

EUROFAMCARE

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

The National Survey Report for Greece

(Deliverable N° 18)

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Contents

FOREWORD AND ACKNOWLEDGEMENTS.....	6
1 INTRODUCTION	8
1.1 AIMS AND STRUCTURE OF THE EUROFAMCARE PROJECT	8
1.2 INTRODUCTION TO THE GREEK NATIONAL SURVEY REPORT	10
2 ISSUES AND CHALLENGES IN CARER SUPPORT: A CONSIDERATION OF THE LITERATURE . 12	
2.1 INTRODUCTION.....	12
2.2 RESEARCH ON FAMILY CARE IN GREECE	12
2.3 HISTORICAL AND POLICY CHANGES IN ATTITUDES TOWARDS FAMILY CARE	13
2.4 SUPPORTING FAMILY CARERS: IDENTIFYING SOME KEY ISSUES	13
2.4.1 <i>WHY support family carers?</i>	14
2.4.2 <i>WHO to support: Older people, family carers, or both?</i>	16
2.4.3 <i>WHAT do we mean by carer support?</i>	17
2.4.4 <i>WHEN to support carers?</i>	19
2.4.5 <i>HOW and WHERE should support be provided?</i>	21
2.5 DEVELOPING BETTER CARER SUPPORT SERVICES	21
2.5.1 <i>Availability</i>	22
2.5.2 <i>Accessibility</i>	23
2.5.3 <i>Appropriateness and acceptability</i>	24
2.5.4 <i>Affordability</i>	26
2.6. MOVING FORWARD	27
REFERENCES.....	27
3 ASSESSMENT TOOL	35
3.1 INTRODUCTION.....	35
3.2 CAT ITEMS AND INSTRUMENTS	36
3.2.1 <i>CAT administration</i>	36
3.3 ITEM TRANSFORMATION	41
3.4 SCALE DEVELOPMENT	45
3.5 THE COMMON ASSESSMENT TOOL – FOLLOW-UP QUESTIONNAIRE (CAT-FUQ): ITEM AND SCALE DEVELOPMENT AND DESCRIPTION.....	51
REFERENCES.....	54
4 SAMPLING, RECRUITMENT AND REPRESENTATIVENESS OF THE SAMPLE.....	56
4.1. AIMS OF CHAPTER 4	56
4.2. METHOD AND SAMPLE	56
4.2.1 <i>Sample units</i>	56
4.2.2 <i>Sampling strategy</i>	57
4.2.3 <i>Recruitment procedure</i>	59
4.2.4 <i>Number of planned respondents</i>	59
4.2.5 <i>Type of sampling</i>	59
4.2.6 <i>Sampling parameters</i>	59
4.2.7 <i>Distribution of the sample based on urban-rural parameters</i>	59
4.2.8 <i>Recruitment modes of family caregivers</i>	61
4.2.9 <i>Sampling strategy in Greece</i>	61
4.3 REPRESENTATIVENESS OF GREEK SURVEY SAMPLE (FAMILY CAREGIVER AND THE CARED FOR OLDER PERSON).....	62

4.4. DISCUSSION.....	63
5 MAIN CHARACTERISTICS OF THE SAMPLE – CARED-FOR OLDER PEOPLE AND THEIR MAIN FAMILY CARERS	65
5.1 AIMS OF CHAPTER 5	65
5.2 METHODOLOGY USED TO COLLECT, ANALYSE AND PRESENT THE DATA	65
5.3 MAIN FINDINGS.....	65
5.3.1 PROFILE OF CARED-FOR OLDER PEOPLE	65
5.3.1.1 Socio-demographic characteristics	65
5.3.1.2 Place of residence and household composition	66
5.3.1.3 Older person’s financial situation	67
5.3.1.4 Older person’s health situation and needs for support	68
5.3.1.5 Older person’s level of dependency	70
5.3.2 PROFILE OF FAMILY CARERS	74
5.3.2.1 Socio-demographic characteristics of carers.....	74
5.3.2.2 Education, personal and employment characteristics of family carers	75
5.3.2.3 Carers’ family situation	78
5.3.2.4 Carers’ financial situation	79
5.3.2.5 Carers general caring situation	80
5.3.2.6 Carers’ health status and quality of life	81
5.3.2.7 Factors influencing decision to care and main reason for caring.....	85
5.3.2.8 Carers’ opinions on future care	85
5.4 DISCUSSION.....	86
REFERENCES.....	87
6 DIFFERENT CARE SITUATIONS	89
6.1 AIMS OF CHAPTER 6	89
6.2 METHOD	89
6.2.1 Procedure	89
6.2.2 Description of clusters	91
6.3 FINDINGS	92
6.3.1 Care situations, motivations for caring and views on future care	94
6.4 FINAL COMMENTS.....	96
REFERENCES.....	97
7 NEED FOR SUPPORT, SERVICE USE, SERVICE SATISFACTION AND SERVICES PAID FOR	98
7.1 AIMS OF CHAPTER 7	98
7.2. METHODOLOGY USED TO COLLECT, ANALYSE AND PRESENT THE DATA	98
7.3 MAIN FINDINGS	99
7.3.1 Older peoples’ needs for support	99
7.3.2 Who provides the support?.....	101
7.3.3 Services supporting family carers – use, satisfaction and cost.....	103
7.3.4 Services for older people - use, satisfaction and cost.....	106
7.3.5 Reasons for not using or stopping using services.....	108
7.3.6 Sources of information and help in accessing services.....	114
7.3.7 Barriers to service use	115
7.3.8 Importance of different types of support.....	116
7.3.9 Importance of different service quality characteristics.....	118
7.4 DISCUSSION.....	118
<i>Final comments on the use of services in a European perspective</i>	<i>120</i>

