
Residential and semi-residential services							
Permanent residential (social / nursing / medical)	1.9	3.3	5.4	14.9	0.2	11.1	6.0
Temporary residential social	0.1	1.1	8.6	13.1	-	-	3.7
Day care centres health and / or social care	0.7	2.0	9.2	10.1	0.3	4.2	4.3
Technical equipment / home environment adaptation	3.6	20.3	27.3	51.1	15.5	24.9	23.4
Other services used by elder	-	1.8	0.7	-	1.7	4.4	1.5

* Cross-national categories of services are based on the (reclassified) national lists of services.

^ This category may be less than the sum of the two underlying sub-categories (ambulatory and home based), since the same person might use both kind of services (which “collapse” when they are fused together).

° In the case of Sweden, the distinction between ambulatory and domiciliary services has not been carried out.

Domestic care services (mainly related to housework and cleaning tasks) reach the same level and pattern of diffusion observed for formal personal care services (about one sixth of the overall sample), with Germany and Sweden here showing the broadest network and Poland the least developed one. Slightly different is the provision of **services addressing the emotional, psychological and social needs** of the elderly, which are most widespread in Poland, the UK and Germany, mainly thanks to their home based delivery in these countries (in Poland reflecting in particular the high frequency of the local catholic priest’s home visits). One country, i.e. Sweden, emerged as the one where **mobility needs** have been tackled systematically, with almost 38 % of all respondents profiting from **transport services**, which in contrast are almost absent in Greece and Poland (which are also two very rural countries), and only a little more widespread in the UK and Germany. **Organisational support,** mainly in the form of social work aiming at providing help to the older person in finding the most appropriate pragmatic solutions to the different problems deriving from his / her care needs, was received by only 7.5 % of the whole sample, at double the levels in the UK and Germany, and in the latter country this mainly assumed an “ambulatory” form (i.e. not home delivered). The well-known more widespread availability of **residential and semi-residential care facilities** in Sweden, the UK and Germany is well reflected in the answers provided by the EUROFAMCARE sample, which for the Scandinavian country denotes also a very widespread diffusion of technical aids as well as of interventions aimed at adapting the older person’s home environment, mentioned by over half of respondents.

The information collected with regard to the **frequency of service use** (table 98) shows that medical and nursing services delivered at home are, albeit less widespread (as shown in previous Table), more frequent than ambulatory ones, especially in Germany. This pattern is even more marked for rehabilitation services, that reach particularly high levels of weekly frequency in Germany and Sweden, remaining however relatively high in all countries, and in general for almost all home based services (such as for instance personal care and domestic care).

Table 98: How frequently are services used by elder? (% of elderly using services <u>at least weekly</u>, by country)*

Used service	**Greece (N = 1,014)**	**Italy (N = 990)**	**UK (N = 995)**	**Sweden (N = 921)**	**Poland (N = 1,000)**	**Germany (N = 1,003)**	**All (N = 5,923)**
Services addressing health care needs							
Medical and nursing services^	10.2	23.9	19.5	18.3	16.9	41.3	22.1
▪ ambulatory	9.3	2.4	9.9	-	5.1	20.8	9.9
▪ home based	12.4	25.1	33.1	-	23.4	52.2	32.7
General hospital	7.2	*	7.3	14.8	*	*	6.0
Rehabilitation services^	62.8	61.8	37.6	30.7	48.5	84.9	54.1
▪ ambulatory	*	37.5	-	-	37.6	84.0	67.0
▪ home based	67.5	73.8	-	-	72.2	86.0	75.7
Temporary residential health care	-	*	*	-	-	*	18.5
Services addressing personal care needs							
Home based personal care services	50.8	62.4	90.7	93.9	24.7	19.7	57.7
Cohabiting / co-resident non-family paid care	81.5	100.0	*	*	*	*	91.9
Privately paid non-family carer in temporary residential setting or in hospital	55.0	*	-	-	-	-	51.7
Home based (domestic) care services	62.9	91.4	83.4	73.2	43.1	85.0	77.5
Emotional / psychological / social services^	50.8	54.0	69.6	27.8	31.9	39.8	46.1
▪ ambulatory	51.7	*	66.2	-	-	*	50.0
▪ home based	*	78.2	71.1	-	33.0	40.5	45.8

Used service	**Greece (N = 1,014)**	**Italy (N = 990)**	**UK (N = 995)**	**Sweden (N = 921)**	**Poland (N = 1,000)**	**Germany (N = 1,003)**	**All (N = 5,923)**
Transport services	*	29.4	58.9	38.4	*	26.4	38.2
Organisational support (social work)^	-	*	20.6	*	23.3	16.1	15.4
▪ ambulatory	-	*	-	-	*	*	*
▪ home based	-	-	-	-	*	33.3	27.1
Residential and semi-residential services							
Permanent residential (social / nursing / medical)	87.6	97.0	90.7	96.8	*	83.2	91.0
Temporary residential social	*	*	16.2	21.3	-	-	19.1
Day care centres health and / or social care	*	75.0	87.8	95.5	*	82.9	88.9
Technical equipment / home environment adaptation	*	90.9	67.1	81.9	37.1	53.3	68.4
Other services used by elder	-	55.6	*	-	*	87.5	64.1

* Percentages are indicated only if more than 10 cases are reported per service per country, and calculated on the total number of elder using that services in that country (cf. Table 95).

° In the case of Sweden, the distinction between ambulatory and domiciliary services has not been carried out.

7.3.1.3 Care allowances

Support to older people and their family carers can be provided not only in the form of services, but also through allowances and financial benefits aimed at better meeting care related costs. Table 99 provides an overview of these care allowances, a topic respondents were asked to provide information on, and distinguishes between those received by the older person from those targeting the caregiver.

The first relevant information is the fact that a only slightly more than **one third of the older dependent cared-for people referred to in** the EUROFAMCARE sample **received at least one kind of care allowance**. This percentage varied strongly cross-nationally, with over 60 % of German older people (closely followed by Polish and British) but only 2 % of Greek older people (and 7 % of Swedish ones) in this position, Italians being at the overall average. This information needs however to be integrated with the one regarding the **amount received**[11], which reveals, despite the high quota of missing answers traditionally characterising questions aiming at quantifying financial aspects, that Germany is in this respect the most “generous” country, with over 15 % of respondents receiving more than 6,000 € per year (equivalent to an average of 500 Euros per month), followed by the UK (with 7.7 % of the sample in this group, compared to an average value of 4.6 %).

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[11] The results presented here do not change in their essence even when purchasing power standards are taken into account, which in 2003 were the following (compared to the EU-25 average level): Germany: 1.1164; Greece: 0.8038; Italy: 0.9888; Poland: 2.1714; Sweden: 11.0560; UK: 0.7273.

The UK (16 %), together with Italy (18 %), shows also the highest percentage of respondents receiving allowances between 3,600 and 6,000 Euros yearly. In contrast, older Poles received the lowest level of care payments (less than 1,200 Euros per year), thus clarifying that the widespread diffusion of care allowances in this country is associated with a low mean amount. As a result, their position in terms of the average amount of care allowances is much closer to that of Greek and Swedish recipients (ranging between 65 and 230 Euros per year), rather than that of British, Italian and German ones (who yearly received 2,742, 3,445 and 3,702 Euros respectively).

Quite different is the situation regarding **family carers**, since **only a very marginal minority** of them (3.6 %) **benefits from** any form of **care allowance**, and these were mainly concentrated in the UK (where over a tenth of them is in this position) and Poland (8.3 %). Again, however, it is British carers who receive a more substantial amount of allowances (almost always above 1,200 Euros, but in many case also over 3,600 Euros per year), most Polish carers having to content themselves with less than 1,200 Euros per year.

Table 99: Care related allowances / payments received by older persons and family carers (% of older persons / carers receiving a care allowance)

Older Persons:		Greece (N = 1,014)	Italy (N = 990)	UK (N = 995)	Sweden (N = 921)	Poland (N = 1,000)	Germany (N = 1,003)	All (N = 5,923)
not receiving a care allowance*	N =	992	637	434	852	419	397	3731
	%	97.8	64.3	43.6	92.5	41.9	39.6	63.0
receiving a care allowance	N =	22	353	561	69	581	606	2192
	%	2.2	35.7	56.4	7.5	58.1	60.4	37.0
… of less than € 1,200 / year	N =	-	2	14	1	469	15	501
	%	-	0.2	14	0.1	46.9	1.5	8.5
… of € 1,201-3,600 / year	N =	8	18	103	54	9	102	294
	%	0.8	1.8	10.4	5.9	0.9	10.2	5.0
… of € 3,600-6,000 / year	N =	5	179	159	12	2	79	436
	%	0.5	18.1	16.0	1.3	0.2	7.9	7.4
… of over € 6,000 / year	N =	3	39	77	-	1	155	275
	%	0.3	3.9	7.7	-	0.1	15.5	4.6
missing answers	N =	6	115	208	2	100	255	686
	%	0.6	11.6	20.9	0.2	10.0	25.4	11.6
Average amount of allowances paid per older person (in Euros)		64.5	3,445.1	2,742.1	163.9	229.1	3,702.3	1,384.2

Family carers:		Greece (N = 1,014)	Italy (N = 990)	UK (N = 995)	Sweden (N = 921)	Poland (N = 1,000)	Germany (N = 1,003)	All (N = 5,923)
not receiving a care allowance*	N =	1013	984	895	911	917	992	5712
	%	99.9	99.4	89.9	98.9	91.7	98.9	96.4
receiving a care allowance	N =	1	6	100	10	83	11	211
	%	0.1	0.6	10.1	1.1	8.3	1.1	3.6
… of less than € 1,200 / year	N =	-	-	2	-	60	-	62
	%	-	-	0.2	-	6.0	-	1.0
… of € 1,201-3,600 / year	N =	1	2	42	1	6	-	52
	%	0.1	0.2	4.2	0.1	0.6	-	0.9
… of over € 3,600 / year	N =	-	-	30	5	-	-	35
	%	-	-	3.0	0.5	-	-	0.6
missing answers	N =	-	4	26	4	17	11	62
	%	-	0.4	2.6	0.4	1.7	1.1	1.0
Average amount of allowances paid per carer (in Euros)		2.4	10.5	463.6	61.7	36.1	0.0	100.1

* This group includes also missing answers to the question whether a care allowance is received or not (since they might be assimilated to a non-receiver situation).

7.3.2 What are family carers' experiences in using services?

The empirical findings presented in this section summarise the main opinions of family carers on the use of support services, reflecting their experience in terms of costs, satisfaction, difficulties and preferences. The analysis is limited to the family carers’ point of view, but often includes their perception of the characteristics and quality of services used by the cared-for older person and this has necessarily been taken into consideration.

7.3.2.1 Cost of support services for family carers

Being generally delivered by public or volunteer organisations, most of the **support services used by family carers** are provided free of charge (table 100). This is especially true for information and assessment services, while respite care (in UK and Germany), socio-emotional support (in Italy and Germany) and specialist doctors (in most countries and with a much higher frequency) require more often a co-payment by the users, so that on the whole almost 5 % of carers report an overall co-payment of more than 50 Euros per month (i.e. more than 300 Euros in the last six months, see table 101).

Table 100: How many carers do not need to pay for the support services they use? (Percentage of carers not paying for used services, by country)*

Specific support services for carers	Greece	Italy	UK	Sweden	Poland	Germany	All
Socio-emotional support (counselling, social work, support or self help groups etc.)	*	50.0	100.0	94.7	*	69.2	86.4
Information (about disease, caring, available services and benefits, help lines, internet)	*	*	93.0	*	96.2	84.9	92.5
Respite care (including supervision of elder)	*	*	68.2	94.3	*	10.0	74.0
Training for caring	*	*	88.2	*	*	81.0	88.5
Assessment of caring situation	*	*	95.0	*	*	*	92.0
Other specific services for carers	*	*	20.0	100.0	57.7	*	68.3
Generic services used by family carers							
GP	71.5	99.4	99.6	1.9	*	*	83.0
Specialist doctor	51.1	31.8	48.4	5.6	*	*	44.2
General hospital	80.0	*	97.1	*	*	*	88.5
Other generic services used by carers	56.6	60.5	56.3	11.3	*	*	46.2

* Percentages are indicated only if more than 10 cases are reported per service per country, and calculated on the total number of carers using that services in that country (cf. Table 95).

Table 101: How much do carers pay for the services they use? (% values calculated on the total of carers who used services in the last six months, by country)

Overview of costs paid by carers for all services used in the last 6 months	Greece (N = 335)	Italy (N = 202)	UK (N = 390)	Sweden (N = 186)	Poland (N = 373)	Germany (N = 198)	All (N = 1,684)
No costs	60.6	80.2	87.4	56.5	94.1	77.8	78.1
Between 1 and 120 Euros	22.7	10.9	4.4	35.5	4.0	10.6	12.9
121-300 Euros	7.5	4.0	3.6	4.3	1.1	5.1	4.1
301-600 Euros	4.8	0.5	2.3	2.7	0.5	2.0	2.2
601-3,000 Euros	3.9	3.5	1.0	1.1	0.3	3.0	2.0
Over 3,000 Euros	0.6	1.0	1.3	-	-	1.5	0.7

7.3.2.2 General satisfaction with used support services

The carers' level of satisfaction concerning the support services used is quite high (table 102), which should not be a surprise and is in accord with the vast literature existing on patients' satisfaction, showing that most service users are reluctant to express manifest dissatisfaction about them to previously unknown interviewers (who might be belonging to the organisation providing the service, thus possibly affecting their future use of the same). Keeping this in mind, the only situation where a result distinctly below average is recorded concerns assessment procedures in the UK and information services in Germany.

Table 102: Do used services meet carers' needs? (% of carers answering "yes", by country)*

Services used by family carers	Greece (N = 1,014)	Italy (N = 990)	UK (N = 995)	Sweden (N = 921)	Poland (N = 1,000)	Germany (N = 1,003)	All (N = 5,923)
Specific support services for carers							
Socio-emotional support (counselling, social work, support or self help groups etc.)	*	100.0	89.6	98.9	*	93.8	94.5
Information (about disease, caring, available services and benefits, help lines, internet)	*	*	94.7	*	94.8	86.3	92.2
Respite care (including supervision of elder)	*	*	90.5	98.1	*	*	94.7
Training for caring	*	*	100.0	*	*	95.2	96.2
Assessment of caring situation	*	*	73.7	*	*	*	75.0
Other specific services for carers	*	*	*	95.5	88.0	*	91.9
Generic services used by family carers							
GP	95.4	92.9	92.4	90.7	^	*	93.3
Specialist doctor	90.0	97.7	100.0	88.9	^	*	93.4
General hospital	88.1	*	94.3	*	^	*	92.0
Other generic services used by carers	94.5	94.4	91.0	96.1	^	*	93.2

* Percentages are indicated only if more than 10 cases are reported per service per country, and calculated on the total number of carers using that services in that country (cf. Table 95).

^ This service has been considered within the category of "Information support services for carers".

7.3.2.3 Factors affecting accessibility of care services

When accessing services, the **most relevant help** identified by family carers is given by **health care professionals**, who in Germany and Italy constitute the absolute majority for all the first answers provided (table 103). The primacy of the formal health care sector in this respect is even more evident when we observe that the **informal support coming from**

other family members, friends and neighbours is on average more often recognised as most helpful in accessing services than formal **social care providers** (such as social care services, local authorities and information or counselling centres), especially in the Mediterranean countries and with the only exceptions being the UK and Sweden. In the latter country, in particular, the supporting role of social care actors in accessing services is even more relevant than that ascribed to health care institutions. The importance of **volunteer organisations** (including under this term all kinds of NGOs, support groups, religious organisations as well as trade unions) is somewhat more evident in the UK, Germany and, but to a letter extent, Italy, while **proximity to services** (or **good transportation** to reach them) emerges as a rather crucial factor in Poland. In two countries the **availability of a health insurance fund** (in Greece) **or long term care insurance scheme** (in Germany) is also appreciated as a helpful means to access services, while in Greece and Poland the availability of **personal savings or financial resources is a more** frequent factor in using services than elsewhere.

Table 103: As a caregiver, who or what do you consider to have been the greatest help to you in accessing services / support? (% values of first answers only, by country)*

	Greece (n = 781)	**Italy (n = 899)**	**UK (n = 690)**	**Sweden (n = 769)**	**Poland (n = 875)**	**Germany (n = 913)**	**All (n = 4,927)**
Health (medical / nursing) care professionals	30.6	50.5	42.5	39.3	27.9	56.1	41.5
Family, friends & neighbours	41.6	31.3	10.9	7.7	11.2	23.4	21.4
Social services / local authorities / information or counselling centres	16.6	13.5	22.6	50.8	4.8	12.6	19.6
Carer's personal experience and knowledge	19.7	8.0	5.5	8.8	1.0	7.9	8.4
Volunteer & non profit organisations (NGOs, religious organisations, support groups, trade unions)	5.0	7.7	10.9	1.9	2.7	9.8	6.3
Information / advertisements in mass media, leaflets etc.	7.2	4.0	1.2	0.8	5.3	6.2	4.2
Good transports / service proximity	1.2	0.5	0.9	1.6	13.7	0.3	3.1
Health and / or social insurance	5.1	0.1	-	0.1	-	11.4	3.0
Financial resources, savings	7.4	2.0	0.7	0.1	7.0	0.2	2.9
Other factors	0.3	8.1	7.5	3.9	22.4	10.0	9.0

	Greece (n = 781)	Italy (n = 899)	UK (n = 690)	Sweden (n = 769)	Poland (n = 875)	Germany (n = 913)	All (n = 4,927)
Don't know, never tried to use them	0.5	0.7	13.5	1.4	13.8	5.0	5.7
None, nothing	0.1	6.0	12.2	8.5	11.9	6.9	7.5

* This was an open question, for which respondents could answer with up to 3 answers for most important factors, and these were recoded through a content analysis into the categories reported above.

Complementary to factors helping carers access services are the **difficulties** they experience (table 104). Overall it is noticeable that the presence of factors clearly hindering their use are not reported as frequently as helpful ones, as just described., and revealing overall a high percentage of family carers not reporting any difficulties at all, especially in Sweden, the UK and Germany (a fact that may be considered an indicator of the higher service accessibility experienced by users in these three countries compared to the others). Notwithstanding, the list of problems experienced by family carers is not a short one, starting with the **complexity of bureaucratic procedures** – especially in the Mediterranean countries and Germany - and the **expensiveness of services,** particularly bemoaned in Greece and in Poland. The same two countries share the common destiny of being affected by a **lack of adequate transportation** to enable service access by some of the potential users, often residing in remote rural areas. **Lack of appropriate information** seems to be perceived as a problem more frequently in the UK, Poland and Italy, while in the last two countries (but also in Greece) it is the **length of waiting lists** which bothers larger numbers of family carers. Other relevant factors impeding service access have been identified within the general aspect of **poor service quality**, which especially in Greece seems to be related to their low flexibility in terms of hours for service delivery, while Swedish carers complain more often about the **(too) few available services**.