<i>Usage of support services by family carers</i>	120
<i>Carers' experience in using services</i>	121
REFERENCES.....	123
8 SERVICE PROVIDERS' VIEWS ON SERVICES FOR FAMILY CAREGIVERS AND OLDER PEOPLE IN GREECE	124
8.1 AIMS OF CHAPTER 8	124
8.2. METHOD AND SAMPLE	124
8.2.1. <i>Sample</i>	124
8.2.2. <i>Recruitment</i>	126
8.2.3. <i>Method of analysis</i>	128
8.3. REPRESENTATIVENESS.....	128
8.4. MAIN FINDINGS.....	128
8.4.1. <i>Service providers' views on services for family caregivers - goals, benefit, quality, attitude, future development</i>	128
8.4.2 <i>Usage and Access</i>	129
8.4.3 <i>Coverage</i>	131
8.4.4 <i>Quality</i>	132
8.4.5 <i>Goals and Benefits</i>	134
8.4.6 <i>Costs</i>	135
8.4.7 <i>Attitudes</i>	135
8.4.8 <i>Future Developments</i>	136
8. 5. DISCUSSION.....	139
9 THE ONE-YEAR FOLLOW-UP STUDY	140
9.1 INTRODUCTION.....	140
9.2 AIMS OF CHAPTER 9	140
9.3 METHODOLOGY.....	140
9.3.1. <i>Follow-up Study design and procedure</i>	140
9.3.2. <i>The Follow-up Questionnaire and the implementation of the FU study</i>	141
9.3.3 <i>Specific problems of the Greek FU survey</i>	141
9.4 RESULTS OF THE GREEK FU SURVEY	142
9.4.1 <i>Subjects, sample size, response rates and reasons for non response</i>	142
9.4.2 <i>Representativeness of the FU sample (T2) in relation to the initial samples (T1)</i>	143
9.5 MAIN FINDINGS OF THE GREEK FOLLOW-UP SURVEY.....	144
9.5.1 <i>Continuity versus discontinuity in care: Reasons for discontinuity in care</i>	144
9.5.2 <i>Mortality in the sample of cared-for older people</i>	145
9.5.3 <i>Discontinuity of care - possible predictors</i>	146
<i>Analyses and statistics</i>	146
9.5.4 <i>Change in living arrangements in relation to the distance of the carer's home from the cared-for person</i>	146
9.5.5 <i>Changes in carers' occupational status, restrictions on professional career and other restrictions due to care</i>	147
9.5.6 <i>Changes in the level of the older people's physical and mental condition</i>	149
9.5.6.1. <i>Physical disability after a year</i>	149
9.5.6.2. <i>Mental disability after a year</i>	151
9.6 SUMMARY REMARKS:.....	152
REFERENCES.....	153
10 SUMMARY OF MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATIONS	155

10.1 SUMMARY OF MAIN FINDINGS FROM THE GREEK NASUR	155
10.2 CONCLUSIONS AND RECOMMENDATIONS FROM THE GREEK NASUR.....	156
ANNEX 1 THE MEMBERS OF THE EUROFAMCARE GROUP	159
ANNEX 2 THE MEMBERS OF THE INTERNATIONAL ADVISORY BOARD	160
ANNEX 3 LIST OF CO-ORDINATORS AND INTERVIEWERS FOR EUROFAMCARE GREEK NATIONAL SURVEY	160

Foreword and acknowledgements

The family care of all those in Greek society who are dependent on others for support in the activities of daily living has long been a neglected issue. There is a tacit assumption by both citizens and the Greek state that the work of family care is entirely the responsibility of families and only in the minor sense of some tax concessions, is there any recognition that there are additional responsibilities and costs when undertaking care.

In 1990 two of the authors of this report undertook a small, qualitative study for the European Foundation for the Improvement of Working and Living Conditions in Dublin on the family care of dependent older people in Greece (Mestheneos, Triantafillou 1993). In depth interviews with family carers in 2 remote villages in the island of Lesbos as well as in Athens, provided a rich source of information on their situation, experiences, problems and satisfactions in caring for their dependent older relatives. At that time services for older people were very slowly developing and there was little recognition of the needs of family carers for support. Yet demographic changes over the past and the imminent decades means there are a greater number of older people surviving for longer periods and needing help from a declining number of family carers. At the same time other social changes such as urbanisation, women's increasing participation in the paid labour market and even the intensity of work, makes the issue of family care one that requires public debate and reflection. Is family care of dependent older people only a matter for private individuals and households or should the public sector take on some responsibility for helping and supporting family carers in the work of caring? Greek governments have accepted the common European Union goal, originally expressed in the Treaty of Lisbon, of attempting to increase the employment rate¹ by ensuring that more people enter or stay in the labour market. This necessitates encouraging more women and more older workers to enter and remain in the labour market since this is the only way of increasing national wealth and payments into the social insurance funds, which currently bear the costs of longevity and the increased numbers receiving pension.

These policy issues are not unique to Greece; all the Member States are faced by most of these same dilemmas. Again there is nothing specifically unique about the amount of family care being given in many countries in Europe; in virtually all countries with the partial exception of some of the Scandinavian countries with well funded and high quality health and welfare services, the main support for older dependent people is the family and the individual carer. However there is a growing difference between those countries like Greece which still provide very little acknowledgement of the needs of family carers, and those countries which recognise that family carers need to be supported for both economic, practical and moral reasons.

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This report provides a basis for understanding the situation of family carers in Greece and identifying their main needs. Our heartfelt thanks are given to:

- the 1014 family carers who gave their time to allow us to complete the long questionnaire in the survey;

¹ The policy to develop day care centres and provide support for some centres for those with Alzheimer, marks a positive move towards helping family carers.

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Sextant Research Group, the Greek Research Team for EUROFAMCARE.

1 Introduction

Judy Triantafillou and Elizabeth Mestheneos

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 dependent people in Europe**. It aimed to fill a knowledge gap concerning the characteristics, coverage, existence, acceptability and usage of services supporting family carers in Europe at both the trans-European and the pan-European levels, with the objective of formulating suggestions:

- at the **macro-level**, on implementing comprehensive, more carer-friendly policies for older people in Europe;
- at a **meso-level**, for developing new partnerships between service providers, local authorities and caring families, and implementing innovative user-oriented services and
- at a **micro-level**, on how to systematically and adequately disseminate knowledge about caregiving, thus contributing to significantly improving the situation of the cared-for older people and at the same time improving 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 are family carers' experiences 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 support measures for family carers, where can such measures be found, and what are their deficiencies?
- How can they 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.

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

1. A **baseline survey** of ca. 6000 family carers (1000 per country) using an agreed protocol for sample selection and implementation of the survey, a common assessment

tool/questionnaire (CAT) for face-to-face interviews with the sample of family carers, data input and mainly quantitative, but some qualitative, data analysis.

2. A **follow-up study** of the original sample of family carers 1 year after the baseline interviews
3. 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 research studies form the basis of this report – **the Greek National Survey Report**.

A further report which is used and referred to in the Greek NASUR is the **Trans-European Survey Report (TEUSURE)** which provides an overview and synthesis of the results of the total survey sample from the 6 core countries, with relevant comparative analyses aimed at illustrating differences between country samples and specific sub-samples, as well as providing answers to the research questions. These analyses attempt to determine the factors involved in the interdependency between the family carers' needs and the needs of the cared-for older person and to 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 a **Pan-European** level, the six core countries and a further 17 European countries wrote **National Background Reports (NABARES)** using a standardised evaluation protocol (STEP) to describe the current situation of family carers and policies and services for their support, including examples of good practice. The reports were based on secondary analysis of existing information and expert interviews and/or focus groups, and provided the input for a **Pan-European Background Report (PEUBARE)**, which has been translated into Greek and is available on www.sextant.gr The **Examples of Good Practice** from all the NABARES have been collected together into a further report which is also available on the EUROFAMCARE website.

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, implemented by the Trans-European group and AGE throughout the 3 years but concentrated in the final year and subsequently, was the research action phase, **REACT** which 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 were also designed to 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, which aims to establish a European network of carer's organisations and researchers in this field to promote knowledge about family care and lobby for greater awareness of the immense work done by carers for dependent older people and the general society, as well as the development of policies and practices for their support.

A draft of a European Carer's Charter is under development 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.

A further outcome for the REACT phase in Greece is the development of a special information page for family carers on the 50+Hellas web site www.50plushellas.gr, dedicated to providing support and information to both family carers and those they care for.

1.2 Introduction to the Greek National Survey Report

The Greek NASUR was a unique opportunity not only to answer the more general questions set at the European level, but to also collect basic data on family care in Greece through the survey of a 1000 carers. The report follows a common format adopted by all participating countries, though the data refer specifically to the Greek findings.

Chapter 2 gives an overview on the state of the art of the literature on family carers of older people in Europe and support services for them, in particular focussing on the partnership approach to care and the international literature on this. It also refers to the very limited bibliography reported in the Greek NABARE .

In **Chapter 3** the EUROFAMCARE Common Assessment Tool (CAT) is described in detail. The chapter focuses on the development of items and instruments, questionnaire pilots, item' transformation, scale development and the psychometric characteristics of scales used as well as the translation process into Greek.

Chapter 4 deals with the Greek sampling and recruitment procedures and discusses the problem of representativeness.

In **Chapter 5** there is an overview of the main characteristics of the national sample. The first part shows the profile of the cared-for older people: socio-demographics, financial situation, living and household situation, health status, level of dependency and needs for support. The second part describes the profile of the family carers: socio-demographics, education and employment, financial situation, family and general caring situation, health situation and quality of life, as well as factors influencing their decision to care and their views on future care provision.

While the earlier chapters are mainly descriptive, **Chapter 6** deals with the development of a typology of caregiving situations in Europe, using a cluster analysis approach. It gives an answer to 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 clusters and their distribution are described. The implications of this for the situation of Greek caregivers are underlined.

In **Chapter 7** the analyses focus on the use of services by both older people and their family carers, as well as the take up of allowances and the experiences of family carers: the costs, their preferences and satisfaction with services. This chapter gives answers to the questions as to service availability, family carers' experiences in using them, the barriers that stop family car-

ers from using support services and the degree to which services reach those most in need of support.

The topic of **Chapter 8** is the Greek 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 provider's perspective using a qualitative approach. Additionally the importance of quality characteristics and types of service as well as future developments in services are described.

Chapter 9: The one-year Follow-up Study provides a time limited but important longitudinal dimension to the research, given the dynamic nature of care and the need to understand the factors influencing changes in care arrangements.

Chapter 10 summarises the main findings of the Greek National survey 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 Greece 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.