Table 104: **As a caregiver, who or what do you consider to have caused the greatest difficulties to you in accessing services / support? (% values of first answers only, by country)***

Perceived difficulty	Greece (n = 811)	Italy (n = 790)	UK (n = 918)	Sweden (n = 507)	Poland (n = 858)	Germany (n = 759)	All (n = 4,643)
Bureaucratic (complicated) procedures	15.8	28.0	5.4	7.5	3.6	18.6	13.1
High costs, economic reasons	18.0	7.6	6.1	3.9	29.0	8.2	12.8
Lack of information on existing services and access to them	-	14.6	11.3	7.5	12.0	6.9	8.9
Distance / lack of adequate transportation services	20.3	4.8	0.8	2.4	12.9	1.6	7.4
Long waiting lists	8.4	10.6	0.7	4.1	14.6	0.5	6.6
Poor quality of services	10.0	6.5	9.3	5.7	2.2	2.1	6.1
Non flexible hours for service delivery	27.2	1.9	0.8	1.8	0.3	0.8	5.7
Few available services	6.2	3.0	2.0	10.3	3.9	1.2	4.0
Lack of acceptance by the elderly	4.4	3.4	4.9	1.6	2.0	4.6	3.6
Restrictive criteria of access to services	2.0	2.0	1.2	1.4	10.5	1.8	3.3
Other reasons	14.2	14.7	23.1	17.4	19.7	31.6	20.2
Don’t know, never tried to use them	-	1.9	9.6	2.0	10.3	3.7	4.9
Nobody / nothing	18.6	26.1	40.3	43.8	11.2	40.1	29.1

* This was an open question, to whom respondents could answer indicating up to 3 most important factors, which have been recoded through a content analysis into the categories reported above.

7.3.2.4 Reasons for not accessing formal services

The results described above can be usefully integrated with the findings concerning the reasons for not accessing care services provided by family carers who did not use any services at all[*] (table 105). The main, almost obvious reason for not using services is that many potential users – irrespective of their actual conditions or necessities – **do not feel they need them**, and it is interesting to note that such an opinion is less widespread in Mediterranean countries than elsewhere. A relevant ground for non usage can be identified in the **negative attitude of the carer or of the older person**, reflecting in general a preference for more informal solutions, self-tailored care and a lack of trust in care providers / workers, particularly widespread in Sweden, Germany and the UK. **High costs** are a third major reason for not using services – especially in Germany, Greece and Poland – while the **lack of informa-**

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[*] This question was actually answered also by many respondents who did use at least one service (however the average number of services used by the respondents to this question was significantly lower: 2.4 by the older person and 0.2 by the carer, compared to 3.8 and 0.5 respectively among non respondents).

tion is lamented above all by Mediterranean carers. The peculiarly negative situation in Greece is in this respect confirmed by the much higher percentages of Greek carers reporting a generalised **unavailability of services**, **physical access problems** (due to long distances or lack of adequate transportation) as well as the **poor quality of services**.

Table 105: If you don't use any services, what are the reasons why you do not access them?* (% values by country)

Reason	Greece (N = 91)	Italy (N = 177)	UK (N = 192)	Sweden (N = 260)	Poland (N = 304)	Germany (N = 345)	All (N = 1,369)
Don't need them	40.7	49.7	54.2	61.9	67.8	67.0	60.4
Older person's or carer's attitude	16.5	17.5	22.4	31.5	10.5	27.8	21.8
High costs, economic reasons	17.6	10.2	5.7	6.9	15.1	22.3	13.6
Lack of knowledge / information	14.3	12.4	9.4	3.1	7.9	5.2	7.5
Services are not available	28.6	4.5	3.1	-	3.9	1.7	4.2
Mobility problems, architectural barriers, distance (too far away)	15.4	5.1	1.5	0.8	3.6	0.9	3.0
Poor quality of services	12.1	2.8	3.1	3.1	0.7	2.6	3.0
Not entitled to use them	4.4	2.8	1.0	-	-	2.0	1.3
Complicated bureaucratic procedures	2.2	3.4	-	0.8	-	1.4	1.1
Other reasons	8.8	17.5	17.7	7.8	8.2	10.4	10.5

7.3.2.5 Reasons for not using needed services

A partial confirmation of the above findings is provided by the data contained in table 106 reporting the reasons for not using services which the older person or the carer feel would be useful. The **expensiveness of services** and the **lack of information** about their existence represent in this respect the most widespread reasons, with particularly high levels in Poland and Greece for the first reason, and Greece and Italy for the second one. In Sweden and the UK non usage of services is instead more often related to a form of **aversion and refusal by the older person**, thus revealing a probably higher (and possibly more readily accepted) level of empowerment of the older generations in determining for themselves how they should be cared for, however a view not always necessarily shared by their family carers. Further reasons for non usage of service are those of **not fulfilling the requirements providing entitlement to service access** (most relevant in Italy), the fact that **services are no longer available**, their excessive distance (especially in Poland), the **complicated bureaucratic procedures** necessary to access them (particularly bothering British carers) and their low quality.

Table 106: Are there any services that you (as carer) or the older person you care for need, but you have not used so far? If yes, what were the reasons for this? (% values of first answers only, by country)^

	Greece	Italy	UK	Sweden	Poland	Germany	All
Carers / OPs who need services that	25.6	31.9	23.5	23.7	24.7	26.6	26.0
they have not used so far (= 100 %)	(n = 251)	(n = 300)	(n = 230)	(n = 205)	(n = 247)	(n = 266)	(n = 1,499)
For which reasons?							
Too expensive	43.0	30.0	10.4	5.4	42.9	31.2	28.2
Didn’t know about them	38.1	33.0	18.7	13.2	27.9	25.6	26.8
Lack of cooperation (refusal) by OP*	6.7	5.7	27.8	33.7	5.7	12.0	14.2
Not entitled to use them	6.8	15.4	10.4	5.9	10.1	12.0	10.4
Service is no longer available*	0	6.7	7.8	9.3	7.3	7.5	6.3
Too distant	7.5	3.7	1.3	1.0	17.4	5.3	6.1
Bureaucratic complicated procedures*	0	2.3	28.3	2.4	0.8	3.0	5.8
Low quality	7.5	3.0	4.3	4.9	3.6	7.1	5.1
Other reasons	0	17.7	19.1	42.0	13.0	23.3	18.5

* These services derive from the open answers (which respondents could add at the end of the multiple choices explicitly listing the other services).

^ Results calculated on all provided answers do not differ substantially from those reported in this table.

7.3.2.6 Reasons for stopping using some needed services

A final remark on this topic can be formulated with regard to the reasons for quitting using some still needed services (table 107), which confirm the relevance of **costs** (a reason relevant in Germany, as well as Greece and Poland), the perceived **low quality** (with the only exception being Poland) and the fact of **no longer being available**. It should be again underlined that in those countries with a more articulated formal care systems (Sweden, UK and Germany) the **lack of cooperation by the older person** is a frequent reason for stopping using services which carers actually report as still being needed, thus revealing that a specific aim of service providers in these countries should be to increase the acceptability of provided services. The **loss of entitlement criteria** is a further reason for “exit”, particularly in Germany and Italy, while **distance** (often coupled with a lack of adequate transports, both public and private ones) confirms to be a major problem mainly in Poland and Greece.

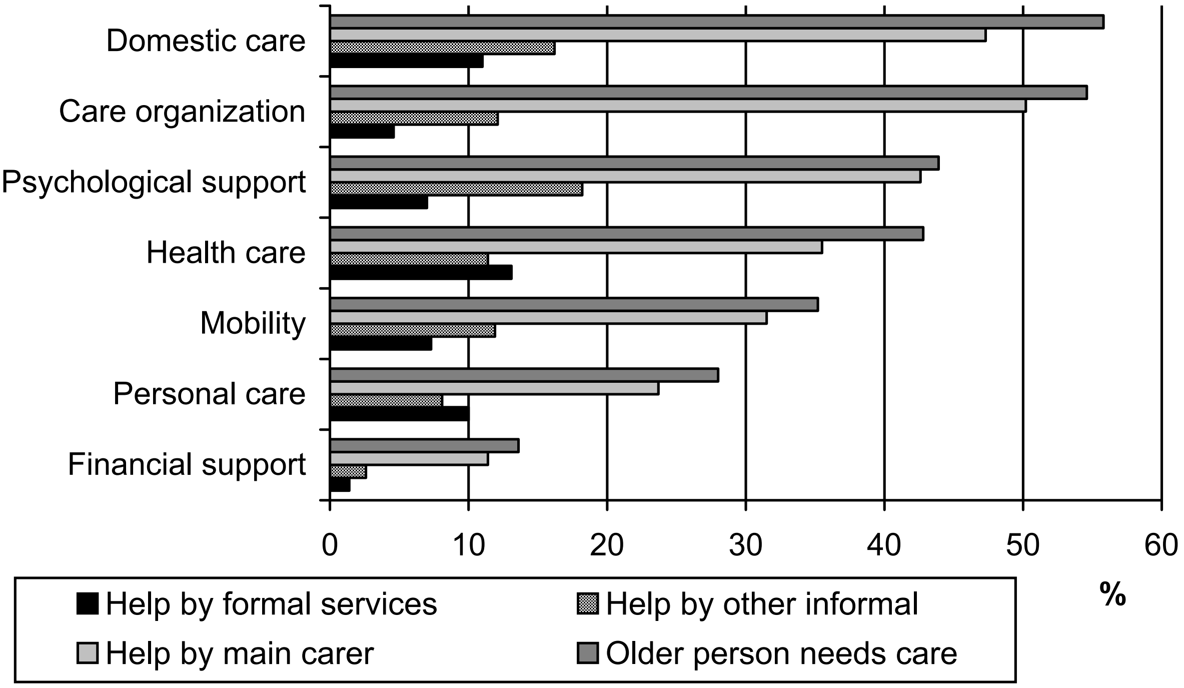
Table 107: Are there any services that you (as carer) or the older person you care for still need, but have stopped using? If yes, what were the reasons for your decision? (% values on all valid answers by country)

	Greece (n = 80	Italy (n = 77)	UK (n = 146)	Sweden (n = 117)	Poland (n = 113)	Germany (n = 119)	All (n = 650)
Carers / Older persons who stopped using still needed services	8.1	8.5	14.8	13.7	11.3	11.9	11.3
For which reasons?							
Too expensive	36.3	28.6	12.3	12.0	44.2	42.0	28.1
Low quality	23.8	19.5	22.6	28.2	9.7	20.2	20.7
No longer available	12.8	22.1	27.4	12.8	11.5	9.2	16.3
Lack of cooperation (refusal) by OP	6.2	5.2	15.1	17.9	2.7	12.6	10.8
No longer entitled to use them	6.4	14.3	6.2	10.3	5.3	16.8	9.7
Too distant	13.8	5.2	4.8	2.6	16.8	2.5	7.2
Other reasons	0	24.6	26.7	29.9	26.5	36.1	25.5

7.3.3 Do services reach the persons (family carers or older persons) in need of support?

A further issue tackled by the EUROFAMCARE survey was to understand whether existing services are really able to reach the persons in need of support. A partial answer to the question is provided, with regard to the dependent older persons, in figure 3, where the percentage values of the older persons completely relying on others' help and of the sources of support available to them are reported, and distinguished by different areas of need. The first information that can be derived is that **domestic care** (such as housework) and **care organisation** (i.e. organising and managing care, e.g. by contacting services) are those areas where most older persons (over 50 %) are completely reliant on others' help, followed by **psychological support** and **health care** (over 40 %), **mobility** (about 35 %) and **personal care** (less than 30 %), while only about 13 % of the whole sample needed **financial support**. In all areas of need, support from **the main family carer is almost always present** (the main gaps being recorded in the area of domestic care and of health care), while much less frequent is the **help provided by other family members or informal carers** (which reaches the highest peaks – between 15 % and 20 % of relevant cases – for psychological support and domestic care). The help provided by formal care services is quite marginal – at least from a quantitative point of view – covering more than 10 % of relevant cases only in the field of health care, domestic care and personal care.

Figure 3: Over 65 year old persons completely relying on others for help, by type of care needs and source of help (% values)



These data make clear that in Europe the needs of many dependent older people are mostly met by the family and informal support network, and only secondarily by means of formal care services. This information is however still insufficient to understand whether the response currently provided under such circumstances is satisfactory, or whether more help is needed for specific areas of need. An answer to this question is provided by means of the data reported in table 108, distinguishing findings by country, which underlines that cross-nationally the **most frequently requested help** (over 38 % of the whole sample) refers to the area of **emotional and psychological support** (which includes need for companionship, reassurance etc.). These data seem to reveal that, although this is the sector where family carers are most frequently providing support themselves (cf. figure 3 above), they feel that such help is still insufficient to respond to the older person's need for reassurance and emotional support (in particular when no spouse or partner is available), so that more resources in this area would be most welcome. The sense of their own contribution's insufficiency perceived by family carers in this area is more frequent than in other areas, and with over 44 % of relevant cases only second to the need for more **financial support** (57.5 %), which however is a relevant need for only a fifth of the whole sample. **Domestic care** followed by **mobility** (such as for instance better transportation) are the second and third areas where services are lacking, followed by that of health care, care organisation & management as well as personal care, while **financial management** represents the least problematic area. Cross-nationally, a clear pattern emerges whereas Mediterranean (and especially Greek) family carers show the greatest demand for more services in all areas compared to other countries, with few exceptions (such as for instance Swedish and German carers who also frequently ask for more emotional & psychological support, and Polish carers who want more financial help).

Table 108: For which areas of need would family carers like to have more help for the cared-for older person? (data by country, % values)

Need		Greece	Italy	UK	Sweden	Poland	Germany	All	
								% on all dependent OP	% on whole sample
Emotional / psychological / social	N	896	900	847	672	876	897	= 5,088	5,923
	%	63.8	49.2	33.5	44.6	32.4	43.1	44.6	38.3
Domestic care	N	855	900	862	687	921	932	= 5,157	5,923
	%	55.7	45.1	31.4	21.3	26.2	32.3	35.7	31.1
Mobility	N	716	893	780	563	798	914	= 4,664	5,923
	%	60.1	45.9	32.1	25.2	28.9	35.7	38.4	30.2
Health care	N	892	819	636	613	721	808	= 4,489	5,923
	%	55.3	48.1	29.2	18.1	29.3	28.8	36.3	27.5
Care organisation and management	N	733	870	663	608	750	720	= 4,344	5,923
	%	62.5	39.1	29.0	12.0	22.8	31.5	33.6	24.6
Personal care	N	660	737	587	549	461	770	= 3,764	5,923
	%	55.3	44.8	35.6	20.9	26.9	31.7	36.8	23.4
Financial support	N	528	404	297	85	374	338	= 2,026	5,923
	%	74.2	64.1	40.1	17.6	61.0	44.7	57.5	19.7
Financial management	N	795	851	645	583	771	779	= 4,424	5,923
	%	36.9	24.0	18.1	3.9	13.4	9.8	18.4	13.7

* Percentage values refer to the positive answers on the reported total number of valid answers to this question.

7.3.4 Which types of support and characteristics of services are considered to be important by caregivers? And to what extent are these currently met?

When asked what type of support family carers believe to be the most important (table 109). the majority of them identified the fact of getting appropriate **information as the most important support.** both with respect to **the disease** or illness of the cared-for older person (especially in Sweden) and the **availability and accessibility of help and support** (particularly in Italy and the UK). Other relevant types of support mentioned are **opportunities for the older person to undertake activities he / she enjoys**, or for the carer to have a **holiday or break from caring,** the possibility of **combining caregiving with paid employment** (this being especially desired by Swedish carers, in a country with very high employment rates for both women and older age groups). Greek and Polish carers stand out also for the high relevance attached to the **opportunity to spend more time with their own families**, while British, Swedish and again Greek carers recognise more than others the importance of being able to count on **opportunities to enjoy activities outside of caregiving**. National specificities are evident also with regard to the wish to receive **help in planning future care** – considered particularly relevant by British carers, who express also more frequently than others the need **to make the older person's environment more suitable for caring** – as well as to the preference manifested by Greek and Polish carers for **financial support to provide good care**, but also by Swedish respondent for more emotional and psychological support through **opportunities to talk over their problems as carers**.

Table 109: The importance of different types of support to family carers (by country, % values*)

Need		Greece	Italy	UK	Sweden	Poland	Germany	All
2. Information about the disease that the older person has	N	1,009	987	982	916	999	1,000	5,893
	%	74.4	71.9	66.5	85.0	74.8	64.8	72.8
1. Information / advice on type and accessibility of help & support	N	1,009	988	988	915	999	1,002	5,901
	%	70.3	81.2	76.6	72.8	48.7	53.4	67.0
6. Opportunities for the older person's to undertake activities they enjoy	N	1,005	979	974	913	1,000	995	5,866
	%	60.9	48.1	62.9	54.8	52.1	44.2	53.8
5. Opportunities to have a holiday or take a break from caring	N	1,002	987	976	908	1,000	998	5,871
	%	60.3	48.7	59.3	56.8	42.5	48.4	52.6
8. The possibility to combine care giving with paid employment	N	809	773	672	313	738	717	4,022
	%	49.3	57.4	48.5	72.5	55.8	40.4	52.2
12. Opportunities to spend more time with their family	N	896	887	827	576	983	838	5,007
	%	60.0	43.5	55.0	52.3	58.9	38.1	51.5
4. Opportunities to enjoy activities outside of caring	N	1,005	983	979	906	997	994	5,864
	%	52.5	34.5	57.9	53.1	45.2	45.5	48.1
7. Help with planning future care	N	1,005	988	974	905	1,000	997	5,869
	%	55.4	46.1	60.2	35.2	41.2	34.4	45.5
11. More money to help provide things they need to give good care	N	1,007	986	977	902	1,000	997	5,869
	%	64.2	48.8	39.8	17.5	58.7	27.2	43.1
14. Help to make older person's environment more suitable for caring	N	999	985	978	898	998	981	5,839
	%	50.2	41.1	62.5	45.2	34.2	24.4	42.9
9. Opportunity to talk over their problems as a carer	N	1,006	985	981	916	998	1,002	5,888
	%	44.2	30.8	46.9	66.3	29.1	35.1	41.7
3. Training to help family carers develop the skills they need to care	N	1,009	984	973	905	998	997	5,866
	%	41.6	40.2	34.0	24.3	19.6	27.3	31.3

Need		Greece	Italy	UK	Sweden	Poland	Germany	All
13. Help to deal with family disagreements	N	764	880	566	206	960	600	3,976
	%	32.5	22.0	31.6	33.0	25.5	18.0	26.2
10. Opportunities to attend a carer support group	N	1,002	982	976	911	996	1,000	5,867
	%	30.1	20.9	29.0	34.7	15.1	16.1	24.2

* Percentage values refer to the answers "very important" for the total number of valid answers, thus excluding missing answers and inapplicable cases (the latter being possible for answers n. 8, 12 and 13 only). The number before each item identifies its original rank within the questionnaire.

Surprisingly, less than one third of all carers, see as an important type of support, and these mainly concentrated in the two Mediterranean countries, want **training to develop skills needed in caring** and similarly only one fourth of the sample want help in dealing with family disagreements or opportunities to attend a support group (slightly more requested by Swedish, Greek and British carers).

Interesting information integrating the desires of family carers with that concerning the most relevant support for carers concerns the question **whether the needs underlying such supports are met** (cf. figure 4, where data reports the percentage of carers considering a specific support "very important", although currently this is not being met[12]). The available data permits an initial observation that **there are only two types of support that for almost all the six countries reflected an unsatisfying situation**: "information and advice on the type of support available and how to access it" (with the only exception of Germany) and "financial support to help provide things carers need to give good care" (with no exception).