Additionally, the in-depth comparative knowledge from the six systematically chosen countries covering very different welfare and socio-economic systems, offers the potential to Greek decision-makers 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 this 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 and possibilities to promote the partnership approach in family care.

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

Elizabeth Mestheneos and Mike Nolan

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) noted, 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).

2.2 Research on family care in Greece

One of the first qualitative reports on family care in Greece, (Amira 1990) described the role of family care, while a later report by the same author and others, evaluating the “Help-at-Home” programme, provides a cost benefit analysis of the service, comparing this to the costs of residential care, though this was not focused on the benefits to family carers (Amira 2002). Triantafillou and Mestheneos in a qualitative study and in a number of articles on family care and services supporting older people and family carers have reviewed the support given to family carers and the private arrangements they are forced into making e.g. the use of migrant care workers. Since this original study there have been no further studies on family care though data from the European Household Survey and the EuroBarometer study provide some information on the probabilities of older people living near their families with some data on attitudes, patterns of help and support etc. (Walker, 2001, Iakovou 2000, 2001)

European research studies, such as PROCARE, provide descriptions of the services available for older people in Greece, together with some reflections on their use by family carers and whether or not family carers are “integrated” into the work of care teams. (Sissouras et al 2002, Leichsenring et al 2004.) The National Action Plans for Social Inclusion, published originally in 2001, are based on government plans for various groups of vulnerable people in the population, including older people though no specific mention is made of family carers of dependent older people. (Hellenic Ministry of Health and Welfare. 2003, EC 2001). Aspects of Greek public pol-

icy to support older dependent people are reviewed in the OECD and WHO reports. Only one research based article has been written on elderly abuse for the Council of Europe (Pitsiou, Spinelli 1995).

2.3 Historical and policy changes in attitudes towards family care

Fifteen years ago, at the time of the original European Foundation study, political debates and policy initiatives in the area of family care 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'.

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 examine how the results from the Greek national survey as well as the findings from the Greek National Background Report connect with these, whilst also raising questions that require further exploration.

2.4 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 and though 'hardly mentioned' in the 1960's (Brody 1995), 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) 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 clear 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 in supporting carers, particularly from a policy perspective?

2.4.1 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). This trend is far from universal and, as many of the 23 National Background Reports (NA-BARE's) demonstrated, family care is still not on the policy agendas of several European countries, including Greece, 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 or the absence of family. 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.

However, as noted in the Swedish National Background Report, within the past decade, there has been a growing recognition that demographic changes are creating increasing needs for care in an ageing population, which together with declining birth rates and more women working outside the home have resulted in fewer numbers of younger generation family members available to help provide care, and leading to an acknowledgment of the state's inability alone to provide **all** care for older people and a "re-discovery of family care." Thus in Sweden, as in some other countries, 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 that, as in Italy, the issue is now receiving greater attention.

However, despite these and other 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, as noted in the Greek section of the PROCARE report (Sissouras et al 2004), 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 (Soderino 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 e.g. UK, Netherlands, and 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 all of 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) while the availability of paid carers for older dependent people needing long term care is also problematic.

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 demand (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. While in the UK, the Scottish Executive responsible for policy in Scotland for family care recognises that many of its recommendations will require significant changes in existing professional culture and practice, in Greece we are very far from putting most of these issues on the policy agenda, since even the role of family carer is still largely unrecognised, both by the general public and by policy makers. One promising recent development was the conference in November 2006 on “The Caring family” organized by IKPA (Institute for Social Welfare and Solidarity) which was also supported by 50+ Helias. .

Thus, whilst in countries where the topic of family care is on the policy agenda, motivations for supporting family carers remain primarily pragmatic, there is some evidence of an emerging ‘rights’ based framework in a few countries; whereas, the answer to the question WHY support family carers in Greece may continue to be evaded by governments for as long as state intervention and support for dependent older people is perceived as necessary ONLY when the family “fails” to be able to provide for all needs of all its older members. This attitude is perpetuated by the poorly elaborated welfare state rights of Greek citizens, which has implications for the conceptual interest and ability of local authorities or the national government to consider that they need to support FCs.

However there have been signs of change as in the National Action Plan for 2007 – 2013 developed by the Greek Ministry of Health and Social Solidarity reference is made to the need to support families caring for dependent people,

A closely related issue in family care is WHO to support and it is to this question that attention is now turned.

2.4.2 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, as is the case for Greece. The Pan European Background Report, based on 23 national reports, 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). Whilst most effort has necessarily to be directed at supporting the older person, such support can have indirect benefits for carers themselves. There were also indications that in several countries dedicated support services for family carers are emerging (see www.sextant.gr and <http://www.uke.uni-hamburg.de/eurofamcare> for the Good Practice Guide). WHO currently provides support to family carers is a closely related issue with the national reports suggesting that family carers' first point of call, and most frequent form of support, is informal, with help being provided by family, friends or neighbours. Increasingly in a number of countries, family carers are purchasing help directly, often in the form of 'live in' support workers. This is particularly prevalent in Southern European countries, resulting in a growing and often unregulated workforce, with few safeguards on the quality of care provided (see PEUBARE). This is the situation in Greece, and as the findings from the National Survey indicated, was important for a significant section of the population. In many countries the only formal source of support for carers comes from voluntary, charitable or religious organisations. In Greece several such voluntary initiatives are playing a growing role in supporting family carers e.g. the Greek Alzheimer's Association, the Hellenic Gerontological and Geriatric Association, the Athens Association for Alzheimer and related disorders, as well as several others. (see www.50plus.gr).

The evidence from the 23 national reports suggests 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.

2.4.3 WHAT do we mean by carer support?

The question of what is meant by carer support is not straightforward since it 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 National background reports is the provision of **respite care**, usually seen as the provision of temporary care for the older person, with the main objective and benefit being respite for the carer. Respite care 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 indication that it is present in some form in all the EUROFAMCARE countries, including Greece, 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' were an explicit and resourced target of the 'Carers National Strategy' (DoH 1999), provision remains inadequate (Scottish Executive 2005b).

The listed types of support for family carers that are found in practice include information about available services, services that ease their load, assistance in accessing services, advocacy, training, expert carer programmes, individualised counselling and support groups, emotional

support, assessment of need for support, respite care, financial support, benefits and entitlements, home aids and adaptations and new technologies.

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, tailored to 'successive stages' of caring which often have their own specific needs (Jani-le-Bris 1993). Most reflect an instrumental motivation underpinning much carer support, with most effort being currently directed at services intended to maintain carers in their role. Thus 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), and 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 one-dimensional view, research and assessment often 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. and thus move beyond the '*usual recitations of burdens experienced*'

Another key consideration when addressing the 'WHAT' of carer support is to reflect upon the primary target of action (Schulz 2001): 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 measures used to indicate success are either absent or inappropriate.

Intervention studies often make a leap of faith from a relatively discrete intervention (such as an educational programme) to a longer-term outcome such as reduced burden or improved general well-being, without paying adequate attention to intervening effects. (Zarit and Leitsch 2001) Interventions need to be targeted on aspects of caregiving that are the most amenable to change (Braithwaite 2000).

However this sort of carefully tailored approach, increasingly advocated within the research based literature, is not reflected in the way that support services are currently 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 7).

Table 1: Suggested constituents of comprehensive carer support programmes

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

2.4.4 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 and other recent studies indicate that carers' needs change over time and that support should be tailored so as to reflect these differing needs. While these studies do not suggest that caring follows a uniformly similar path, they do identify 'threads of

continuity' (Aneshensel et al 1995) or 'discern consistency' (Montgomery and Kosloski 2000) in the care giving 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.

Aneshensel et al (1995) used the metaphor of caring as a 'career' while others have developed and tested these temporal models (Nolan et al 1996, 2003) showing that caring has 3 broad sequential phases :

- 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, thus limiting 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. 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:

PREparedness - 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 National Background reports. The provision of inappropriate support may explain why several studies in a number of countries have indicated the on-going 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. Such needs are often ignored in the situation of 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, and how it can be delivered.

2.4.5 HOW and WHERE should support be provided?

With respect to HOW and WHERE support is best provided Schulz (2001) raises several questions, for which there are as yet no definitive answers e.g. 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.

2.5 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 the 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, where 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.

2.5.1 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 from the non-existent, to those focused 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 resources, 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 throughout Europe.

2.5.2 Accessibility

Accessibility, relates to a number of dimensions with the most obvious being 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. 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 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 issues arising from the 'unique' caring situation, that thus fix specific goals at a 'specific point' in time; includes a broad and comprehensive range of interventions and the use of multiple evaluative criteria to judge their success or lack.

While the new policy rhetoric in several countries states that assessment should provide the opportunity to engage carers as 'true partners' (Audit Commission 2004, Nies 2004a), recent evaluations suggest that this is rare. Not only does this represent a 'lost opportunity' to forge positive relationships (Audit Commission 2004) but even worse 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 (and summarised in the Good Practice report. www.sextant.gr), but 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.

Exacerbating the problems of assessment, eligibility for services is determined largely by the objective circumstances of carers. Thus in the UK the dominant approach to the assessment of carers' needs targets services 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). 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 where *assessment processes are more interactive and holistic, giving carers the opportunity to determine more fully what they need.*

2.5.3 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 since it is deemed inappropriate or of unacceptable quality. Carers make subtle judgments 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.

The acceptability of help is often dependent on the quality of the personal relationship and rapport between professionals and carers 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, and 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). Important lessons about the appropriateness and acceptability of support can potentially be learned 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 key factors determine 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'. 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 is 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*'. The carers identified selected essential elements to the achievement of appropriate and acceptable services: these should:

- promote a good quality of life for the cared for person and for the carer;
- give carers recognition and support in the caring role;
- provide support that is consistent with the carers' values, routines, expertise (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 that:

- 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.

The similarities between Nicholas' practice-orientated study and theoretical and conceptual debates are striking and suggest that the 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', drawing 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 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 include:

- 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, p590)

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 direst 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 developed by EUROFAMCARE addressed the type of support carers would like and the quality criteria they apply (see chapter 3), and thus contributes to informed debate in this area.

2.5.4 Affordability

The income levels of both those being cared for and those providing care as well as the actual real costs of providing care have to be reviewed in understanding the current use of services. Though many services are provided in all countries free of charge by the public sector, or the dependent older person or the family carers are provided with extra income to cover additional caring costs involved, the suitability, adequacy, availability and the ability of the family carer to control the service delivery, means that many are forced to pay extra for services or else bear the brunt of care on their own.

The high extra costs e.g. out of pocket payments, that have to be incurred by those aged over 50 years using health services in Greece has been researched recently (SHARE, Axel Börsch-Supan et al eds. 2005), while other data on how the Greek population perceives, uses and evaluates health and health services, completed in 2003, provides a basis to evaluate the socio-economic distribution of health, (dis)-satisfactions with health services and their current cost to the Greek population. (Kyriopoulos, Gregory, Haralambos 2003) These findings are par-

alleled by the Greek National survey results which confirm that Greek family carers bore the highest costs of all the 6 countries in providing care for their dependent relatives.