Figure 4: Gap between "important" and "met" types of supports

TYPE OF SUPPORT	**EL**	**IT**	**UK**	**SE**	**PL**	**DE**	**ALL**
2. Info about disease of elder	4	14	**-4**	12	**-7**	**-9**	1
1. Info/advice on available help	29	44	25	20	14	**-1**	22
6. Activities for older person	30	26	10	4	**-10**	**-10**	8
5. Holidays or breaks from care	29	16	4	1	**-4**	**-5**	7
8. Better combination care-work	26	21	**-8**	**-8**	**-15**	**-10**	1
12. More time with own family	11	3	**-3**	1	**-18**	**-6**	-4
4. Activities outside of caring	18	**-4**	3	**-10**	**-29**	**-10**	-6
7. Help with planning future care	35	29	17	**-1**	**-4**	**-13**	11
11. More money for better care	55	40	12	4	41	11	28
14. Improve elder's home	21	18	4	**-18**	**-3**	**-20**	**-1**
9. Talk over carer's problems	18	**-8**	**-3**	**-10**	**-28**	**-23**	**-11**
3. Training for family carers	14	15	**-5**	**-5**	**-5**	**-13**	1
13. Help in family disagreements	8	**-4**	**-12**	2	**-26**	**-8**	**-9**
10. Attend a carer support group	21	3	**-13**	**-5**	4	**-29**	**-4**
Overall average	22	14	2	**-2**	**-6**	**-10**	3

A second phenomenon made evident in the data reported in figure 4 is that carers living in Mediterranean countries (and Greece in particular) show a high (and sometimes even very high) level of desire for support which are currently unmet, while Polish and especially Ger-

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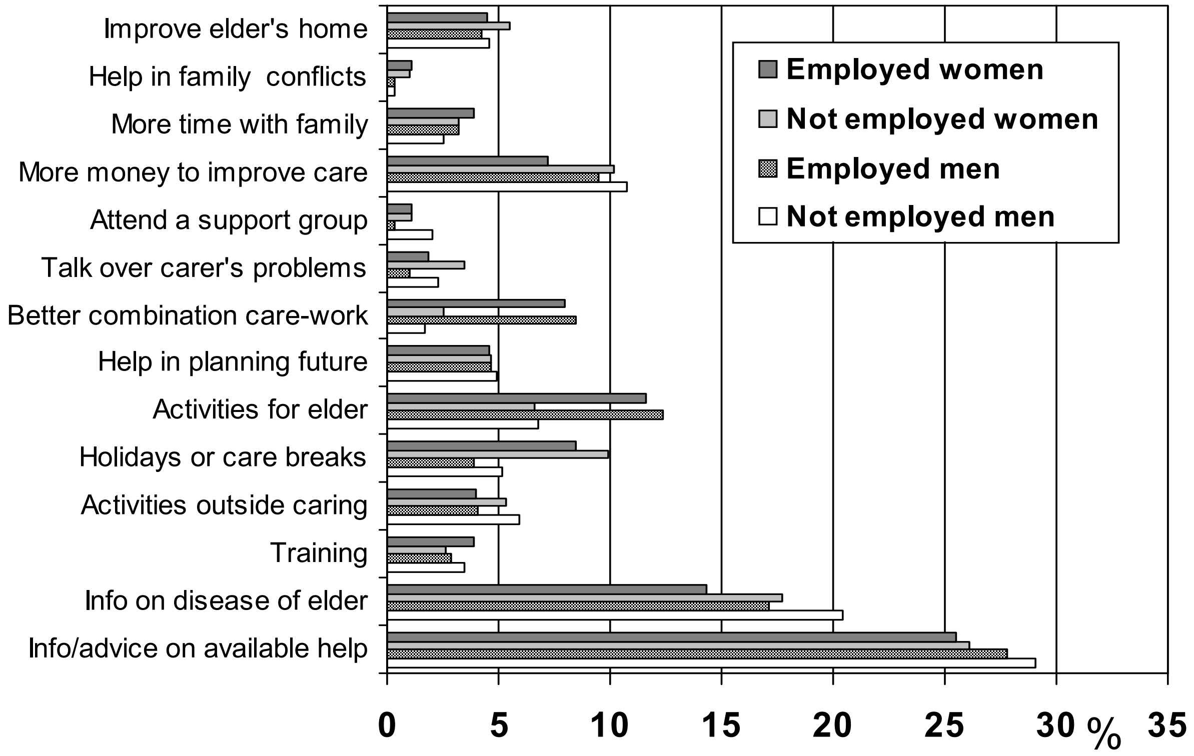
[12] The percentage reported in each cell of this graph results from the difference between the percentage of carers considering that specific type of support as "very important", and the percentage of carers stating that the same is being met for them. Grey cells indicate a gap of over 20 points (thus indicating a clear lack of a needed support, bold ones a negative gap (i.e. a support being met relatively often compared to its relevance in the carers' eyes).

man carers find themselves in an almost opposite situation i.e. one in which most of their need for support is met even if they are not considered very important, while British and Swedish carers are in an intermediate position.

A final aspect worth underlining with respect to gender and employment status (cf. figure 5), is that **employed men and women** report requiring more measures aimed at improving the possibility of adequately **combining caregiving with paid employment**, on the one hand, and **opportunities for the older person to undertake activities they enjoy**, on the other end. This reveals quite clearly the necessity of improving the supply of services and measures aimed at relieving working carers and offering them more chances for a better balance between family and professional responsibilities, especially in the light of the European aims of increasing the employment rate amongst older workers. A further difference which should be stressed is the fact that **women,** both employed and unemployed, **ask more frequently than men for opportunities to have a holiday or take a break from caring**, confirming that women – being more intensively involved in the hands on care of the most dependent elderly – more often run the risk of become the "second victim" of the older person's dependency, unless appropriate relief opportunities are granted to them.

Figure 5: Support considered most important by gender and employment status



A further topic investigated by the EUROFAMCARE survey has been the **relevance of different service characteristics** (table 110). In this respect, carers' opinions are clear about the fact that, cross-nationally, the most relevant aspect service providers must pay attention to is that **care workers treat the older person with dignity and respect**. Related qualities which also are most appreciated by family carers are the fact that a service should be able to **improve the quality of life of the older person**, an aim for which many carers seem to be a pre-requirement that **help is provided on time** (i.e. "at the time it is promised" and / or "most needed") and that **care workers have the necessary skills and training**. For all these aspects, Mediterranean and Swedish carers express the highest levels of agreement. Less relevant are other aspects such as that **carers themselves are treated by carer workers with dignity and respect** (except for Greece and Sweden), the **cost of services** (which however remains a widespread concern in Poland and Mediterranean countries), and even less important **that services take into appropriate account the carers' role** (carer's views are listened to, help improves the carers' quality of life, help focuses on both carers' and older person's needs, help fits into the carers' daily routine) or the fact that **help is provided each time by the same care worker**.

Table 110: How important are specific service characteristics for family carers? (by country, % values*)

Need		Greece	Italy	UK	Sweden	Poland	Germany	All
5. Care workers treat older person with dignity and respect	N	1,005	988	984	915	1,000	1,000	5,892
	%	94.6	96.4	91.0	97.9	86.4	86.7	92.1
8. The help provided improves the quality of life of the older person	N	1,005	988	987	909	998	1,000	5,887
	%	90.6	92.8	87.9	93.9	79.4	77.7	87.0
1. Help is available at the time they need it most	N	1,011	989	990	911	1,000	1,003	5,904
	%	93.6	93.3	85.7	91.7	86.5	69.1	86.6
4. Care workers have the skills and training they require	N	1,007	989	987	912	1,000	1,000	5,895
	%	88.1	92.9	81.7	88.3	79.2	74.1	84.0
3. Help arrives at the time it is promised	N	1,010	987	983	902	999	1,000	5,881
	%	90.6	87.3	84.9	86.3	73.8	67.7	81.7
6. Care workers treat carers with dignity and respect	N	1,005	988	983	910	1,000	1,000	5,886
	%	88.0	74.1	79.2	84.2	69.1	61.0	75.8
10. The help provided is not too expensive	N	1,004	987	982	896	998	991	5,858
	%	83.3	76.5	71.1	59.9	76.4	55.1	70.6
7. Carers views and opinions are listened to	N	1,007	989	987	910	1,000	998	5,891
	%	67.4	59.0	78.7	91.2	56.9	48.2	66.5
9. The help provided improves the carers' quality of life	N	1,004	988	977	900	997	999	5,865
	%	75.9	59.4	68.9	71.9	52.9	51.1	63.2
12. Help focuses on the carers' needs as well as those of the older person	N	1,006	986	981	888	998	1,000	5,859
	%	81.9	67.3	58.8	57.5	46.3	52.1	60.7

Need		Greece	Italy	UK	Sweden	Poland	Germany	All
11. Help is provided by the same care worker each time	N	1,004	989	978	909	999	997	5,876
	%	59.9	48.6	65.4	73.8	52.2	40.5	56.5
2. The help provided fits in with carers own routines	N	1,011	989	986	894	999	997	5,876
	%	73.0	55.5	64.6	46.5	45.8	47.8	55.7

* Percentage values refer to the answers "very important" on the total number of valid answers (thus excluding missing answers).

In this case too it has been possible to understand **whether the service characteristics considered most relevant by family carers are also currently met** (figure 6). It can be observed that these qualities considered most relevant are also those most frequently unmet, thus revealing an unsatisfactory situation in at least four out of the six countries considered. Again, it is the Mediterranean countries, and especially Greece, which show the most problematic situation, and Poland and Germany the least worrying one (with the main Polish exception related to the expensiveness of services).

Figure 6: Gaps between "important" and "met" service characteristics (%)

Service characteristics	EL	IT	UK	SE	PL	DE	ALL
5. Dignity/respect with elder	32	18	4	6	-1	-2	11
8. Help improves elder's QoL	29	21	7	10	-5	-9	10
1. Help available at needed time	44	30	16	13	9	-5	19
4. Care workers' skills & training	37	16	9	7	0	-9	11
3. Help arrives at promised time	39	20	12	2	-11	-16	10
6. Dignity/respect with carer	24	-6	-6	-9	-20	-30	-6
10. Help is not too expensive	50	33	2	-1	20	3	20
7. Carer's opinion is listened to	9	-19	2	3	-28	-35	-11
9. Help improves carer's QoL	31	-2	-6	-10	-25	-31	-5
12. Help focuses on both's needs	29	5	-4	-23	-30	-23	-5
11. Help by same care worker	6	-4	-4	13	-18	-19	-4
2. Help fits with carer's routine	35	7	-10	-33	-27	-32	-6
Overall average	22	6	2	0	-9	-14	2

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

This chapter attempts to assess the subjective evaluation of the caring situation by the carer on the basis of the negative Impact factor (as described in Chapter 3), and to find if the use of a support service by elderly / carers (in general and within the different categories) has an impact on the carer's burden. Multivariate regression analysis (standard, stepwise backward and forward) was used to find determinants of the negative impact of caring on carers. The total score of Negative Impact of caring scale was used as the dependent variable for multiple regression analysis.

The initial multivariate regression model (Model 1) was constructed with independent variables presented in table 111, describing both the situation of the older person (demographic features, financial situation, functional abilities and caring needs) and carer (demographic features, caring tasks, reasons for starting caring, support network, positive impact of caring) as well as using services in general. The variables were chosen according to the model of carer and elder service use and carer quality of life derived from the work of Aneshensel and colleagues (Aneshensel et al., 1995) presented in Chapter 3, and previously associated with emotional distress or satisfaction with care in family carers from the literature (Walker, Pratt & Eddy, 1995). Some of the variables were constituted from the total scores on different scales constructed from other variables as described in Chapter 3.

The next question asked was if the country of residence, as an independent variable, influenced the Negative Impact of caring. The second multivariate regression model (Model 2) was created in order to include the independent variables from Model 1 as well as dichotomized variables derived from the question about "country of living" (we inserted 5 of them, by indicating with the value "0" five of the six country variables).

The last model tested (Model 3) was constructed from Model 2 variables combined with (non-) usage of different categories of services (as indicated in Table 94 at the beginning of this chapter) used by carers and older persons, with the aim of checking on whether the use of specific categories of services is connected with the carer's subjective evaluation of the caring situation. The analysis was performed in stages. Standard regression was used to assess the relationships among variables in the model. To eliminate independent variables that did not provide additional prediction for the variables already in the equation, stepwise backward regression was used, in order to check the proportion of variance attributable to some independent variables after the variance due to the specific variables in the equation is accounted for.

Table 111: Variables included in the multivariate regression models analyzing chosen determinants of the Negative Impact factor

Variable	Label / Value
MODEL 1	
I. Characteristics of cared- for older person	
Demographics	
Age	65-79 years = 0; 80+ = 1
Living alone	no = 0; yes = 1
Financial situation	
Older person has got financial support needs	no = 0; yes = 1
Caring needs	
ADL ability	total score on Barthel's Index
IADL ability	total score on IADL scale
Behavioural problems	total score on behavioural problems scale
Memory problems	no = 0; yes = 1
Overall need for assistance	total score on the scale
II. Characteristics of carer	
Demo-graphics	
Gender	men = 0; women = 1
Age	< 60 years = 0; ≥ 60 = 1
Place of living	rural = 0; urban = 1

Variable	**Label / Value**
MODEL 1	
Cohabitation with the cared-for older person	different houses = 0; same house = 1
Employment	non working = 0; working = 1
Caring tasks	
Average number of hours of care for the elder in a week	
Elder's needs covered by Carer	total score on the scale
Number of elderly people cared for by the caregiver	
Number of other (non-elderly) people cared- for by the caregiver	
Support network	
Elder's needs covered by informal support other than Carer	total score on the scale
Quality of Support in caregiving	total score on COPE Index subscale
Reasons for starting caring	
Emotional bonds (love, affection) influenced Carer's decision to care for Elder	no = 0; yes = 1
Starting caring was a compulsory situation for the Carer	no = 0; yes = 1
Positive impact of caring	
Positive Value of caregiving	total score on COPE Index subscale
III. Services	
Usage	
Elder's needs covered by formal support	total score on the scale
Total number of services used by Elder during the last 6 months	
Total number of services used by Carer during the last 6 months	
Non- usage	
There are services that Elder / Carer need but they have not used them so far	no = 0; yes = 1
Carer perceived need for more support	total score on the scale
Availability	
Formal help provided to Elder / Carer is not too expensive	no = 0; yes = 1
MODEL 2	
Model 1 variables	*As above*
Country of living (5 of 6 variables inserted to the model)	
Poland / Greece / Italy / Great Britain / Germany / Sweden	no = 0; yes = 1
MODEL 3	
Model 2 variables	*As above*
Usage of different categories of services recoded on the European level 1 (variables EU1_nAR, where n- the consecutive number of the EU categories of services)	service not used = 0; service used = 1

The results of the standard multivariate regression analysis of Model 1 are presented in table 112. Together the independent variables included in the Model 1 accounted for 45.76 % of the total variance on the Negative Impact of caring score (N = 3,796, adjusted R2 = 0.458, SE 3.3, F = 115.33, $p < 0.0001$). In the last column variables significant in stepwise backward regression of Model 1 are marked: together they accounted for 45.4 % of the total variance of dependent variable (adjusted R2 = 0.4537).

The second model tested included independent variables indicating the carer's country of residence. Their inclusion added 6.5 % of the variance explained, as Model 2 explained 52.3 % of dependent variable variance (N = 3,796, adjusted R2 = 0.523, SE 3.1, F = 126.98, p < 0.0001). In contrast to Model 1, cost of services was not a significant variable in stepwise backward regression in Model 2, but it was indeed the total number of services used by elder as well as the fact of living in Poland, Sweden or Greece (Polish carers tended to have lower and Swedish or Greek carers higher scores on Negative Impact of Caring scale then carers from other countries).

The standard multiple regression analysis of Model 3 revealed that it explained 52.6 % of Negative Impact of caring variance (N = 3,796, adjusted R2 = 0.5262, SE 3.09, F = 72.442, p < 0.0001), since the inclusion of different types of services usage by Carer or Elder has added only 0.4 % of variance explained.

The stepwise backward regression analysis of Model 3 pointed to the same significant independent variables as in Model 2, the only new variable emerging being the fact of using the support of a cohabiting / co-resident (non-family) paid carer. This independent variable significantly contributed to the dependent variable variance explanation, and its usage was connected with higher scores on Negative Impact of Caring (reflecting the fact that it is a care solution usually employed by carers experiencing a high care burden).

The stepwise forward regression was used to check the proportion of variance attributable to independent variables after variance due to accounted for variables in the equation. Table 113 presents the consecutive steps of this analysis, revealing that all presented variables were significant in stepwise backward regression, adding a significant proportion to the variance explanation (together: 52.31 %).

Table 112: Standard multivariate regression analysis of independent factors associated with Negative Impact of caregiving (Model 1)

Independent variable	B unstandardized coefficient	S.E. standard error of B	ß standardized coefficient beta	p probability value	Variables significant in stepwise backward regression
Constant	16.2	0.62		< 0.000001	
I. Characteristics of cared-for older person					
Elder's Age	0.18	0.11	0.02	NS	
Elder lives alone	0.16	0.16	0.02	NS	
Elder has got financial support need	0.46	0.14	0.05	< 0.001	
Barthel Index score	-0.02	0.003	-0.11	< 0.000001	***
IADL score	0.22	0.04	0.11	< 0.00001	***
Behavioural problems	0.34	0.03	0.19	< 0.000001	***
Memory problems	-0.30	0.14	-0.03	< 0.05	
Overall need for assistance	-0.13	0.07	-0.05	NS	
II. Characteristics of carer					
Gender	0.24	0.14	0.02	NS	
Age	0.50	0.14	0.05	< 0.001	
Place of living (urban)	0.09	0.12	0.01	NS	
Cohabitation with the cared-for older person	0.54	0.17	0.06	< 0.002	***
Employment	0.33	0.13	0.04	< 0.02	
Average number of hours of care to elder / week	0.007	0.001	0.08	< 0.00001	***
Elder's needs covered by Carer	0.26	0.05	0.11	< 0.00001	***
Number of elderly people cared for by the caregiver	0.1	0.13	0.01	NS	
Number of other (non-elderly) people cared- for by the caregiver	0.06	0.04	0.02	NS	

Independent variable	**B unstandardized coefficient**	**S.E. standard error of B**	**ß standardized coefficient beta**	**p probability value**	**Variables significant in stepwise backward regression**
Elder's needs covered by informal support other than Carer	-0.1	0.03	-0.05	< 0.0001	***
Quality of Support in caregiving	-0.21	0.02	-0.14	< 0.000001	***
Emotional bonds (love, affection) influenced Carer's decision to care for Elder	0.04	0.24	0.002	NS	
Starting caring was a compulsory situation for the Carer	0.87	0.11	0.1	< 0.000001	***
Positive Value of caregiving	-0.38	0.03	-0.19	< 0.000001	***
III. Services					
Elder's needs covered by formal support	-0.04	0.04	-0.01	NS	
Total number of services used by Elder	0.01	0.02	0.008	NS	
Total number of services used by Carer	0.06	0.06	0.01	NS	
There are services that Elder / Carer need but they have not used them so far	0.68	0.13	0.07	< 0.000001	***
Carer perceived need for more support	0.29	0.03	0.016	< 0.000001	***
Formal help received is not too expensive	-0.44	0.11	-0.05	< 0.0001	***

Table 113: Stepwise forward multivariate regression analysis of independent factors associated with Negative Impact of caregiving (Model 3)^

Independent variable	Step	B	S.E.	ß	p	Adjusted R2
Constant		16.25	0.49		< 0.000001	
Behavioural problems	1	0.32	0.02	0.18	< 0.000001	0.1719
Quality of Support in caregiving	2	-0.19	0.02	-0.12	< 0.000001	0.2755
Carer lives in Greece	3	2.90	0.02	0.26	< 0.000001	0.3363
Barthel Index score	4	-0.02	0.003	-0.10	< 0.000001	0.3957
Positive Value of caregiving	5	-0.44	0.03	-0.22	< 0.000001	0.4308
Elder's needs covered by Carer	6	0.23	0.03	0.10	< 0.000001	0.4583
Starting caring was a compulsory situation for the Carer	7	0.71	0.11	0.08	< 0.000001	0.4749
Average number of hours of care for the elder in a week	8	0.005	0.001	0.05	< 0.0002	0.4844
Carer lives in Sweden	9	1.32	0.23	0.1	< 0.000001	0.4929
Carer perceived need for more support	10	0.2	0.02	0.11	< 0.000001	0.5034
There are services that Elder / Carer need but have not used so far	11	0.7	0.12	0.07	< 0.000001	0.5079
Cohabitation with the cared-for older person	12	0.7	0.13	0.08	< 0.000001	0.5113
Carer lives in Poland	13	-0.46	0.19	-0.04	< 0.02	0.5154
Usage of cohabiting non-family, paid carer	14	1.36	0.32	0.05	< 0.0001	0.5181
Total number of services used by Elder	15	-0.02	0.04	-0.01	NS*	0.5200
Elder's needs covered by informal support other than Carer	16	-0.09	0.02	-0.05	< 0.0001	0.5216
IADL score	17	0.15	0.04	0.07	< 0.001	0.5231

Legenda: B: unstandardized coefficient; S.E: standard error of B; ß: standardized coefficient beta; p: probability value; adjusted R2: adjusted squared multiple correlation.

^ Only variables significant in stepwise backward regression are presented in this table.

* Variable significant in the stepwise backward regression.

7.4 Final remarks

Comparative data in the field of care service provisions should always be interpreted with caution, since the contents and meaning of single services are very much nationally defined, thus not always completely comparable across countries and within different care systems.

7.4.1 Usage of support services by family carers

Keeping this in mind, the illustrated findings seem however to reveal with adequate clarity that family carers of older people in Sweden, the UK and Germany can count on a more developed network of specific "formal" support services that, besides delivering the necessary information on how to deal properly with the caregiving situation (this being however less evident or necessary in Sweden), provides them above all with a core of respite care and socio-emotional care services (such as for instance counselling, social work or self-help groups). These are on the contrary almost totally absent in Greece, Italy and Poland, countries where in contrast caregivers often find support from more traditional, "generic" services, i.e. from services not originally created to specifically address family carers' needs, but which play a type of substitution role in this respect in relieving and sustaining family carers in their everyday tasks. This is primarily true for General Practitioners, (who seem also to play a relevant role in the UK) who are key figures in providing, especially where no other services are available, the information necessary to access appropriate services for the acute or long term care of the frail older person, accomplishing at the same time an important task of advice, counselling and probably emotional and psychological support for the family carers.

As far as the **intensity** of service use is concerned, **respite care** seems to reach a reasonable (i.e. weekly) frequency of use only in the UK and Sweden (with over half of cases in this situation), while the same can be said on average for only one carer out of five enjoying formal **socio-emotional support**. Much less frequent in contrast is the recourse to **generic services**, thus revealing that their use, although very widespread, remains usually a very "irregular" or "mild" one.

7.4.2 Care allowances

Support to family carers is provided in the UK and Poland, to a certain extent (i.e. in about one tenth of cases), also in the form of **direct care allowances** (i.e. monetary payments directly received by the carer), although the mean amount granted to British carers is much higher than that assigned to Polish ones. Much more widespread are **allowances paid to the frail older person** – even if aimed at covering the (effective or figurative) costs of care provided by others – from which benefit over one third of Italian cases but well over half of German, Polish and British ones, though remaining a quite residual form of support in Sweden and Greece. Again, Polish recipients can count also in this respect on much lower average amounts than their Italian, British and, above all, German counterparts.

7.4.3 Carers' experience in using services

The first aspect regarding family carers' experience in using support services is their **cost**. On the whole, empirical evidence emerging from the EUROFAMCARE studies reveals that most of these services (when available) are **usually delivered for free or with a generally low contribution from the recipients,** being most of them funded through public agencies. However, in some countries the need for some kinds of support services is evidently higher than their availability (on a public basis), so that family carers see themselves compelled to **pay sometimes private providers** to receive them (this being the case of Italy and Germany for socio-emotional support services, as well as of the UK and, again, especially Germany for respite care). The overall paid amount remains however, apart from few exceptions, quite low on average (with less than one carer out of ten paying carers having to spend more than 20 Euros per month).

Overall **satisfaction** about the capacity of the (few) used services to meet carers' needs is on average quite high, with lower levels being recorded only for the assessment of caring situation (a procedure which however seems to be performed on a more regular – and carer-aware – basis only in the UK) and, but to a lesser extent, the information services provided in Germany.

A further aspect considered by the survey is **access** conditions to available services and support. The **greatest help**, in this respect, is identified by carers in the support coming from **health care professionals**, who are revealed to be the “gatekeepers” of the overall service care system in all analysed countries (and especially Germany and Italy), with the only exception being Sweden. In this Scandinavian country it is the **social services** which are the protagonists in playing this positive role (at least in the eyes of family carers), although the health care sector remains still quite relevant (thus probably reflecting a high integration between the two in this country). They are quite marginal, on the contrary, in Poland, Germany, Greece and Italy where, especially in the Mediterranean countries, it is **family, friends and neighbours** (i.e. other informal support networks) who are particularly relevant in providing access to care services.

Obstacles in accessing services and support are identified by carers mainly in the **bureaucracy and complicated procedures** needed to be able to use them (which seem particularly burdensome in Italy, Germany and Greece), their **high costs** (representing a barrier especially for Polish and Greek carers), the **lack of information**, their **distance or lack of adequate transportation** to reach them (particularly problematic in Greece and Poland), the existence of **long waiting lists** (lamented especially by Polish and Mediterranean caregivers) and the perception of a **poor service quality** (more frequently in Greece and the UK). The latter reason (which reveals to be relevant also in Sweden), together with the high cost of services (in this case meaningful in Germany, too), represent also the **main grounds for carers to stop using still needed services**, where a role is played however also by the fact that some services are **no longer available** (mainly in UK and Italy). **High costs** and **lack of adequate information** prove to be the major reasons for **not using needed but never used services** in country characterised by a generally lower economic and educational level of their older population (mainly Greece, Italy, Poland and, to a letter extent, Germany), while in the remaining countries (Sweden and the UK, but partly also in Germany) the relatively less frequent usage of services might be justified by the **older person’s or carer’s own personal attitude**, possibly reflecting a higher level of users’ empowerment and deliberate choice of not resorting to – often perceived as not enough tailor-made – services, which might reduce their own degree of independency or freedom.

7.4.4 Carers’ opinion about most relevant types of support and services characteristics

What are the **most important types of support** in the eyes of carers? **Information and advice** about the disease suffered by the older person as well as on how to access available services are on the top of carers’ list of preferences, followed by the “**opportunity by the older person to undertake activities they enjoy**”, holiday or **care break opportunities** for carers, including the possibility to **spend more time with the family**, as well as to **better combine caregiving and paid employment**. Less relevant are carer support groups, training opportunities and the possibility to talk about problems or deal with family disagreements.

Again, strong **cross-cultural differences** can be observed, especially when we analyse whether the expressed preferences are currently being met or not. In this respect, we can first of all distinguish the **Mediterranean countries**, where the extent of virtually all types of support currently provided to family carers can be judged as insufficient, since they reach only part of those considering them important. **Sweden and the UK** are characterised by a more balanced situation between demand and the provision of most types of support, although in Sweden a certain lack can be observed in some specific areas (information and recreational activities for the elderly), while in the UK even some situations of "overabundant support " seem to occur (with regard to the availability of carer support groups and counselling on carers' problems and family disagreements). The latter phenomenon of "overabundant support " is even more accentuated in **Poland and Germany**, where many of the types of support types considered as most relevant by carers are currently met to a high degree, thus revealing a situation of overall satisfaction. This can probably be explained by quite different reasons in the two countries: in Poland more by the users' prevailing low expectations towards formal service provision (confirmed also by the fact that the only largely unmet support here is "more money for care"); in Germany more in connection with the wide range of services introduced in the last few years after the introduction of the Long Term Care Insurance scheme. All in all, however, the most unmet type of support **throughout Europe** is **financial help**, followed by **information on access to existing services**.

A similar situation emerges with regard to the **most relevant service characteristics**. Those more often considered as "very important" by carers are overall the necessity that "care workers **treat the older person with dignity and respect**", the ability of the service to "**improve the quality of life of the older person**", as well as its **timeliness**, and that "**care workers have the skills and training** they require". Less important are services that "fit in with carers own routines", are provided by the same care worker or consider carer's needs, quality of life and opinion, revealing quite clearly that the most relevant worry for family carers concerns the quality of the treatment reserved to the older person, and not to themselves. As already mentioned, the question on **how such preferences are currently met** by the actual service provision shows cross-national differences which reflect and even accentuate the pattern already described above for the preferred types of support: in **Greece** and (but this time to a lesser extent) **Italy** services are mainly characterised by carers as not being satisfactory in terms of their crucial service characteristics; **Sweden and the UK** fall into an intermediate, more balanced position (showing however a slightly better situation in the Scandinavian country); **Poland and Germany** enjoying a condition of relatively widespread carers' satisfaction on the current ability of services to meet the required characteristics.

7.4.5 Service effectiveness

A preliminary analysis of the **determinants of the negative impact of caring** on family carers shows that this is mainly associated with the characteristics and **needs of the older person** (depending on his / her health status and functional abilities but also **living arrangements**), the **intensity of the caring tasks** performed by the carer (in terms of hours of care provided per week), the strength of the **carer's support network** and the **type of services** used. The usage of some types of services (such as general hospital / acute care, home based domestic services, cohabiting non-family paid carer and emotional / psychological / social support services) is connected with a more negative impact of caring, probably explained by the fact that the **usage of such services is more widespread among more frail elderly-carers dyads** (frailty being intended here more broadly than functional activity alone as measured by ADL / IADL – which were controlled for – thus including emotional status and other health related problems). With regard to cross-national differences, carers tended to show a **more negative impact of caring in Greece and Sweden, and less negative in Poland** than carers in other countries.

It should be finally underlined once again that, in order to be fully comprehensible and to prove the direction of the detected associations, these preliminary findings will need to be integrated by those derived from the analysis of the follow-up survey focussing on determinants of change in carers' conditions and service use (which are discussed in chapter 9), and "purified" from cross-national differences due to possible sampling effects, by basing future analyses on the cluster of homogeneous caregiving situations (as presented in chapter 6).

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8 Service for supporting family carers of older people from service providers´ perspective

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8.1 Introduction

There are two parts involved in a service - providers and users, and they both have influence on the final results. The extensive interviews with the family caregivers have give a broad picture of their situation and service usage. The service provider interviews are a complement to the interviews with family caregivers in order to elucidate service support also from a service provider perspective. An aim for the whole EUROFAMCARE project is to produce valuable information about the challenges of today as well as the future concerning family care giving and services.

The six countries involved have different preconditions, social welfare systems, traditions etc, which affect the family carer's situation and service level.

There are different social attitudes towards family care in the countries involved. A simplified description is: In Greece and Poland there are high social expectations on the family to provide care, and no formal recognition. It is almost the same in Germany but with an increasing formal recognition. Sweden and UK have a somewhat different situation with relatively low social expectations on the family, and increasing formal recognition. However even within an individual country there are wide variations in the approaches to family care.

Attitudes towards family care also often connected with levels of formal service provision for the older person. The legislation concerning service support for older people and family caregivers is an important framework for formal provided services. The most shared service for older people and their families is medical health care service, which is accessible in all countries. Beyond that level there are major differences.

The primary legal responsibility for the care of dependent older people is the following: In Germany, Greece, Italy and Poland is the child care obligation specified, financial and / or care, the state assumes responsibility only if the family is unable to do so. This involves often some kind of assessment. Whilst in Sweden and UK the state, whether at national, regional or local level have primary responsibility, with varying systems to support family carers. This implies that services are provided according to need, with or without a financial contribution from the individuals. This is also based on some assessment.

More detailed information is available in EUROFAMCARE National background reports. National survey reports and Pan-European background report.

8.2 Purpose

The purposes of this study were to gather information about service providers' perspective on services provided for family carers and the older people, specifically:

- Aims of the services

- Main benefits for family carers
- Problems for family carers in accessing services
- Issues in service charges
- Areas of service needs not met
- Assessment and monitoring of the needs of family carers
- Current and future developments and challenges

8.3 Method and sample

8.3.1 Data collection

The data has been collected mainly by telephone interviews with service providers (in Germany by postal questionnaire and in Greece by personal interviews). A common questionnaire was used, the Service Providers Questionnaire (SPQ), which was standardised for use in all six countries (enclosure).

The SPQ contained five sections:

A. basic background information about the respondents and their organisation

B. semi-structured questions about services for family carers

C. semi-structured questions about services for older people that might relieve family carers

D. structured questions about the types of services and quality characteristics of support that family carers need and prefer

E. an overview of provided services, access, usage, cost, satisfaction, need of improvement and gaps between needs and access / provision (enclosure)

The questions in section D were identical to the questions asked of family carers in the Common Assessment Tool (CAT) and Follow Up Questionnaire used in the National Surveys of family carers, and designed to provide comparable data.

Potential responding organisations and respondents were identified through snowballing e.g. via co-ordinators and interviewers from the prior family caregiver interviews and through interviewed service providers.

The identified potential respondents were contacted by telephone, the project explained and their agreement to take part in an interview established in principal. This was then followed by mailing or posting a written explanation of the project and a copy of the interview schedule.

Once the respondent had the opportunity to consider this material a telephone interview was carried out at a date and time of their choosing.

Interviews were carefully noted and in some cases audio-taped (UK) during the interview and transcribed directly afterwards.

8.3.2 Method of Analysis

Content analysis was used on the semi-structured questions and with the open answers in section B and C. The analysis was guided by a common guide with following main categories:

- Goals and benefit
- Usage and access
- Coverage, quality
- Attitude towards family carers
- Costs
- Future development

In the analysis guide each of the main categories was followed by questions to be used as support for synthesizing the interview content (enclosure).

Quantitative data from section A and D and E was entered into SPSS a statistical package for descriptive analysis to be undertaken.

8.3.3 Sampling strategy

The geographical sampling for the service provider interviews followed that of the original sampling areas for the interviews with family caregivers, representing metropolitan, urban and rural areas.

A theoretical sampling procedure was applied to include all relevant types of services offered to family carers and older people. The sampling framework allowed for interviews to be conducted with management representatives of different types of service providers in each area: public social and health service organisations, religious organisations, voluntary organisation and private / commercial organisations. The aim was to interview at least 5 service providers per area.

8.3.4 The sample

A total of 201 service providers responded, between 21 and 53 service providers per country (table 114). Most of them were working in metropolitan and urban areas, and about a quarter in rural areas.

The majority were head or manager for a service organisation, while about half of the Greek sample was practitioners. In the total sample most respondents were working in public social care organisations, though the samples of Germany, Italy and UK had the highest proportion of service providers from within the voluntary sector.

Most were working within medium (11-50 employees) and large (over 50) organisations. The Greek and German samples had the highest proportion of respondents who worked within small (10 or less employees) organisations.

Nearly half of the respondents' organisation provided no special service to family caregivers. A quarter provided more than 50 % of their service directly to family caregivers. Most of the organisations provided services for older people but many also considered that those services had an impact on the family caregivers' situation.

Table 114: Description of the sample

Country	**DE**	**EL**	**IT**	**PL**	**SE**	**UK**	**Total**
Total sample	**N = 35**	**N = 21**	**N = 53**	**N = 41**	**N = 25**	**N = 26**	**N = 201**
Respondents' role	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	N (%)
Head	18 (52.9)	4 (19.0)	35 (66.0)	29 (70.7)	6 (24.0)	6 (23.1)	98 (49.0)
Manager	9 (26.5)	7 (33.3)	10 (18.9)	5 (12.2)	9 (36.0)	16 (61.5)	56 (28.0)
Practitioner	5 (14.7)	8 (38.1)	6 (11.3)	6 (14.6)	6 (24.0)	2 (7.7)	33 (16.5)
Other	2 (5.9)	2 (9.5)	2 (3.8)	1 (2.4)	4 (16.0)	2 (7.7)	13 (6.5)
Type of area							
Metropolitan	22 (62.9)	3 (14.3)	21 (39.6)	25 (61.0)	0 (0.0)	1 (5.9)	63 (32.8)
Urban	7 (20.0)	12 (57.1)	20 (37.7)	11 (26.8)	20 (80.0)	11 (64.7)	81 (42.2)
Rural	6 (17.1)	6 (286)	12 (22.6)	5 (12.2)	5 (20.0)	5 (29.4)	48 (25.0)
Type of organisation							
Public social care	3 (8.6)	12 (57.1)	12 (22.6)	16 (39.0)	15 (60.0)	6 (23.1)	64 (31.8)
Public health care	1 (2.9)	4 (19.0)	12 (22.6)	8 (19.5)	7 (28.0)	4 (15.4)	36 (17.9)
Religious denomination	5 (14.3)	0 (0.0)	3 (5.7)	3 (7.3)	1 (4.0)	4 (15.4)	16 (8.0)
Voluntary organisation	13 (37.1)	2 (9.5)	19 (35.8)	7 (17.1)	1 (4.0)	9 (34.6)	51 (25.4)
Private business	10 (28.6)	2 (9.5)	4 (7.5)	7 (17.1)	1 (4.0)	3 (11.5)	27 (13.4)
Other	3 (8.6)	1 (4.8)	3 (5.7)	0 (0.0)	0 (0.0)	0 (0.0)	7 (3.5)
Number of employed people							
Small (10 or less)	16 (45.7)	10 (47.6)	8 (15.1)	11 (26.8)	6 (24.0)	3 (11.5)	54 (26.9)
Medium (11-50)	14 (40.0)	8 (38.1)	25 (47.2)	15 (36.6)	9 (36.0)	9 (34.6)	80 (39.8)
Large (more than 50)	5 (14.3)	3 (14.3)	20 (37.7)	15 (36.6)	10 (40.0)	14 (53.8)	67 (33.3)
Portion of the services intended for older people							
Less than 50 %	5 (14.7)	2 (9.5)	9 (17.0)	19 (47.5)	2 (8.3)	9 (34.6)	46 (23.0)
More than 50 %	4 (11.8)	7 (33.3)	20 (37.7)	19 (47.5)	16 (66.7)	12 (46.2)	78 (39.0)
100 % or nearly 100 %	25 (73.5)	12 (57.1)	24 (45.3)	2 (5.0)	6 (25.0)	5 (19.2)	76 (38.0)
Portion of the services intended for family carers							
No service	17 (48.6)	10 (47.6)	22 (41.5)	28 (73.7)	5 (20.0)	7 (26.9)	89 (44.9)
Less than 50 %	11 (31.4)	3 (14.3)	21 (39.6)	6 (15.8)	11 (44.0)	10 (38.5)	62 (31.3)
More than 50 %	5 (14.3)	3 (14.3)	7 (13.2)	2 (5.3)	3 (12.0)	3 (11.5)	23 (11.6)
100 % or nearly 100 %	2 (5.7)	5 (23.8)	3 (5.7)	2 (5.3)	6 (24.0)	6 (23.1)	24 (12.1)
Number of carers using the services	5 to 3,000	100 to 500	15 to 2,000	30 to 3,000	10 to > 2,000	18 to > 4,0000	

8.4 Results

The results focus primarily on services provided for the family caregivers and to a lesser extent on services for the cared-for older people.