2.6. 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 NA-BARE'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 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 of them, and for the first time provides a genuinely pan-European perspective on policies relating to the support of family carers.

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3 Assessment tool

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3.1 Introduction

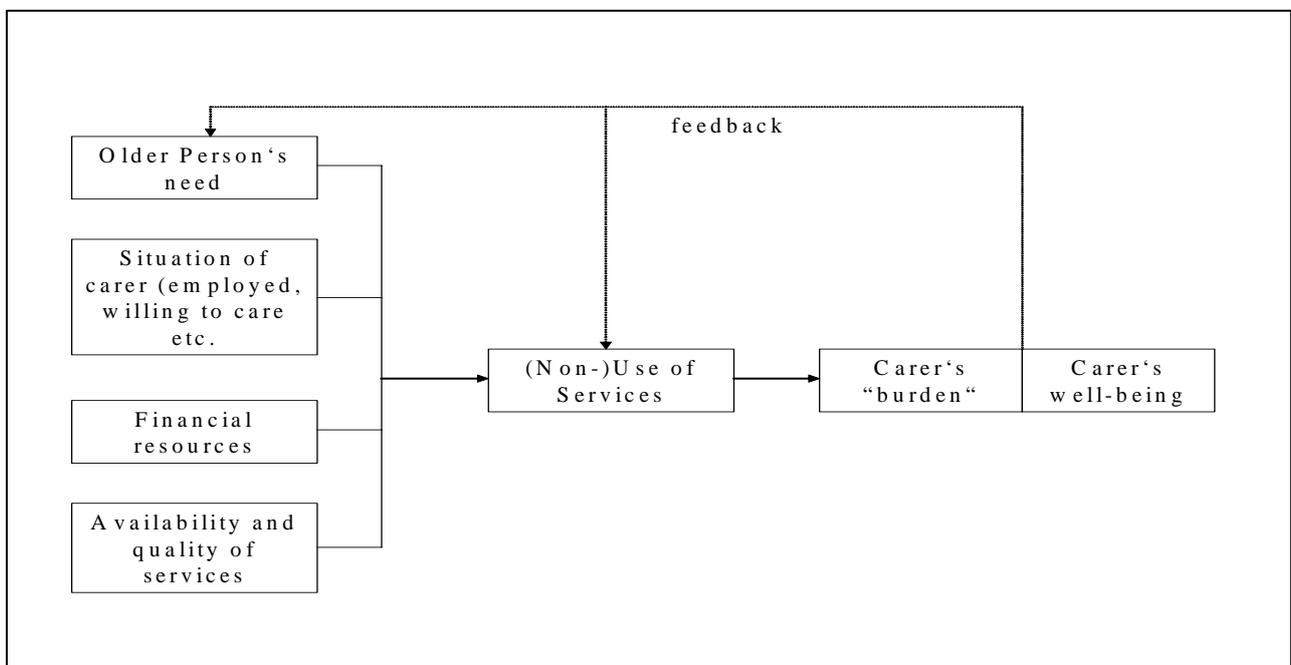
This chapter describes the assessment tools that are used for family carers in the EUROFAMCARE project and is the same as described in the EUROFAMCARE Trans-European Survey Report (TEUSURE) Chapter 3.

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 to ensure that satisfactory equivalent meanings and verbal stimuli were achieved in all languages (Brislin 1970, Sechret, Fay, Zaidy, 1972 p.41). 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.

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

Adapted from Aneshensel et al. (1995)



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. In the Greek case the final question asked about the carers' biggest worry (Tis sas kaei) as a way of concluding the interview and ensuring the family carers had an opportunity to freely express themselves.

In addition those family carers who were grandparents were asked a few questions about their role as carers of their grandchildren. 194 respondents provided answers on their caring work with grandchildren.²

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).

Mode of recruitment

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

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).

² This was done to provide quantitative data for a post graduate student undertaking work on Grandparenting within the Marie-Curie Training Network. See www.sextant.gr

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).

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.

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.

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.

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).

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). The respondent's perception of the older person's level of 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).

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 his/her 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).

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)

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)

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).

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.

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.

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).

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.

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).

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).

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).

Caregiving allowances

Four items (country specific) asked whether the carer or elder received financial support or allowances because of the care situation. For each item, the response options were 'Elder yes=1, no=0; Carer yes=1, n=0', dependent upon the appropriateness of the designated recipient for the respective allowance/financial support.

An additional item allowed the respondent to indicate whether they or their elder received any other form of financial support (specified; response options as above). The total amount of benefits received for carer and elder were then required (open response format), indicated for both as per week (1), per month (2) or per year (3).

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 any more'; because carer/elder was 'no longer entitled to use it'; or 'other' (specified). A similar question protocol was used to identify if there 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).

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 1 and 2.

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).

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.

Table 1: CAT transformed elder-related 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

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.

Carer's caregiving situation

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

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

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

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).

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).