8.4.1 Goals and benefits

Most commonly the main goal for services concerning family caregivers mentioned by service providers in the six counties was the support and relief the family carer. Most services focus on increasing the quality of care for the dependent older person which service providers consider indirectly bring relief for the family caregiver. It was a commonly held view among respondents that the goals of services were to maintain quality of life of family carers, giving them a sense of relief, reducing their stress, making them more happy and empowered; thus improving the family carers' ability to care which subsequently benefits the cared-for person.

The main goal in relation to the cared-for person was to maintain their quality of life by making it possible for them to remain in their own home.

8.4.2 Service and coverage

This section is concerned with how service providers look upon family carers' needs, how they assess and meet those needs and explores unfulfilled needs from a service provider perspective.

Type of services: According to the service providers the most common services given to family caregivers were counselling services, training courses, carer support groups, assessment of carers' needs and services for ethnic groups. The less frequently offered services were monetary provision, temporary home service, internet service and in Greece home service provision (table 115), although analysis of the interviews showed variation within as well as between the countries.

Table 115: Frequency of different service types provided for family carers (N = valid, includes only those who provide service for family carers)

Country Provide service for FC	DE N = 18		EL N = 11		IT N = 31		PL N = 13		SE N = 20		UK N = 19		Total N = 112	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)*	n	(%)
Training courses	8	(44.4)	1	(9.1)	19	(61.3)	8	(61.5)	7	(35.0)	14	(73.7)	57	(50.9)
Telephone service	5	(27.8)	1	(9.1)	13	(41.9)	3	(23.1)	9	(45.0)	14	(73.7)	45	(40.2)
Internet service	1	(5.6)	1	(9.1)	12	(38.7)	1	(7.7)	9	(45.0)	13	(68.4)	37	(33.0)
Carer support groups	8	(44.4)	2	(18.2)	16	(51.6)	4	(30.8)	16	(80.0)	13	(68.4)	59	(52.7)
Counselling services	15	(83.3)	8	(72.7)	16	(51.6)	9	(69.2)	14	(70.0)	13	(68.4)	75	(67.0)
Home service provision	9	(50.0)	0	(0.0)	17	(54.8)	4	(30.8)	10	(50.0)	13	(68.4)	53	(47.3)
Temporary home service	6	(33.3)	1	(9.1)	2	(6.5)	4	(30.8)	5	(25.0)	10	(52.6)	28	(25.0)
Assessment of carers needs	2	(11.1)	4	(36.4)	11	(35.5)	4	(30.8)	15	(75.0)	16	(84.2)	52	(46.4)
Monetary provision	0	(0.0)	3	(27.3)	10	(32.3)	2	(15.4)	3	(15.0)	5	(26.3)	23	(20.5)

Country **Provide service for FC**	**DE** **N = 18**		**EL** **N = 11**		**IT** **N = 31**		**PL** **N = 13**		**SE** **N = 20**		**UK** **N = 19**		**Total** **N = 112**	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)*	n	(%)
Crisis management	2	(11.1)	1	(9.1)	11	(35.5)	3	(23.1)	11	(55.0)	13	(68.4)	41	(36.6)
Integrated planning provision	1	(5.6)	2	(18.2)	14	(45.2)	5	(38.5)	13	(65.0)	7	(36.8)	42	(37.5)
Service for ethnic groups	8	(44.4)	1	(9.1)	1	(3.2)	8	(61.5)	7	(35.0)	14	(73.7)	57	(50.9)

Furthermore, services to older people that might relieve family carers reflected difference between the country samples. The most frequently provided services for older people were health care services as medical service, rehabilitation and inpatient care, house keeping services was also a commonly offered service (table 116).

Table 116: Frequency of different service types provided for older people (N = valid, includes only those who provide service for older people)

Country Provide service for OP	**DE** **N = 34**		**EL** **N = 21**		**IT** **N = 53**		**PL** **N = 40**		**SE** **N = 24**		**UK** **N = 26**		**Total** **N = 198**	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
House keeping services	4	(11.8)	4	(19.0)	25	(47.2)	12	(30.0)	9	(37.5)	12	(46.2)	66	(33.3)
Cleaning provision	0	(0.0)	5	(23.8)	19	(35.8)	11	(27.5)	9	(37.5)	7	(26.9)	51	(25.8)
Meals on wheels provision	2	(5.9)	1	(4.8)	13	(24.5)	8	(20.0)	9	(37.5)	7	(26.9)	40	(20.0)
Transport services	1	(2.9)	1	(4.8)	25	(47.2)	10	(25.0)	5	(20.8)	9	(34.6)	51	(25.8)
Domestic Care provision	3	(8.8)	0	(0.0)	7	(13.2)	9	(22.5)	0	(0.0)	6	(23.1)	25	(12.6)
Social home visits	3	(8.8)	6	(28.6)	21	(39.6)	14	(35.0)	7	(29.2)	6	(23.1)	57	(28.8)
Safety monitoring system	1	(2.9)	0	(0.0)	11	(20.8)	0	(0.0)	9	(37.5)	6	(23.1)	27	(13.6)
Medical service provision	3	(8.8)	10	(47.6)	24	(45.3)	23	(57.5)	11	(45.8)	7	(26.9)	78	(39.4)
Rehabilitation provision	0	(0.0)	5	(23.8)	17	(32.1)	8	(20.0)	14	(58.3)	8	(30.8)	52	(26.3)
Partly inpatient care	8	(23.5)	1	(4.8)	14	(26.4)	7	(17.5)	11	(45.8)	10	(38.5)	51	(25.8)
Residential care provision	0	(0.0)	2	(9.5)	12	(22.6)	8	(20.0)	15	(62.5)	6	(23.1)	43	(21.7)

Assessment of family carers needs:

Generally the interviewed service providers in the individual countries did not use predefined assessment documentation to evaluate the needs of family caregivers, since they considered that they did not have the opportunity and / or the instruments to compile a formal assessment document. Planning care for the older person was an opportunity commonly used to assess the needs of family carers. However, there were exceptions, specifically where providers used structured questionnaires etc, to explore family carers' needs at an individual level as well as on a group level. However, there appeared to be no framework for this at a local, regional or national level, responsibility for deciding how carers' needs would be assessed was left to the discretion of individual mangers of service provider organisations.

Unfulfilled needs:

There was a large variation of what was considered as unfulfilled needs among respondents. In some of the countries service providers focused on the gaps in services to meet the needs of the older person e.g. home care, day care, night care and respite care etc also highlighting the needs of special groups of older people such as those with cognitive and other mental health problems.

With regards to family carers service providers stressed the need for more psychological support, more educational input and support which was more tailored to the needs of the individual carer.

The inequity of supply, economic availability and geographical distribution of services was also highlighted.

Service providers' responses indicated that there was a large variation in the coverage of services to meet the needs of carers between the countries. In Greece, Germany, Italy and Poland the service providers recognised that there were gaps in their service to older people and to larger extent those for family caregivers. In Sweden and UK the situation was described as the opposite (table 117).

Table 117: Service and coverage of service for family caregivers and older people

Country	Services for family caregivers				Service for older people			
	Number provided services*		Uncovered gaps in their services		Number provided services*		Uncovered gaps in their services	
	n	(%)	n	(%)	n	(%)	n	(%)
Germany	57	(100)	15	(26.3)	25	(100)	17	(68.0)
Greece	33	(100)	8	(24.2)	38	(100)	11	(28.9)
Italy	142	(100)	79	(55.6)	188	(100)	142	(75.5)
Poland	50	(100)	11	(22.0)	110	(100)	39	(35.5)
Sweden	114	(100)	16	(14.0)	99	(100)	7	(7.1)
UK	144	(100)	75	(51.4)	90	(100)	40	(44.4)
Total	**540**	**(100)**	**204**	**(37.8)**	**550**	**(100)**	**256**	**(46.5)**

* Services provided by the respondents' organisation.

8.4.3 Usage, access and costs

In general the interviewed service providers believed that their services were not fully utilised and acknowledged that there were difficulties for users in accessing services (table 118 and 119) and that this problem was more acute for services designed for family caregivers than for older people. However, there was some exception as in Poland.

The greatest barrier to the use of available services centred on reaching family caregivers and older people with adequate information and knowledge concerning existence of the service, the eligibility criteria for using the service, the kind and range of support it might offer them, the quality of the service and its cost to them.

Another barrier to use of services was the beliefs and attitudes of family carers and older people for example the wish to remain independent, to manage problems and needs within the family and not to involve strangers and society.

An important way to reach people in need of services with information is via personal contacts, as where health and social care staff plays an important role. The professional groups can give individualised information and also help family carers and older people to overcome their resistance to use services. The staffs' own knowledge, perceptions and attitudes are therefore important for how family caregivers' needs will be recognised and treated.

The limited availability of services, the geographical distribution, and restrictions based on the older person's level of dependency and income of the family acted as barriers for those who were aware of services.

Respondents indicated that in their experience costs restricted the use of services in some countries (table 118 and 119). Notably carers had to turn to more expensive private service providers where service provision was inadequate within the public welfare system. In such circumstances carers, who could afford to do so, were more likely to use private services. This has led in some countries e.g. Poland and Greece, to an unofficial system of payment within public service to get access to the limited services available.

Table 118: Usage, access, costs aspects of services provided for family carers

Country	**Number of provided services***		**The service is fully utilised**		**Problems with accessing service**		**Problems with costs**	
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
Germany	57	(100)	42	(73.7)	42	(73.7)	9	(15.8)
Greece	33	(100)	8	(24.2)	8	(24.2)	4	(12.1)
Italy	142	(100)	66	(46.5)	45	(31.7)	13	(9.2)
Poland	50	(100)	35	(70.0)	16	(32.0)	0	(0.0)
Sweden	114	(100)	59	(51.8)	23	(20.2)	0	(0.0)
UK	144	(100)	104	(72.2)	56	(38.9)	23	(16.0)
Total	**540**	**(100)**	**314**	**(58.1)**	**190**	**(35.2)**	**49**	**(9.1)**

* Services provided by the respondents' organisation.

Table 119: Usage, access, costs aspects of services provided for older people

Country	**Number of provided services***		**The service is fully utilised**		**Problems with accessing service**		**Problems with costs**	
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**
Germany	25	(100)	11	(44.0)	13	(52.0)	11	(78.6)
Greece	38	(100)	11	(28.9)	4	(10.5)	2	(5.3)
Italy	188	(100)	144	(76.6)	58	(30.9)	54	(28.7)
Poland	110	(100)	89	(80.9)	52	(47.3)	37	(33.6)
Sweden	99	(100)	58	(58.6)	10	(10.1)	0	(0.0)
UK	90	(100)	82	(91.1)	25	(27.8)	19	(21.1)
Total	**550**	**(100)**	**395**	**(71.8)**	**162**	**(29.5)**	**123**	**(22.4)**

* Services provided by the respondents' organisation.

8.4.3.1 The importance and supply of different types of support

There were also differences between the country samples in the types of service they provided and what they considered important, however there were some more generally applicable views expressed in the structured questionnaire section. Service providers in all six countries indicated that information about available support services was the most important type of support for family carers. This was, as indicated earlier, the most frequently provided service. Overall the providers perceived opportunities to have a holiday or take a break; and help to make the older person's environment more suitable for caring were the most important types of supports after information giving (table 120).

The three types of services that were less frequently rated as 'very important' in the structured part of the questionnaire were: help to deal with family disagreements; the opportunity to combine care giving with paid employment; and more money to help provide things need to give good care.

The greatest gap between appreciating how ‘very important’ a service was and its provision was seen in services that gave opportunities for family caregivers to have a holiday or break; although similar gaps could also be detected between aspiration and reality in the provision of opportunities to spend more time with the family and support that brings more money to help provide things need to give good care.

However there was a certain balance between what providers rated as ‘very important’ services and what they provide concerning: information about available support; help to deal with family disagreements; and opportunities to talk over problems as a carer; the latter being one of the most frequently provided services in all countries.

Table 120: The provided amount of different types of support and their importance to family carers from service providers point of view

Type of Service			DE N = 35	EL N = 21	IT N = 53	PL N = 41	SE N = 25	UK N = 26	Total N = 201
Information about available support	Provided	N	34	19	52	39	25	26	195
		%	97.1	89.5	90.4	87.2	96.0	96.2	92.3
	Very important	N	34	21	53	41	25	26	200
		%	94.1	85.7	92.5	90.2	96.0	100.0	93.0
Information about older person's disease	Provided	N	32	19	52	39	25	25	192
		%	68.8	73.7	50.0	64.1	60.0	60.0	60.9
	Very important	N	33	21	53	41	25	26	199
		%	48.5	90.5	37.7	87.8	80.0	76.9	70.9
Training to help family carers develop caring skills	Provided	N	34	19	52	39	25	26	195
		%	52.9	52.6	61.5	51.3	68.0	65.4	58.5
	Very important	N	33	21	53	41	25	26	199
		%	69.7	85.7	86.8	90.2	48.0	80.8	78.9
Opportunities to enjoy activities outside of caring	Provided	N	34	19	52	39	24	26	194
		%	47.1	42.1	42.3	30.8	62.5	80.8	48.5
	Very important	N	33	21	53	41	25	26	199
		%	51.5	81.0	67.9	51.2	96.0	96.2	70.4

Type of Service			**DE N = 35**	**EL N = 21**	**IT N = 53**	**PL N = 41**	**SE N = 25**	**UK N = 26**	**Total N = 201**
Opportunities to have a holiday or take a break	Provided	N	34	19	52	39	25	26	195
		%	50.0	26.3	40.4	30.8	52.0	73.1	44.6
	Very important	N	33	21	52	41	24	26	197
		%	87.9	71.4	75.0	73.2	95.8	96.2	81.7
Opportunities for the older person to undertake activities they enjoy	Provided	N	34	16	51	37	25	26	189
		%	52.9	56.3	52.9	35.1	60.0	73.1	53.4
	Very important	N	33	19	52	41	24	26	196
		%	63.6	84.2	69.2	80.5	92.0	92.3	78.1
Help with planning future care	Provided	N	33	18	51	39	24	26	191
		%	84.8	27.8	68.6	61.5	79.2	76.9	68.6
	Very important	N	32	20	52	41	25	26	196
		%	56.3	75.0	75.0	75.6	60.0	96.2	73.0
Possibility to combine care giving with paid employment	Provided	N	31	19	49	39	24	26	188
		%	38.7	0.0	16.3	33.3	33.3	46.2	28.2
	Very important	N	32	20	51	40	22	26	191
		%	28.1	60.0	56.9	72.5	68.2	57.7	57.1
Opportunities to talk over problems as a carer	Provided	N	33	19	52	39	25	26	194
		%	84.8	78.9	75.0	71.8	96.0	96.2	82.0
	Very important	N	33	21	53	41	25	26	199
		%	66.7	85.7	73.6	56.1	100.0	96.2	76.4
Opportunities to attend a carer support group	Provided	N	34	19	50	38	25	26	192
		%	44.1	15.8	38.0	13.2	84.0	57.7	40.6
	Very important	N	33	21	52	41	25	26	198
		%	45.5	81.0	63.5	58.5	76.0	76.9	64.7
More money to help provide things need to give good care	Provided	N	33	19	52	38	24	25	191
		%	27.3	10.5	17.3	28.9	25.0	38.5	24.6
	Very important	N	31	21	53	41	25	25	196
		%	32.3	76.2	50.9	82.9	28.0	80.0	58.2
Opportunities to spend more time with the family	Provided	N	31	19	51	39	20	26	186
		%	45.2	31.6	35.3	20.5	25.0	65.4	36.6
	Very important	N	33	21	53	41	21	26	195
		%	42.4	76.2	79.2	80.5	47.6	80.8	69.7
Help to deal with family disagreements	Provided	N	33	19	50	38	24	26	190
		%	51.5	57.9	44.0	52.6	70.8	46.2	52.1
	Very important	N	33	21	53	41	23	26	197
		%	36.4	76.2	58.5	56.1	56.5	50.0	54.8

Type of Service			DE N = 35	EL N = 21	IT N = 53	PL N = 41	SE N = 25	UK N = 26	Total N = 201
Help to make the older person's environment more suitable for caring	Provided	N	34	19	51	39	25	25	193
		%	73.5	68.4	43.1	64.1	68.0	64.0	61.1
	Very important	N	34	21	53	39	25	25	197
		%	61.8	95.2	84.9	82.1	92.0	76.0	81.2

8.4.4 Quality from family carers' perspective as perceived by service providers

The most common form of service evaluation took place in direct dialogue between service providers and family carers. Examples of more structured evaluation were the use of focus groups and questionnaires, statistical analysis of requests for support etc. The service providers' suggested that family carers were generally satisfied and frequently more satisfied with the services they received themselves than for those provided for the older person (table 121). Few service providers appeared to use structured evaluation of carers' views of the quality of services to improve them.

Difficulties connected with the evaluation of the quality of services from a family carers' perspective were also mentioned the service providers perceived that because family carers are dependent upon the services provided that this inhibited their ability to criticise the services they received. Furthermore, some respondents considered that because of a lack of national, regional or local agreement about quality and quality measurements carers found it difficult to decide which service providers offered a high quality of services.

The service providers have a variety of suggestions about what needed to be improved. A common observation was that services need to be better and more equally distributed and that there was a need for broader, more flexible and individualised services. However, there were huge differences between the countries in terms of what services they were able to provide at the time of the study and what were the most limiting factors to service provision in each participating country. Service providers indicated that they needed better resources in terms of finance, educated staff and skilled voluntaries, together with less bureaucracy were needed to allow them to make the improvements they believed were needed. The overall impression was that services providers wished to be able to provide more support for family caregivers in the first instance, however but also that they believe that services for older people also need to be improved.

Table 121: Quality aspects of services provided for family carers and older people

Country	Services for family caregiver						Service for older people					
	Number of provided services*		Problems with carer satisfaction		Service in need for improvement		Number of provided services*		Problems with carer satisfaction		Service in need for improvement	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Germany	57	(100)	7	(12.3)	30	(52.6)	25	(100)	10	(40.0)	12	(48.0)
Greece	33	(100)	2	(6.1)	16	(48.5)	38	(100)	1	(2.6)	14	(36.8)
Italy	142	(100)	11	(7.7)	84	(59.2)	188	(100)	39	(20.7)	127	(67.6)
Poland	50	(100)	1	(2.0)	17	(34.0)	110	(100)	5	(4.5)	16	(14.5)
Sweden	114	(100)	0	(0.0)	66	(57.9)	99	(100)	14	(14.1)	17	(17.2)
UK	144	(100)	19	(13.2)	51	(35.4)	90	(100)	11	(12.2)	31	(34.4)
Total	540	(100)	40	(7.4)	264	(48.9)	550	(100)	80	(14.5)	217	(39.5)

* Services provided by the respondents' organisation.

8.4.5 The importance of, and ability to meet service quality characteristics

There were more consensuses among respondents about which are the most important types of services than there was in those items concerned with importance of and ability to meet, quality characteristics of services. These questions also belonged to the structured questionnaire section. Furthermore, the response rate concerning their provision of the quality characteristics is overall lower, which has to be considered when reading the percentages of what is provided. Several service providers said that the question was not applicable on their services, especially in Greece.

However all respondents believed it to be very important that care workers treat the older person and the family carer with dignity and respect (table 122). These were also some of the most met quality characteristics according to the service providers. Many respondents also emphasised that it was very important that help is available at the time that family carers need it most; however some responding service providers found it difficult to provide services with the flexibility to meet this criteria.

The three types of services were rated less than as 'very important' by service providers and were in general the least likely of the service characteristics to be met; these were: help is provided by the same care worker each time; the help provided fits in with carers own routines; the help provided is not too expensive.

With some exceptions there was some degree of balance between what service providers rated as ‘very important’ characteristics and what they provide with some exceptions. Though there were still gaps between what they considered to be important and to what extent it was being met when looking at the numbers of service provider that have answered the questions about provision of quality characteristics.

Table 122: The occurrence of quality characteristics and their importance to family carers from service providers point of view

Quality characteristics			DE N = 35	EL N = 21	IT N = 53	PL N = 41	SE N = 25	UK N = 26	Total N = 201
Help is available at the time they need it most	Provided	N	28	10	49	38	22	25	172
		%	92.9	90.0	87.8	92.1	95.5	88.0	90.7
	Very important	N	33	21	52	41	25	26	198
		%	81.8	100.0	96.2	90.2	100.0	96.2	93.4
The help provided fits in with carers own routines	Provided	N	26	11	48	36	18	23	162
		%	96.2	81.8	83.3	80.6	94.4	91.3	87.0
	Very important	N	33	20	52	41	24	26	196
		%	54.5	50.0	67.3	56.1	54.2	76.9	60.7
Help arrives at the time it is promised	Provided	N	29	7	47	38	22	24	167
		%	100.0	71.4	93.6	97.4	95.5	100.0	95.8
	Very important	N	33	21	52	41	24	26	197
		%	75.8	81.0	80.8	85.4	83.3	92.3	82.7
Care workers have the skills and training they require	Provided	N	28	10	48	38	24	23	171
		%	100.0	100.0	87.5	100.0	100.0	91.3	95.3
	Very important	N	33	20	52	41	25	26	197
		%	72.7	100.0	92.3	92.7	92.0	92.3	89.8
Care workers treat older person with dignity and respect	Provided	N	29	1	50	38	24	23	165
		%	100.0	100.0	94.0	100.0	100.0	95.7	97.6
	Very important	N	33	21	52	41	25	26	198
		%	90.9	100.0	98.1	97.6	100.0	100.0	97.5
Care workers treat carers with dignity and respect	Provided	N	30	2	49	38	24	24	167
		%	100.0	100.0	91.8	100.0	100.0	95.8	97.0
	Very important	N	32	20	52	41	25	26	196
		%	84.4	95.0	94.2	95.1	100.0	88.5	92.9
Carers views and opinions are listened to	Provided	N	30	3	47	38	25	26	169
		%	100.0	66.7	89.4	97.4	100.0	100.0	95.9
	Very important	N	32	21	51	41	25	26	196
		%	53.1	66.7	76.5	87.8	96.0	88.5	78.1
The help provided improves the quality of life of the older person	Provided	N	28	0	48	38	23	24	161
		%	100.0	N / A	97.9	97.4	95.7	100.0	98.1
	Very important	N	32	20	52	41	25	26	196
		%	62.5	90.0	96.2	90.2	92.0	88.5	87.2
The help provided improves the carers' quality of life	Provided	N	27	3	48	37	22	25	162
		%	88.9	66.7	93.8	91.9	100.0	100.0	93.8
	Very important	N	32	20	52	41	25	26	196
		%	46.9	75.0	92.3	70.7	76.0	96.2	77.0

Quality characteristics			DE N = 35	EL N = 21	IT N = 53	PL N = 41	SE N = 25	UK N = 26	Total N = 201
The help provided is not too expensive	Provided	N	24	3	38	36	21	13	135
		%	70.8	66.7	76.3	91.7	100.0	100.0	85.2
	Very important	N	32	17	52	40	23	24	188
		%	46.9	76.5	61.5	85.0	39.1	66.7	63.3
Help is provided by the same care worker each time	Provided	N	27	8	47	37	21	23	163
		%	81.5	87.5	70.2	73.0	85.7	95.7	79.1
	Very important	N	32	19	52	41	24	26	194
		%	43.8	63.2	40.4	51.2	41.7	61.5	48.5
Help focuses on the carer's needs as well as those of the older person	Provided	N	27	4	47	36	23	22	159
		%	100.0	75.0	89.4	66.7	100.0	100.0	88.7
	Very important	N	31	19	52	41	25	26	194
		%	54.8	100.0	76.9	34.1	60.0	69.2	63.4

8.4.6 Attitude towards family carers

Service providers did not consider family carers to be a homogenous group and understood each caring situation to be unique. They considered family carers to be important partners in supporting older people because of their involvement in the older person's environment and their knowledge of the older person's situation. Service providers saw family carers as a resource both for the professionals and for the older person, and as indirect consumers of care services for older people. Consequently service providers considered that they listened to the views and opinions of family carers who were subsequently supported with services such as knowledge about diseases and care etc, to enable them to continue to provide care and support to the older person.

This idea of partnership was not described by every situation nor is it a concept commonly understood by all respondents. Some providers indicated that they believed family carers to be too demanding and were critical of carers' complaints. For example complaints by family carers of the quality of services provided using the very limited resources available.

However service providers also reported some instances where family carers were not prepared to collaborate with service providers in such circumstances it was considered difficult to establish a constructive dialogue. Furthermore, service providers noted difficulty in working with families to promote the best interests of a dependent older person where there was evidence of conflicting interests and priorities among family members.

8.4.7 Future development

All respondents recognised that the major challenge for service provision in the future lay in providing sufficient support for the increasing numbers of older people and their family carers predicted as the demography of Europe changes and the numbers of older people grow. At the same time, some countries have anticipated changes in residence patterns which would manifest in younger people living at a farther distance from older family members; these factors together with increasing numbers of women entering the labour market will place an increasing burden on support service provision for both older people and family carers. Although service providers expressed a range of views on the need for the development of services in the future respondents failed to identify strategies to address these issues at a national, regional or local level.

The need for a systematic approach to identifying existing unmet need was recognised by respondents; as was the necessity of developing collaborative working patterns and networking opportunities for different authorities and service providers within health and social care, public, private and voluntary organisations. Some respondents indicated that there were few or no specific support organisations for family caregivers and identified this, or at the very least, an increased level of organisation for family support as priority for service development.

Furthermore, the need for increasing the education and training available for professional carers was highlighted generally but most pointedly by Italian and Greek respondents.

Service providers also see the need for further development of specific care services for older people namely, home care, day care and care for special groups such as people who are terminal ill people and those with learning difficulties or mental health problems.

In addition to developing new types of services respondents also identified developing existing services and improving their quality and usage and forms as an imperative. Furthermore, respondents wanted to see creative ways of financing high quality and well developed support for family carers and money found to support a range support mechanisms for family carers from direct financial benefits to family carers and older people to the development of special support services.

Understanding how to achieve equity in the distribution of service, geographical and economical etc, is further undeniably complex challenge seen as important by respondents which is also connected with the need for flexible and individual services that fit the needs of family carers and older people.

Finally service providers recognised a need for them to continue to develop innovative ways of ensuring that older people and family carers become aware of available services and have the opportunities to use new technologies as they become available.

8.5 Final comments

8.5.1 Comments on methodology

This study used primarily a qualitative approach in keeping with the aim of gaining the views and opinions of people who have experience of providing a range of services for family carers and older people. A theoretical sampling procedure was applied to include all relevant types of service offers for both family carers and dependent older people. The final sample included the most relevant care service organisations operating in the sites / regions where the EUROFAMCARE survey on family carers has been carried out. In most countries it highlights above all public (social and health) and voluntary care units, and to a lesser extent religious and private care providers. Nearly half the organisations in the sample provided services for older people alone and not directly for family carers.

The analysis of the open questions showed both similarities and differences between and within the countries and some main issues where exposed. These aspects, of course, cannot be generalised for all service providers, but still major problems and concerns of providers are reported here and are helpful in illuminating the views of service providers on situation of family carers.

The sample from each country was small (between 21 and 53 service providers) and consequently ungeneralisable, however, they do provide background information which assists in contextualising the more substantial qualitative data.

8.5.2 Comments on the findings

Goals and benefits

Most service providers in this sample continued to focus on providing services for older people, a fact that reflects the status of family carers in the legislation of each country in which commonly, the rights of family carers are only weakly acknowledged. Most respondents from each country shared a common goal, to support and bring relief to family carers so that they are able to support the older person in remaining in their home. However even in this the focus is on the maintenance of the older person, although there are also service providers see the service they provide as designed to increase the quality of life and sense of empowerment enjoyed by carers.

Service and coverage

The overall picture of service provision differs between countries as does that of services for family caregivers. Some countries have more developed services for older people and are able to widen their focus and develop special services for family carers, whilst others, such as Greece struggle to provide even limited services for older people. Discrepancies in service provision and development lie in historic, economic, cultural and political differences and views on responsibility of the family and of society for the individual and by implication suggests differences in work and roles assignment of men and women in the individual countries.

The most frequently provided services in the sample as a whole were telephone support services for family carers and medical service provision for older people. The latter shows that the sample consists of many service providers within the health care sector, however it also illustrates that health care services are common and established services for older people in all countries which in turn play an important role for family carers. Other types of services vary much more within and between countries.

One main question is how service providers establish the needs of family carers. Few respondents appeared to undertake a structured assessment of individual needs which would, if in place, also makes it possible to assemble information at a higher level which could then be used for planning service development. This lack of a structured approach to assessing the needs of individual family carers makes it difficult for respondents to say anything about the possibility of their meeting the needs of family carers. The findings demonstrate that service providers consider that they frequently have uncovered gaps in service provision, particularly with regards to services for older people. Except in Sweden and UK all the other responding countries indicated that they had a large unmet need for services for family carers which may indicate that service provider are more acutely concerned with the needs of the older person.

Usage, access and costs

Service providers recognised that there were uncovered gaps in their service provision while at the same time indicating that services were not being fully utilised. This raises the question of how they review service usage and some respondents indicated that they assessed utilisation by the existence of waiting lists.

However, the lack of information family carers receive about the range and availability of services is the greatest barrier for usage and access according to service providers. In other words it is difficult to reach people in need of services and information about a service is the first condition for being able to use it.

Information is also connected with another important barrier and that is the older person's or / and the family carers’ reluctance to use a service they actually need. Personal information and contacts seems to negate this affect thus the staff of health and social care play an important role in gaining the trust of family carers and older people and as such their education, knowledge and attitudes are equally important play an important role in carers and older people accessing services.

The costs of services frequently prevent of restrict the ability of people to access services where there are few available services and few services of good quality within the public welfare system and subsequently a large amount of uncovered need. This creates an unequal situation with less access for those who can not pay and it increases the risk for unofficial payment for accessing services also within public services, this problem was particularly prevalent among service providers in Greece and Poland.

Quality from family cares' perspective -as perceived by service providers

This study suggests a general a lack of systematic approach to the evaluation of services and service quality on a national, regional and local level from the older people and family carers’ perspective. Even where such evaluation frameworks are present most service providers considered that they made their evaluation in direct dialogue with the family carers. Direct dialogue is of course good for an individual adjustment of a service but it is not a systematic approach that can be used for development of services on a more aggregated level. Another problem with this direct dialogue based evaluation is that family carers often are dependent on the service provider and thus do not feel able to speak freely.

Furthermore quality is not just a matter of satisfaction of those using the service as one respondent commented – ‘people are satisfied since there are so little service and they have no real choice’. Quality measures and quality development are important issues since they are connected with usage, people hesitate to use a service if they don't trust it and question the quality. Systematic and reliable quality assessment on the right level is a matter of development and improvement. To make the right decision it is important to base it on reliable facts of what is needed to improve existing and develop new services. It was also particularly noticeable that where service providers valued characteristics less they were less likely to ensure that it was a feature of their service.

The quality issue is also related to the systems in place for educating professional carers. There is need for adequate education and knowledge as well as good attitudes towards older people and family carers from those who shall support them.

Attitude towards family carers

The main attitude as reported by service providers is that family carers are important partners as they are a valuable resource for service providers and older people. This concept of partnership is limited and it appeared that family carers had little real influence on the design or structure of support services for themselves or the older people they cared for. However, family carers are not a homogenous group and difficulties occur when family carers fail to collaborate with the service providers or when there are conflicts within a family. This further emphasises the need for education, knowledge and understanding on the part of service providers at all levels. There are good examples of how to handle such situations but these place demands on the service provider to have the appropriate skills such as insights and skills in ethical and psychological reasoning and handling for example.

Some service providers also point to the fact that service providers have a responsibility to uphold the rights of family carers themselves to be able to maintain their health and quality of life. Many of the family carers are also old people, sometimes even older than the person they care, and this means that they belong to a fragile group as well.

Future development and challenges

There are no out spoken strategies of how to meet future challenges due to the expected demographical changes and changes in living and gender and role patterns. These transformations will put pressure on service providers to change and develop services for older people and family carers. The need for more equal distribution of support in all means geographically, economically etc, is recognised as an important challenge.

This study has highlighted the need for service providers to develop a systematic approach to finding out about the needs of older people and family carers needs today as well as future predicted needs. Needs that are connected with the set goals as relief and support for the family carer are required on all levels: national, regional and local with regard to the different political and economical systems. A rational development would concern quality assurance as well as continuous improvement of quality that takes account of systematic measurements using sound methods. These two, assessments of needs and of quality, contribute evidence for further decisions and development of services for older people and family carers.

Limited resources, both monetary and human, are a reality that defines the ability of countries to develop services. Service providers therefore emphasised the need for collaboration and network development between different service providers and authorities in this field which will increase the usage and effectiveness of available resources.

The availability of adequate professional development and education for staff are connected with the question of sufficient resources and with the quality of service. In some countries this is a substantial problem that needs to be solved.

It is important to increase the awareness and willingness to use services by older people and family carers and one way of doing this is by reaching people with adequate information and knowledge. Another approach is to develop services that are flexible and meet individual needs but also develop further specialist services for special groups such as dementia suffers for example.

9 The One Year Follow-up Study: Preliminary Results

Barbara Bien, Heinz Rothgang, Giovanni Lamura, Judy Triantafillou, Eva Mnich, Kevin McKee, Birgitta Öberg, Roland Becker, Mikolaj Rybaczuk, Bożena Sielawa, Andreas Timm[13]

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?

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[13] Information for contacts: Sections from 9.1 – 9.3.2 have been prepared by the first responsible partner (Poland), and sections from 9.3.3 to 9.3.5 by the second responsible partner (Bremen, Germany).

  - changes in care intensity?
  - 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 IADL (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 section 9.3.4. 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 123. 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 123: Size of T1 and T2 samples: Reasons for non response, and response rates

Country	T1: Sample Size	A priori excluded from (1, 3) resurvey	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				Short interview	Full interview		
			Elder alive	Elder died	Lack of data about Elder	Elder alive	Elder died	Lack of data about Elder					
Germany	1,003	400(3)	0	0	3	5	4	89	51	179	272	74.8	451
Greece	1,014	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	1,000	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	5,923	796	4	1	4	119	15	296	1,319	914	2,448	65.6	3,362

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 124 presents the changes that occurred between T1 and T2 samples. Eventually 3,362 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 124: Transition of the T1 sample into the T2 sample

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Size of the T1 sample	1,003	1,014	990	1,000	921	995	5,923
No of dropped cases	552	732	127	125	346	679	2,561
Size of the T2 sample	451	282	863	875	575	316	3,362
% 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	88	184	161	200	102	914
	39.7 %	31.2 %	21.3 %	18.4 %	34.8 %	32.3 %	27.2 %
With full interview	272	194	679	714	375	214	2,448
	60.3 %	68.8 %	78.7 %	81.6 %	65.2 %	67.7 %	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)[14] have been compared with regard to selected demographic features derived from the baseline study. Figure 7 shows an ideogram reflecting samples' sizes at the European level. Table 125 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

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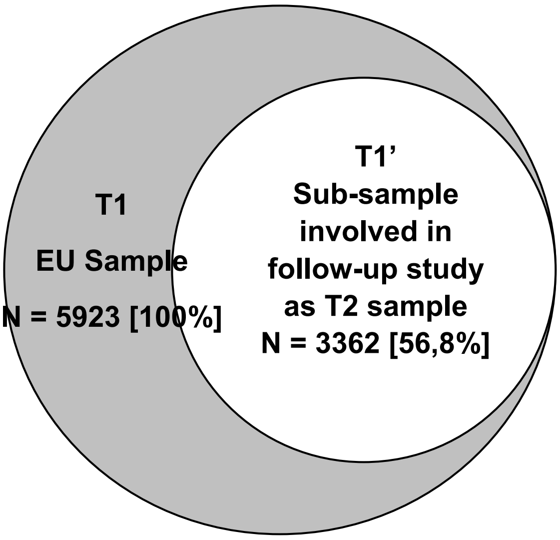
[14] T1 sample refers to the baseline sample; T1' sample is a sub-sample of T1 sample, which was accessible for the Follow-up study. It is an equivalent of T2 sample.

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.

Figure 7: 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 125: Comparison of sample T1 with sample T2 with regard to the distribution of the chosen CAT characteristics (in %)

	Germany		**Greece**		**Italy**		**Poland**		**Sweden**		**UK**		**Total**	
	T1 **N = 1,003**	**T2** **N = 451**	**T1** **N = 1,014**	**T2** **N = 282**	**T1** **N = 990**	**T2** **N = 863**	**T1** **N = 1,000**	**T2** **N = 875**	**T1** **N = 921**	**T2** **N = 575**	**T1** **N = 995**	**T2** **N = 316**	**T1** **N = 5,923**	**T2** **N = 3,362**
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 [e16sex]														
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 [c161sex]														
Male	23.8	22.6	19.14	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 [c21_r] v411														
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 [cogn_r] v411														
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 [nneg_c_7] v514														
Lower	44.8	37.7	26.7	19	40.6	40.4	69.8	70.5	38.9	39.3	54.6	42.9	Lower	44.8
Higher	55.2	62.3	73.3	81	59.4	59.6	30.2	29.5	61.1	60.7	45.4	57.1	Higher	55.2
	P = 0.011		**P = 0.0008**		NS		NS		NS		**P = 0.0003**			
Quality of Life dichotomized [nquol_5] v515														
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 126: Mode of administration of the FU questionnaires

Mode of aministration	Germany N = 451		Greece N = 282		Italy N = 863		Poland N = 875		Sweden N = 575		UK N = 316		Total N = 3,362	
	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	1,157	41.5
Total	451	100	282	100	863	100	875	100	575	100	316	100	2,786	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 126). 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 127), 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 127: Interval between T1 and T2 studies (in days)

Germany	Greece	Italy	Poland	Sweden	UK	Total
N = 451 369±27.5	N = 282 417.8±73.9	N = 863 371.6±18.8	N = 875 380.8±25.5	N = 569 419.9±30.6	N = 310 368.3±49.1	N = 3,350 385.5±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 8: Design of the Follow-up Study

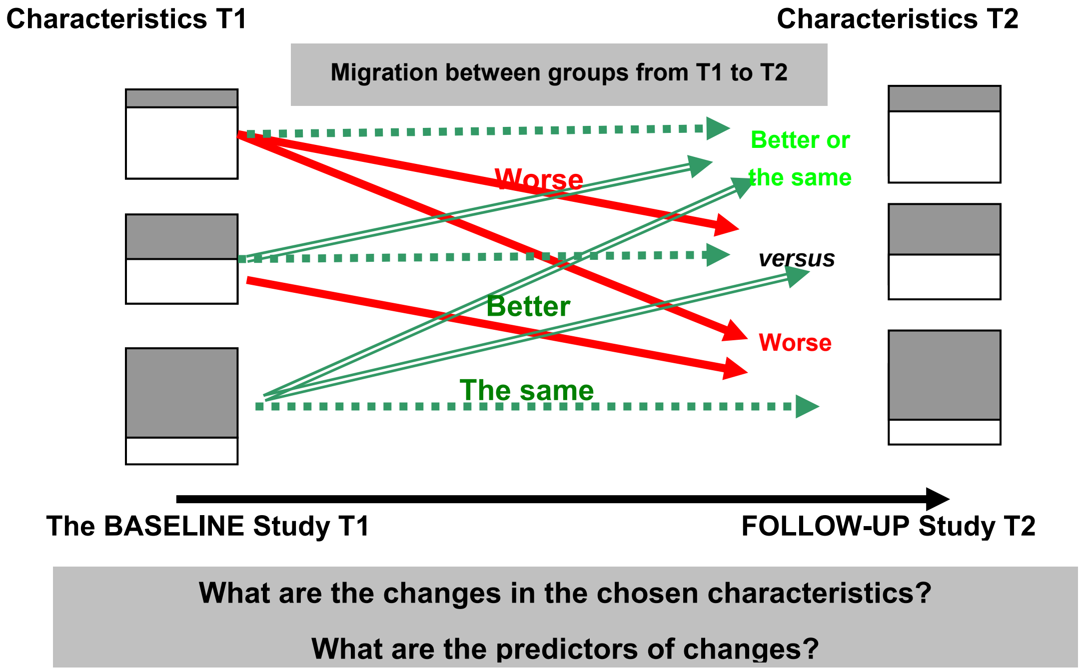


Figure 8 presents the overall design of the Follow-up study. The main aim was to find or discriminate between those carers whose characteristics "changed into a better state" (and / or those unchanged) versus those reporting a "worse" situation with respect to each of the analysed variables. The purpose 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 128: Transition in "global carer's well-being" between time T1 and T2 amongst "still-caring carers" (n = 1,966; missing 482)

		T2 Higher well-being	T2 Intermediate well-being	T2 Lower well-being	Total
T1	Higher well-being	478	228	41	747
	% of row	64 %	30.5 %	5.5 %	100 %
T1	Intermediate well-being	258	379	157	794
	% of row	32.5 %	47.7 %	19.8 %	100 %
T1	Lower well-being	50	134	241	425
	% of row	11.8 %	31.5 %	56.7 %	100 %
Total N		786	741	439	1,966
% of row		40 %	37.7 %	22.3 %	100 %

Based on the results from the baseline study, three cluster of carers were recognizable (total no = 2,344; 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 cluster were identified (total no = 2,037; missing 411). By cross-tabulation, the changes in global well-being are shown in table 128.