Table 2: CAT transformed carer-related variables

Variable name	Categories/Levels	Values
Carer's marital status		
	Widowed, divorced/separated and single	1
	Married/cohabiting	0
Carer's relationship to elder		
	Partner	0
	Child	1
	Son/daughter in law	2
	Others	3
Number of children aged 14 or less in carer's household		
	None	0
	At least one	1
Carer's highest educational attainment		
	Low	1
	Intermediate	2
	High	3
Carer's employment status		
	Retired	0
	All other non-working (e.g., housewife/househusband)	1
	Working	2
Proximity of the respondent to Elder		
	Cohabitant	1
	Non-cohabitant	0
Number of nights of caregiving in typical week		
		0-7
Units of caregiving during week-end		
		0-10
Additional costs index		
		0-5
Number of services used by elder		

		0-15
Number of services used by carer		
		0-15

3.4 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.

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 3.2.3.4) 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 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 of 0 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 independence 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 3.3.2). 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 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.

Table 3: Elder-related scales

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Behavioural problems									
	5894	29 (.50)	2.00 (2.56)	1.00	1.12(.03)	.14(.06)	0.00	9.00	.78
IADL									
	5869	54 (.90)	4.27 (1.74)	5.00	-.63 (.03)	-.64(.06)	0.00	6.00	.78
Barthel Index									
	5684	239 (4.0)	69.70 (29.75)	80.00	-.99(.03)	-.17(.07)	0.00	100.00	.92
Disability index									
	5617	306 (5.2)	5.43(5.04)	4.00	.88(.03)	-.30(.07)	0	17.00	.93
Overall need for assistance									
	5811	112 (1.9)	6.01(1.79)	7.00	-.89(.03)	.07(.06)	0	8.00	.69

Carer-related scales

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.

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

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).

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).

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.

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 ($\alpha = .86$), 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).

Table 4: Carer-related scales

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Negative impact of caregiving									
	5847	76 (1.3)	11.89 (4.35)	11.0	1.07(.03)	.78(.06)	7.00	28.00	.83
Positive value of caregiving									
	5783	140(2.4)	13.45 (2.2)	14.0	-.74(.03)	.01(.06)	4.00	16.00	.65
Quality of support in caregiving									
	5810	113(1.90)	10.78(3.01)	11.0	-.11(.03)	-.69(.06)	4.00	16.00	.66
Well-being index									
	5880	43(.70)	13.89 (5.99)	15.0	-.31(.03)	-.65(.06)	0	25.00	.87
Elder's needs covered by carer									
	5830	93(1.6)	5.31 (2.00)	6.00	-.54 (.03)	-.55(.06)	0	8	.70
Elder's needs covered by informal support other than carer									
	5829	94(1.6)	1.82 (2.26)	1.00	1.12 (.03)	.14 (.06)	0	8	.82
Elder's needs covered by formal support									
	5827	96(1.6)	.85 (1.6)	0.00	2.06 (.03)	3.6 (0.6)	0	8	.86
Carer perceived need for more support									
	5634	289(4.9)	2.13 (2.46)	1.00	.98(.03)	-.25 (.07)	0	8	.86

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 4 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 (Table 5).

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 ($\alpha=.83$), 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).

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%

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

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.

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.

CAT-FUQ Items and Instruments

CAT-FUQ administration

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

case the latter mode of administration was used, the interviewer was required to specify (open response).

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.

CAT-FUQ Main Questionnaire

Elder's residence

An item determined Elder's usual place of residence (see Section 3.2.2.1)

Elder's disability and need

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.

Behavioural problems

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

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).

Carer's demographic and background characteristics

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)

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).

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)

Role inflexibility

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

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).

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).

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).

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).

Additional comments

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

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4 Sampling, recruitment and representativeness of the sample

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4.1. Aims of chapter 4

The aim of this chapter is to present how the data were collected in Greece, the overall sampling strategy used, and a comparison with the results from the other participating countries within the project. Finally consideration is given to the representativeness of the samples.

4.2. Method and sample

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:

- how to prepare the data collection
- how to evaluate the percentage of family carers in the whole population and to develop sampling strategies
- how to train the interviewees
- 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 European level of the data collected on the most relevant caregiving situations, 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. Representativeness means here to collect data which *represents the plurality of possible care situations*, which means the real distribution of care situations in each country is not necessarily reflected. The recruitment of family carers for interviewing i.e. the type of sampling was non-random sample, involving a combination of judgemental and informed expert advice (Lonner and Berry, 1986: 87)

4.2.1 Sample units

The *main family caregiver* in the study was defined as any person who provides at least 4 hours per week of care/support/help to an 65 year old or older relative for any kind of need, except for financial support only.

This definition **includes**, among others, any person who:

- perceives him/herself to be a carer according to the above definition (supporting an older person for at least 4 hours per week);
- organises the care provided by others, and these organisational tasks engage him/her for more than 4 hours per week;
- provides care to an elderly relative living at home; however, in order to take into account the reality of some areas in Southern Europe, where at times carers are expected to provide some kind of care to relatives even when the latter live in residential care settings (nursing homes, sheltered housing etc.), these cases were also accepted into the sample, provided that they met the inclusion criteria as specified by the above definition of primary caregiver.

This definition **excludes** any person who:

- only provides financial support to the elderly relative;
- just “visits” (even if for more than 4 hours per week) an elderly relative living in residential care settings.

In the situation where a carer provided support to more than one elderly person, the data collected referred to the most relevant care giving situation; in case more than one carer provided support to the same person, data had to be collected from the relative providing most care.