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 129: Transition in the "overall quality of life" between time T1 and T2 in all resurveyed carers (n = 3,186; missing 176)

		T2 Higher QoL	T2 Intermediate QoL	T2 Lower QoL	Total
T1	Higher QoL	589	430	126	1,145
	% of row	51.4 %	37.6 %	11 %	100 %
T1	Higher QoL	270	627	335	1,232
	% of row	21.9 %	50.9 %	27.2 %	100 %
T1	Higher QoL	103	269	437	809
	% of row	12.7 %	33.3 %	54 %	100 %
Total N		962	1,326	898	3,186
% of row		30.2 %	41.6 %	28.2 %	100 %

Three cluster 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 129 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 130). More than half of those stopped because of the elders' death.

Table 130: "Continuity" versus "discontinuity" in caregiving for the older relatives over one year

	Germany **N = 451**	**Greece** **N = 282**	**Italy** **N = 863**	**Poland** **N = 875**	**Sweden** **N = 575**	**UK** **N = 316**	**Total** **N = 3,362**
Still caring	272	194	679	714	375	212	2,446
% 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 %
Stopped caring 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 131.

Table 131: Reasons for withdrawal of care, other than older person's death (N = 339)

	Germany **N = 64**	**Greece** **N = 26**	**Italy** **N = 54**	**Poland** **N = 55**	**Sweden** **N = 93**	**UK** **N = 47**	**Total** **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	13	27	32	7	8	100
% by country	20.3 %	**50 %**	**45 %**	**58.2 %**	7.5 %	17 %	29.6 %

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Other events / miss ing data	6	9	1	14	0	15	45
% by country	9.4 %	34.7 %	11.7 %	25.4 %		31.9 %	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 131).

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 132: Mortality rates per chosen characteristics and country (% by category & by country)

	Germany **N = 451**	**Greece** **N = 282**	**Italy** **N = 863**	**Poland** **N = 875**	**Sweden** **N = 575**	**UK** **N = 316**	**Total** **N = 3,362**
In whole sample n = 3,362	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 = 1,459	35 21.2	27 20.0	36 11.6	41 8.4	38 16.5	17 12.9	194 13.3
Age > = 80 n = 1,885	77 27.6 %	35 23.8 %	94 17.0 %	65 16.8 %	67 19.8 %	40 22.0 %	378 20.0 %
Type of locality [g4loca]							
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 = 1,603	45 25.6 %	34 25.4 %	64 12.8 %	28 11.7 %	67 **18.9 %**	36 18.2 %	274 17.1 %
Rural n = 1,044	24 22.0 %	19 16.4 %	28 15.4 %	33 9.7 %	35 17.7 %	17 17.0 %	156 14.9 %
IADL dependency [iadl_t_r]							
Low to moderate n = 1,011	18 23.1	10 12.2	15 6.1	21 5.8	24 14.7	10 10.1	98 9.7
More severe n = 2,324	96 **25.8 %**	51 **25.9 %**	46 **18.1 %**	83 **16.5 %**	82 **20.3 %**	46 **21.7 %**	473 **20.4 %**
Cognitive disorders [cogn_r]							
Intellectually able n = 1,235	20 19.6	19 17.9	35 10.6	28 7.5	39 18.8	21 17.8	162 13.1
Probable / suspected n = 2,109	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 132.

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 133). 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 133: Institutionalisation rates per year and per country (in % of category within country)

	Germany N = 451	Greece N = 282	Italy N = 863	Poland N = 875	Sweden N = 575	UK N = 316	Total N = 3,362
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 = 1,459	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 = 1,885	24 8.6 %	0	13 2.4 %	3 0.8	48 14.2 %	11 6 %	99 5.3 %
Type of locality [g4loca]							
Metropolitan n = 704	14 8.4 %	1 3.1 %	9 5.0 %	0	0	0	24 3.4 %
Urban n = 1,603	16 19.5 %	0	3 0.6 %	4 1.7 %	49 13.8 %	10 5.1 %	82 5.1 %
Rural n = 1,044	10 9.2 %	0	6 3.3 %	1 0.3 %	20 10.1 %	8 8.0 %	45 4.3 %
IADL dependency [iadl_t_r]							
Low to moderate* n = 1,011	4 5.1 %	0	2 0.9 %	1 0.3 %	7 4.3 %	2 2.0 %	16 1.6 %
More severe* n = 2,324	36 9.7 %	1 0.5 %	16 2.5 %	4 0.8 %	63 15.6 %	16 7.6 %	136 5.9 %
Cognitive disorders [cogn_r]							
Intellectually able n = 1,235	7 6.9 %	0	3 0.9 %	1 0.3 %	9 4.3 %	1 0.9 %	21 1.7 %
Probable / suspected n = 2,109	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 [work_r]							
Nonworking n = 2,093	17 5.9 %	1 0.6 %	10 2.0	4 0.8 %	45 11.5 %	13 5.8 %	90 4.3
Working n = 1,249	22 13.9 %	0	8 2.2 %	1 0.3 %	26 14.4 %	5 5.7 %	62 5 %
Negative impact of care in T1 [nneg_c_7]							
Lower negative impact n = 1,536	15 8.9 %	1 1.9 %	3 0.9 %	0	20 9.0 %	2 1.5 %	41 2.3 %
Higher negative impact n = 1,793	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 [nc97qol1]							
Better health (1-3) n = 1,989	26 8.5 %	0	8 1.6 %	2 0.5 %	47 12.7 %	15 7.1 %	98 4.9 %
Worse health (4-5) n = 1,357	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 134: Predictors of withdrawal from care (dependent on older persons)

	"Ex-carers" Elder alive but carer stopped care N = 336 (MD = 3)	**"Still caring" carers** Elder alive and carer still continues caring N = 2,436 (MD = 10)	**Total** N = 2,772 (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 134 (related to the older persons) and in table 135 (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 134). 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 135) 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 135: Predictors of withdrawal from care (dependent on carer) (in % in column within category)

	"Ex-carers" Elder alive but carer stopped care N = 336 (MD = 3)	**"Still caring" carers** Elder alive and carer still continues caring N = 2,436 (MD = 10)	**Total** N = 2,772 (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 %

	"Ex-carers" Elder alive but carer stopped care N = 336 (MD = 3)	**"Still caring" carers** Elder alive and carer still continues caring N = 2,436 (MD = 10)	**Total** N = 2,772 (MD = 13)
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 136: Changes in the intensity of care (No of hours / week) amongst carers still caring between T1 and T2

Difference in an average number of hours of care (T1-T2)	**Germany** **N = 272** **MD = 24**	**Greece** **N = 194** **MD = 2**	**Italy** **N = 679** **MD = 12**	**Poland** **N = 714** **MD = 6**	**Sweden** **N = 375** **MD = 20**	**UK** **N = 212** **MD = 12**	**Total** **N = 2,446** **MD = 82**
No of valid	248	192	667	708	335	194	2,364
An average difference in hours	-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 136). 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 137.

Table 137: Distribution of caregivers by change in an intensity of care during a year

Difference in an average number of hours of care (T1-T2)	**Germany** **N = 272** **MD = 24**	**Greece** **N = 194** **MD = 2**	**Italy** **N = 679** **MD = 12**	**Poland** **N = 714** **MD = 6**	**Sweden** **N = 375** **MD = 20**	**UK** **N = 212** **MD = 12**	**Total** **N = 2,446** **MD = 82**
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 %	1,021 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 IADL dependency *versus* (2) a category with worsened IADL dependency during the follow-up year (table 138).

Table 138: Difference in the intensity of care between T1 and T2 by categories: "IADL better or the same" *versus* "IADL worse" than at T1

	Germany	**Greece**	**Italy**	**Poland**	**Sweden**	**UK**	**Total**
Better or the same IADL 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 IADL 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 IADL dependency than at T1", the average number of hours per week decreased by 3.3, whilst in the sub-group "Worse IADL dependency than at T1", it increased by 2.8. The same direction of change was found in all countries with the exception of Poland. 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 139. 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 139: 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 = 2,420
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	2,122
(% 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 140: 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 = 2,400
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 %	2,141 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 140). 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 141 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 141: Restrictions on professional career in the groups of "current workers" and "current non-workers" (at T2)

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Currently 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	44	250	287	82	37	758
	74.4 %	89.8	90.3 %	94.7 %	78.1 %	77.1 %	88.1 %
Because of caring I had to reduce my working hours	17	5	25	9	15	15	82
	21.8 %	10.2	9 %	3 %	14.3 %	14.3 %	9.6 %
I had to reduce my working hours for another reason than caring	3	0	2	7	8	8	20
	3.8 %		0.7 %	2.3 %	7.6 %	7.6 %	2.3 %

	Germany	Greece	Italy	Poland	Sweden	UK	Total
Currently not working (at T2)							
No of valid cases	N = 135	N = 80	N = 208	N = 359	N = 197	N = 113	N = 1,092
Because of caring I could not carry out my job at all	16	48	17	10	192	31	314
	11.9 %	60 %	27.4 %	2.8 %	97.5 %	27.4 %	28.7 %
Because of caring I had to give up my job	20	1	5	7	1	8	42
	14.8 %	1.2 %	2.4 %	2 %	0.5 %	7.1 %	3.9 %
I stopped work for another reason than caring	99	31	186	342	4	74	736
	73.3	38.8 %	89.4 %	95.2 %	2 %	65.5 %	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 142: 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	2,280
YES	28	38	24	28	31	39	188
	12.3 %	20.1 %	3.7 %	3.2 %	9.7 %	21.4 %	8.3 %
I can / could work only occasionally (at T2)							
No of valid cases	227	189	636	707	271	156	2,186
YES	36	30	19	24	15	50	174
	15.9 %	15.9 %	3 %	3.4 %	5.5 %	32.1 %	8 %

	Germany	Greece	Italy	Poland	Sweden	UK	Total
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	2,395
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, I 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 142). 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 143: 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 = 2,391
T1	Yes, I could find someone quite easily	**700**	361	91	1,152
	% of row	**60.8 %**	31.3 %	7.9 %	100 %
T1	Yes, I could find someone, but with some difficulty"	232	**351**	147	730
	% of row	31.8 %	**48.1 %**	20.1 %	100 %
T1	No, there is no one	65	205	**239**	509
	% of row	12.7 %	40.3 %	**47 %**	100 %
	Total N	997	917	477	N = 2,391
	% of row	41.7 %	38.3 %	20 %	100 %

Other restrictions relate to everyday life (table 142). 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 143 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 144 presents changes in IADL functioning, measured in terms of the number of IADL 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 144: Changes in IADL 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 = 2,339
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 = 2,339
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 IADL 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 IADL functions) the proportions both "improving" and "worsening" in IADL dependency were fewer in comparison to the more ambiguous definition as "not able" (compare percentages at table 144). 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 145).

Table 145: Changes in P-ADL dependency between T1 and T2 (in % from columns)

Number of dysfunctions defined as "not able or able with help"	Germany	Greece	Italy	Poland	Sweden	UK	Total
No of valid cases	N = 244	N = 173	N = 648	N = 700	N = 334	N = 178	N = 2,277
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 146: 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 = 2,409
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 146 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, improvement 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 147 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 147: 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 = 2,333
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 148.

Table 148: Transition in older people' mental status between T1 and T2 within categories from the baseline study (in % within categories)

		T2 Intellectually able	**T2** Behavioural disorders only	**T2** Memory impairment only	**T2** Memory and behavioural disorders	**total**
	No of valid	N = 850	N = 380	N = 184	N = 909	N = 2,323
T1	Intellectually able	**614**	163	53	119	949
	% of row	**64.7 %**	17.2 %	5.6 %	12.5 %	100 %
T1	Behavioural disorders only	100	**109**	17	89	315
	% of row	31.8 %	**34.6 %**	5.4 %	28.2 %	100 %
T1	Memory impairment only	61	36	**57**	95	249
	% of row	24.5 %	14.5 %	**22.9 %**	38.1 %	100 %
T1	Memory and behavioural disorders	75	72	57	**606**	810
	% of row	9.3 %	8.9 %	7 %	**74.8 %**	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 (9.4.3.1);
- the quality of life of caregivers (9.4.3.2);
- the health status of caregivers (9.4.3.3); 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 (9.4.3.4).

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 misinterpretations, “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 149 shows for which part of the carers the positive, negative and overall value of care-giving has improved, worsened or remained constant.[15]

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

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[15] In this table, as in tables 150-152, positive and negative changes are compared. The higher of both numbers are highlighted.

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 deterioration in the positive value of care-giving. So it seems that over time the care-givers' 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 149: Change in the negative impact, positive value, overall impact from T1 to T2

Country and impact	Negative change (% of carers)	No change (% of carers)	Positive change (% of carers)	Valid answers (No.)	Missing (No.)
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

Country and impact	Negative change (% of carers)	No change (% of carers)	Positive change (% of carers)	Valid answers (No.)	Missing (No.)
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 150 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 150: Change in the quality of life from T1 to T2

Country	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 151).

Table 151: Change in the health status of carers from T1 to T2

Country	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 152 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 152: Change in the willing to continue to provide care to elder from T1 to T2

Country	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 9.4.3 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”[16] 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 dependent variable, i.e. outcome measures is analysed. Once again these variables are trichotomised. Table 153 shows the results for “negative impact”.[17] 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 9.4.5.

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[16] The category of "Health services" means those national services which were addressing the health needs of older persons (cf. details in chapter 7th).

[17] In table 153 to 156 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 153: 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: Service use		Change of “negative impact” (Dependent variable)			
		Negative change	No change	Positive change	N
T1	T2	%	%	%	
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 154 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 154: 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: Service use		Change of "positive value" (Dependent variable)			
		Negative change	No change	Positive change	N
T1	T2	%	%	%	
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 155) 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 155: 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)			
		Negative change	No change	Positive change	N
T1	T2	%	%	%	
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	32.3
Yes	No	**41.7**	41.7	16.7	41.7
Yes	Yes	35.8	35.8	**28.3**	35.8
No	No	31.7	48.8	19.5	31.7
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 156) and health status (table 157) 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 158).

Table 156: Effects of "health needs" service use of elders on changes of "quality of life" from T1 to T2 by elder from T1 to T2

Independent variable: Service use		Change of "quality of life" (Dependent variable)			
		Negative change	No change	Positive change	N
T1	T2	%	%	%	
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 157: Effects of "health needs" service use of elders on changes of "health status" from T1 to T2 by elder from T1 to T2

Independent variable: Service use		Change of „health status" (Dependent variable)			
		Negative change	No change	Positive change	N
T1	T2	%	%	%	
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 158: 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

Independent variable: Service use		**Change of “willing to continue to provide care to elder“ (Dependent Variable)**			
		Negative change	**No change**	**Positive change**	**N**
T1	**T2**	**%**	**%**	**%**	
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 159 present those services that were ranked most helpful by interviewees.[18]

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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[18] Interviewees were asked to name the most, second most and third most helpful service. The services mentioned in table 159 are those with the highest number of entries (the mode).

Table 159: Most, second most and third most helpful services for elder in carers‘ opinions

Services for elder	**Germany** **%**	**UK** **%**	**Sweden** **%**	**Poland** **%**	**Italy** **%**	**Greece** **%**
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	**Germany** **%**	**UK** **%**	**Sweden** **%**	**Poland** **%**	**Italy** **%**	**Greece** **%**
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 9.4.4 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 160, 161 and 162 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 160 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 IADLs (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 160 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 160 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 160: 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
Memory problems (worse)						
Memory problems (better)						
Nursing home			7.7			
Situation of carer						
Income of carer					0.9	
Age 46 and older of carer						
Cohabiting with elder						
Children						
People less then 15 in carer’s household						
Woman				0.7		
Single service used by carer						
Specific support services not used in T1 but used in T2						
Specific support services used in T1 but not used in T2				0.6		
Generic services not used in T1 but used in T2						
Generic services used in T1 but not used in T2						
Single service used by elder						
Health needs services not used in T1 but used in T2				2.9		
Health needs services used in T1 but not used in T2						
Physical / personal needs services not used in T1 but used in T2						
Physical / personal needs services used in T1 but not used in T2						
Mobility needs services not used in T1 but used in T2						
Mobility needs services used in T1 but not used in T2						
Emotional / psychological / social services not used in T1 but used in T2						
Emotional / psychological / social services used in T1 but not used in T2				0.4		
Organizing / managing care and support not used in T1 but used in T2						
Organizing / managing care and support used in T1 but not used in T2						
Domestic care services not used in T1 but used in T2						
Domestic care services used in T1 but not used in T2						

Variable	DE	UK	SE	PL	IT	EL
Residential and semi-residential care services not used in T1 but used in T2						
Residential and semi-residential care services used in T1 but not used in T2						
Other services not used in T1 but used in T2						
Other services used in T1 but not used in T2						
R2	0.17	0.27	0.22	0.15	0.18	0.34

Table 161 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 161: 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	
Behavioural problems (better)						
IADL (worse)						
IADL (better)						
Memory problems (worse)					0.3	
Memory problems (better)						
Nursing home						
Situation of carer						
Income of carer				0.9		
Age 46 and older of carer						
Cohabiting with elder						
Children						
People less then 15 in carer's household						
Woman						
Single service used by carer						
Specific support services not used in T1 but used in T2						
Specific support services used in T1 but not used in T2						
Generic services not used in T1 but used in T2						
Generic services used in T1 but not used in T2						

Variable	DE	UK	SE	PL	IT	EL
Single service used by elder						
Health needs services not used in T1 but used in T2						
Health needs services used in T1 but not used in T2						
Physical / personal needs services not used in T1 but used in T2						0.1
Physical / personal needs services used in T1 but not used in T2						
Mobility needs services not used in T1 but used in T2						
Mobility needs services used in T1 but not used in T2						
Emotional / psychological / social services not used in T1 but used in T2						
Emotional / psychological / social services used in T1 but not used in T2						
Organizing / managing care and support not used in T1 but used in T2						
Organizing / managing care and support used in T1 but not used in T2						
Domestic care services not used in T1 but used in T2						
Domestic care services used in T1 but not used in T2						
Residential and semi-residential care services not used in T1 but used in T2						
Residential and semi-residential care services used in T1 but not used in T2						
Other services not used in T1 but used in T2				3.8		
Other services used in T1 but not used in T2						
R2	0.15	0.25	0.11	0.06	0.12	0.25

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 162: 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		
Behavioural problems (better)						
IADL (worse)				0.7	0.6	
IADL (better)						4.3
Memory problems (worse)						
Memory problems (better)						
Nursing home						
Situation of carer						
Income of carer						
Age 46 and older of carer						
Cohabiting with elder						
Children						
People less then 15 in carer’s household						
Woman						
Single service used by carer						
Single service used by carer						
Specific support services not used in T1 but used in T2						
Specific support services used in T1 but not used in T2						
Generic services not used in T1 but used in T2						
Generic services used in T1 but not used in T2						
Single service used by elder						
Health needs services not used in T1 but used in T2						
Health needs services used in T1 but not used in T2						
Physical / personal needs services not used in T1 but used in T2						
Physical / personal needs services used in T1 but not used in T2						
Mobility needs services not used in T1 but used in T2						
Mobility needs services used in T1 but not used in T2						
Emotional / psychological / social services not used in T1 but used in T2						
Emotional / psychological / social services used in T1 but not used in T2						
Organizing / managing care and support not used in T1 but used in T2						
Organizing / managing care and support used in T1 but not used in T2						
Domestic care services not used in T1 but used in T2						
Domestic care services used in T1 but not used in T2						

Variable	DE	UK	SE	PL	IT	EL
Residential and semi-residential care services not used in T1 but used in T2						
Residential and semi-residential care services used in T1 but not used in T2						
Other services not used in T1 but used in T2						
Other services used in T1 but not used in T2						
R2	0.16	0.22	0.10	0.11	0.08	0.31

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

- The vast majority of initial family caregivers were still caring after a year.
- 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).
- 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.
- 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.
- 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 IADL dependency, and increased for those older persons who manifested a worse physical condition.
- 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).
- 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.

- 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.
- 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.
- 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.
- 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.
- 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).
- 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.
- 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.
- Consequently, in 4 out of the 6 country samples a decreasing willingness to care resulted.
- 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 care-givers' well-being, health or burden significantly.
- 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.
- 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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10 Summary of main findings from the Trans-European Survey Report (TEUSURE) and their implications for policy and practice in the support of family carers

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10.1 Introduction

In this chapter we summarise some of the main findings from the TEUSURE and link them to the original research questions and to the implications the findings have for both policy and practice in the support of family carers.

Section 10.2 reports the survey findings related to the questions

- WHY do family carers provide care?
- WHAT are the older persons' needs for care and help as reported by FCs?
- HOW are needs matched to care provision - WHO provides WHAT types of support?

and links them to some of the main issues for family care arising from the results.

Section 10.3 summarises the policy implications of TEUSURE for 3 sectors

- National and EU policy
- Service providers
- Family carers' organisations

and provides specific suggestions as to what actions can be taken by each sector in order to achieve positive changes in systems of support for family carers.

In order to facilitate the reader, abbreviations[19] have been used wherever possible and a table format for sections 1.2 and 1.3.

10.2 Main survey findings and issues arising

10.2.1 WHY do family carers provide care?

Physical illness / disability of the OP is most often declared as the main reason for needing care. In 46 % of all caring situations the family carers reported that the OP has memory problems. 34 % of all cared-for suffer from some behavioural problems and these represent the older people whom carers find most burdensome. Only 10 % of OP were independent in carrying out most activities of daily living.

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[19] Country abbreviations: Germany-DE, Greece-EL, Italy-IT, Poland-PL, Sweden-SE, United Kingdom-UK. Other abbreviations: Older person / people – OP, Family care / carer – FC, Local authority – LA, Non-governmental organization – NGO, Information technology – IT.

"Emotional bonds" (i.e. love and affection) constitute the principle motivation for caring for FCs (57 %), followed by a "Sense of duty" (15 %) and a "Personal sense of obligation" (13 %). Just 3 % said they "Had no other alternative" than to care as the main reason.

10.2.2 WHAT are the older persons' needs for care and help as reported by FCs?

SURVEY RESULTS	**ISSUES ARISING**
Domestic needs	
All countries: **92 %** (High IT 95 %, Low EL 86 %)	■ OP with a FC are least likely to get such services, either because limited home care services have to focus on isolated OP e.g. EL, or because home care services are having to provide more intensive care for fewer but more dependent older people e.g. UK. The wealthier can pay for such a service.
Emotional / psychological / social needs	
All countries: **89 %** (High IT 96 %, Low SE 85 %)	■ A very high need not classically considered as a responsibility of home care services, even though day care, Alzheimer cafes, and community centres may fulfil this function. These latter are important for carers as a way of providing respite care during the day. The potential role of volunteers in providing emotional and psychological support to the OP and thus respite to the FC needs to be further developed.
Mobility needs	
All countries: **82 %** (High IT 95 %, Low EL 72 %)	■ Inside the house: the need for mobility aids, technical adaptations and eventually the wider introduction of IT based technologies, are services that need to be further developed by LAs, NGOs and the promotion of information about their availability. Half of SE respondents got such technical adaptations but few in other countries. ■ Outside the house: environmental modifications, the adoption of new building standards in all built environments needs to be actively promoted by services, NGOs and LA planning departments. ■ Transport services were almost absent in EL and PL, compared with SE where 38 % had such access.

SURVEY RESULTS	ISSUES ARISING
Financial management	
All countries: **80 %** (High IT 92 %, Low UK 67 %)	■ A significant area of need and a major responsibility for FCs, which highlights the problems of protecting OP living alone and / or using services from financial mismanagement and theft. It needs practical organization and legal safeguards regarding the everyday management of the OPs resources. This need may also reflect memory and mobility problems and even low educational levels.
Organising and managing care and support	
All countries: **79 %** (High IT 94 %, Low UK 71 %)	■ Care managers for services can undertake the role of FCs for OP in this area, but there is limited evidence as to how cost-effective they are. The effectiveness of integrated care services and teams needs to be evaluated. An additional issue is that care services have to consider 24 hour and all year round coverage.
Health care needs	
All countries: **79 %** (High EL 88 %, Low UK 66 %)	■ This reflects the needs for support FCs have to supply in utilising health care services, including making appointments and accompanying their OP, ensuring correct medication, preventive and rehabilitative practices, diet etc. This need overlaps with the management of care and with personal care. Some new technologies may aid in this, but needs assessments rarely take into account this need of management.
Physical / personal care needs	
All countries: **66 %** (High IT 78 %, Low PL 46 %) (% differences reflect different levels of dependency as reported by FCs of OP in the 6 country samples)	■ The most dependent OP require daily hands-on care to deal with their personal care needs on a 24-hour, year round basis. Services have to be very well organised to be able to provide the intensity of care required at home in such cases. This is one area where training for FCs and professionals is vital, although many FCs are not very sensitised for the need of training. It is a sensitive area from the perspective of the FC, the OP and the professionals, where conflicts and barriers between service providers are most likely to arise and integrated service provision hard to achieve.
Financial support	
All countries: **36 %** (High EL 53 %, Low SE 13 %)	■ While only a third of FCs report such OPs needs, country variations e.g. the higher figures for EL and IT, reflect low incomes of OP and have implications for the reported high costs of using services.

10.2.3 HOW are needs matched to care provision? WHO provides WHAT types of support?

SURVEY RESULTS	ISSUES ARISING
Recognition	
■ Family carers and health and social services (probably older people too) find it difficult to recognize that family care is occurring unless there is a real incentive for FCs to register (e.g. money, services, rights), or incentives (e.g. training and resources) for services to reach out to FCs and OP. FC is both part of private life and yet may need public support. ■ FC is dynamic but the research shows it is a long term commitment: the average duration of family care in the moment of the interview was reported as 60 months (variation from 47 months in DE to 70 months in PL). ■ 27 % of FCs had stopped caring after one year, two thirds because the OP had died i.e. 17 % death rate for resurveyed FC's OP.	■ Early intervention targeting FCs e.g. recognition and information (local and national media programmes, newspapers etc), health protection, training in care techniques etc. ■ Training of services and care workers to recognise FCs. ■ Political will and resources to provide more help to FCs. ■ Levels of dependency and length of time caring can act as signals to service providers. ■ Information needed on effectiveness of bereavement counselling services.
Who are the family carers and the cared-for?	
■ Women are predominantly both the main carers (76 %) and the main older person cared for (68 %). ■ 50 % of FCs are children of the cared-for OP, though the SE sample had a high proportion of spouse carers. ■ In the UK the proportion of carers drawn from the extended family and neighbours (30 %) was much higher than in other countries. ■ 37 % of OP being cared for were married (56 % in SE). ■ FCs average (mean) age was 55 years and 53 % of OP being cared for were 80+ years old. ■ 96 % of older people were of national origins; only in UK were 20 % of older people of non-ethnic British origins.	■ Older women needing care in some countries constitute some of the poorest people in their population. ■ Current low birth rates have implications for the future supply of FCs. ■ Unknown effects of increases in divorce or non marriage on willingness to care. ■ Demographic ageing means that FCs will also be older. ■ The ageing of the EU migrant population will require culturally specific services; already occurring in the UK and being debated in SE.

SURVEY RESULTS	ISSUES ARISING
Who are the family carers and the cared-for? (cntd.)	
■ 69 % of the OPs needing care lived with someone else, with a tendency for those living alone to be the less dependent. 56 % of FCs live in the same household or in the same building as the cared-for person. 10 % of the carers in the European sample lived further away and needed at least 10 minutes by car, bus or train to get to the cared-for person. ■ A year later, 1 in 10 FCs had moved to the OPs home or the OP moved to theirs (19 % EL, marginal in SE and UK).	■ Mobility and the growth of single person households as income rises, leads to new issues of how to provide services and support FCs. Evidence needed on the effectiveness of and preferences for "sheltered accommodation" combined with family care arrangements in maintaining OPs autonomy.
Employment and working carers	
■ Employed carers (41 %) were less than non-working carers (59 %). Carers are more likely to be employed in the public sector (42 %); private sector (37 %) and 17 % self employed. ■ 15 % of the employed carers had reduced their working hours as a result of caring for elder relatives, and most had experienced a decline in their income as a result. ■ Non-working carers were mainly retired (60 %, 35 % in EL, 91 % in SE) and 26 % said they were housewives / househusbands (54 % in EL, 1 % in SE). ■ For 89 % of FCs a year later there was no change in their employment situation.	■ Women in most countries are disproportionately employed in the public sector, which tends to be more accommodating about care responsibilities, as illustrated by child-care rights. Self-employment possibly also allows some flexibility. ■ Non-working carers are both retirees and housewives / -husbands. Increasing female participation in the formal labour force will reduce the numbers of younger carers who have never been in the labour market and thus create increasing pressures on the reconciliation of work with caring for both men and women.

SURVEY RESULTS	ISSUES ARISING
Services	
▪ Less than one third of FCs had used a support service in the previous 6 months. Very few services are specifically intended for FCs in PL, IT, EL. Only SE, DE and UK have systematic and regularly used respite, socio-psychological and information services for FCs. In IT, EL and PL one result is substitution, with FCs using generic services instead e.g. information, advice and socio-psychological support from the GP, while the hospital is used as a substitute for missing rehabilitation and respite care. ▪ The more frail and dependent the OP the more they use services, but also the greater the negative impact on carers (largest negative effect in EL and SE, lowest in PL). ▪ 94 % of cared-for OP used at least one care service in the previous 6 months (mean 3.5 services), highest in SE, IT, DE, lowest in EL. ▪ Users and non-users of care services saw as a main barrier to use the bureaucratic complex procedures to get access to them (13 %, from 28 % in IT and 19 % in DE, to 4-7 % only in PL, UK and SE) and their high financial costs (13 %, from 29 % in PL and 18 % in EL, to 4-8 % in the other countries), albeit less than 10 % of FCs spend more than 20 € per month for specific support services, since these are often free, but inadequate provision means the alternative is the use of private care. ▪ Lack of information on available support (except for SE), low quality (except for PL), inadequate coverage (especially in PL and EL) and the refusal of OP to accept existing services (especially in UK, SE and, to a lesser extent, DE) represent other major barriers, preventing wider service use.	▪ One third of OP cared for are very dependent and their FCs need appropriate relief. ▪ Expensive acute hospital admissions are sometimes used if there are no alternative forms of respite and rehabilitation support. “Unnecessary / inappropriate” hospital (re-)admission may also reflect inadequate 24hr. supervision, management and evaluation of OPs needs. ▪ There is a high need for simplifying access procedures to services in some countries. Payment for services is less of a problem when OPs pension / income is adequate to cover this (SE), but sometimes it might be reasonable to consider the income of both the OP and the FC when reviewing the costs of services. ▪ Inadequate OPs pensions can only be fairly compensated for by free-to-user services (UK), otherwise FCs bear the costs, either by giving their own care services or paying others. ▪ Local Authorities can systematically assess and evaluate their services both for OP and FCs in terms of accessibility, availability and coverage.

SURVEY RESULTS	ISSUES ARISING
Services (cntd.)	
■ In all countries services have problems in distribution, especially in rural areas (particularly in PL and EL), and covering hours when FCs may be working. Respite care and the actual provision of practical relief is important but less readily available.	■ Public information campaigns could target FCs and promote services at national and local level, and thus aim to cover the many currently unmet needs of both FCs and OP.
■ Access to services takes place mainly through health professionals except for SE where it is social services. But in IT, EL and PL family, friends and neighbours remain the main sources of information. NGOs can be important (especially in UK & DE).	■ Lack of flexibility and inadequate coverage of services were reported by FCs as barriers to use of existing services. How can the optimum balance between formal and informal support networks and services be promoted and achieved?
Most important types of support	
■ Information and advice about the disease / condition of the OP and on how to access services agreed as critical by FCs and service providers. Services to provide FCs with time to have a care break, undertake activities they enjoy, spend time with their families and combine work with caring were what they desired.	■ The important role of NGOs in providing information, advocacy and services, an issue not directly addressed in the survey, needs to be clarified.
Commitment to care	
■ 69 % of FCs were willing to increase the level of care in the next year and almost 59 % would never consider their cared-for OPs placement in a care home, irrespective of circumstances, especially in PL and EL, while in SE 70 % of carers would consider the placement of the cared-for OP in a care home if the health of the OP worsened, and 17 % even if it stayed the same, compared to the European averages of 37 % (if worse) and 4 % (the same).	■ The SE tradition of well funded and extensive welfare state services with high quality residential institutions create open attitudes to the cared-for persons' placement in such centres. OP move to these homes with spouses and almost every second Swedish carer is a spouse / partner of the cared-for person. The quality and cost of residential homes influences decisions to care and PL and EL attitudes are influenced by these factors.

SURVEY RESULTS	ISSUES ARISING
Commitment to care (cntd.)	
■ One year later 5 % of the sample resurveyed reported the OP as being in a nursing home (12 % in SE, 0.1 % in EL). Amongst FCs no longer providing care where the OP was still alive, in one third of the cases the OP had gone into residential care and were characterised by severe ADL and cognitive decline and urban residence.	■ Confirms the critical role of serious dependency caused by decline in ADL and cognitive problems. Demographic projections and health studies suggest more cognitive decline and improvements in serious ADL.
Quality of Life	
■ The highest level of quality of life is found among the UK and the SE carers (67 % and 65 % respectively), and the lowest in the Mediterranean countries (EL 50 % and IT 51 %). ■ Determinants of negative impact of caring on FCs dependent on health of OP, intensity of caring tasks, the carers' support networks and the types of services used.	■ Provides some evidence for the positive role of good service support for FCs. ■ Indicates the need for a wider variety of service support as well as flexible, comprehensive and integrated care services.
Financial Support	
■ Only 4 % of all FCs received care allowances and 37 % of the older people, though large cross national variations in coverage (60 % in DE, 2 % in EL) and in amounts paid, low in PL compared to IT, UK and DE).	■ Highlights cross-national inequalities in financial support for family caregivers and dependent older people and underlines the need for EU policy and guidelines on minimum standards in this area.

10.3 Policy Implications of TEUSURE

10.3.1 National and EU Policy

- Using the Open Method of Coordination, formulate EU guidelines and recommendations on the best and most viable forms of financially supporting dependent OP and FCs for implementation at national levels.
- Achieve an increase in female participation in the labour market (the Lisbon Targets), by promoting service support for family care and redefining family care as work. Psychological research suggests that such an approach would reduce the intrinsic value of caring, i.e., remove much of the positive value currently found in caring and thereby perhaps increase the likelihood of the breakdown of family care.

- Promote and adopt EU standards in training for employment in care services as a step in improving quality in services.
- Create new jobs in the care sector by ensuring that services are planned to be flexible and more extensive, to cover the practical support of family carers, including working carers, on a 24 / 12 basis.
- Optimise existing care resources for dependent older people by supporting family carers, specifically by providing financial and service support.
- Target support for the most burdened family carers i.e. those caring for OP with memory and behaviour problems, by providing practical and flexible respite, day care and information services.
- Invest in "family carers support centres" since they can make savings within the national health and social care systems.
- Promote and adopt national standardised evaluation and monitoring procedures for all services and use these as a basis for future funding.
- Acknowledge and develop measures to regularise the current use of and reliance on migrant care workers, legally and illegally employed in many European countries, and include them in the formal labour market.
- Review the real costs in time and money of accessing and using health and social services to make them more accessible and useful to family carers.

10.3.2 Service Providers

- Improve service provision for older people and family carers in terms of coverage, quality and accessibility by granting appropriate funding or rationalising existing resources to this purpose.
- Develop more imaginative and proactive approaches to informing FCs of existing services e.g. through use of local and national media to increase knowledge about services, improve their social acceptability. This will also act to promote the image of family carers in society.
- Adopt quality standards in training for employment in care services as an integral part of all local services.
- Adopt standardised evaluation and monitoring procedures for needs and services supporting family carers and older people.
- Consider how best to integrate service provision, based on comprehensive needs assessment, to cover the diverse and changing needs of FCs for help and support (medical, social, psychological, financial). This will require the development of specially trained, interdisciplinary teams (public or NGO) to co-ordinate existing services and develop new networks of services at local levels. Appropriate incentives shall be introduced to improve current levels of integration of existing services and inter-disciplinary care work.

- Provide migrant care workers with opportunities for training and registration, to avoid the possible exploitation of both care workers and cared-for and to improve the quality of delivered care.

10.3.3 Family Carers Organizations

- NGOs need to campaign for a recognition of the real costs in time and money of: providing essential care and support to dependent older people accessing and using services.
- NGOs need to advocate for more flexible and extensive services, including both home based and residential respite and emergency care.
- Family carers need more information and NGOs can help provide this.