4.2.2 Sampling strategy

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 epidemiological 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 1000 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 are 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. There are few noticeable regional differences except with respect to remoteness from the metropolitan regions (this includes mountainous areas and 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 remoteness, as follows:

- Attiki including the metropolitan area of Athens-Piraeus and containing nearly 40% of the whole population
- Macedonia including the metropolis of Thessaloniki containing over 20% of the population
- the Peloponnese (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 resident 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 1. 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
	Voioatea	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
6. NorthWestern Greece	Ioannina	Ioannina (City) Ioannina Villages

	Arta	Arta (City) Arta Villages
	Kerkyra	Kerkyra (City) Kerkyra North Kerkyra South

4.2.3 Recruitment procedure

For each of the six areas one or more co-ordinators were identified. In the Region of Attiki there were five co-ordinators, in Thessaloniki two, while in the other regions there was one per region. All co-ordinators received training in Athens from the research team. In the Athens area a further training seminar was held for all interviewers together with the co-ordinators who provided the training. In the other areas each co-ordinator arranged training sessions with their local interviewers. A total of 70 interviewers were used. They were recruited by members of the research team and by the local co-ordinator, some of whom also acted as interviewers. Each interviewer was asked to interview a minimum number (12) of family carers in a selected area of the municipality chosen.

4.2.4 Number of planned respondents

A total of 1000 interviews were planned. In the event a total of 1,014 interviews were completed satisfactorily.

4.2.5 Type of sampling

The sample was non-random as no other possibility existed.

4.2.6 Sampling parameters

- 1) **territorial parameter:** the six different areas described above were selected to be geographically representative of the country.
- 2) **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.
- 3) **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.

4.2.7 Distribution of the sample based on urban-rural parameters

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 Km² 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 Km²³, 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 2. 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.

³ This is the definition of "rural" normally used by the European Union, for instance for the implementation of its structural funds policies (Esposti and Sotte 1999: 139), by ISTAT (the Italian National Institute of Statistics) (ISTAT 2001) and by Eurostat (2001).

4.2.8 Recruitment modes 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 channels⁴:

- 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 reflected in the table below.

Table 3. Mode of recruitment

Mode of recruitment	Frequency	%
Health or social care professional (doctor /social worker)	353	34.9
Religious organizations	43	4.2
Snowball/ Door to door	288	28.5
Voluntary organizations	15	1.5
Advertisement	2	0.2
Lists	8	0.8
Personal contact, neighbour, friend, relatives	292	28.9
other	11	1.1

4.2.9 Sampling strategy in Greece

The main difficulties in recruiting the sample of family carers were:

⁴ For an overview of possible methods to be used for survey purposes cfr. Neuman W.L. (2003) Social Research Methods: Qualitative and Quantitative Approaches. 5th Edition. Boston: Allyn & Bacon; a shorter description of possible biases in caregiving research can be found also in Dura JR, Kiecold-Glaser J K, Sample bias in caregivers research, J. Gerontology: Psychological sciences; n. 45, P200-204, 1990.

- a lack of public familiarity with social research and its uses. Thus people were sometimes suspicious as to the “real” purpose behind the interviews and also wanted to know what direct benefit accrued from participation.
- Interviewers varied in their capacity to obtain access to family carers and agreement to participate in the survey. Access was particularly difficult in exclusively working class areas e.g. Perama in Attiki, which in fact are very few in Greece as there is a very small industrial working class. Most urban areas have a very mixed socio-economic composition. Even within the same block of flats there are considerable differences in income levels – thus the top floor flat is usually occupied by people who are economically quite different from the people living in the basement flat.
- The length of the interview schedule also proved off putting to some family carers and in the event was often exhausting and time consuming. Others enjoyed their first opportunity to express their feelings and experiences of providing care for dependent older relatives.
- Door to door recruitment without any introduction (“cold-calling”), was unsuccessful especially in metropolitan and urban areas, and was abandoned after initial attempts
- Rural interviews occurred either through an initial contact with a service provider, or the interviewer had a personal contact in the village. An initial contact was enough to act as a way of access to the other family carers in the village.

The carers in the sample were overwhelmingly Greek and only 1.1% were of non Greek origin or other ethnic origin. While the Census showed a far higher proportion of non Greek origin, it is likely that this is not a strong bias in the sample since many of the non resident population are migrants, mainly of younger ages . Thus dependent older migrants are unlikely to be present in any number in Greece. It will be the second generation of migrants who will begin to have older parents here and who will have to become family carers in Greece.

4.3 Representativeness of Greek survey sample (family caregiver and the cared for older person)

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. 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 proportions 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, which is 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 both the slightly lower mean age of the Greek carer sample compared to the other countries, as well as 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 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 co-residence is common.

4.4. Discussion

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 working who were 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.

The Tables below provide a picture of the European sample overall and by country

Table 4. Distribution of sample by type of locality (No. and %)

	Greece		Italy		UK		Sweden		Poland		Germany		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Metropolitan	163	16.1	208	21.0	204	20.5	34	3.7	363	36.3	329	32.8	1,301	22.0
Urban	453	44.7	564	57.0	485	48.7	561	61.9	271	27.1	453	45.2	2,786	47.2
Rural	398	39.2	218	22.0	306	30.8	312	34.4	366	36.6	221	22.0	1,820	30.8
Total	1,014		990		995		907		1,000		1,003		5,907	

Table 5. Distribution of sample by recruitment channel used

	Greece		Italy		UK		Sweden		Poland		Germany		Total	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
health or social care professional (eg 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	1.5	8	0.9	7	0.7	20	2.0	285	4.8
Total	1,012		988		995		918		1,000		1,003		5,907	

5 Main characteristics of the sample – cared-for older people and their main family carers

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5.1 Aims of chapter 5

As the first national study of family carers, the results concerning the profile of those who provide care to dependent older people are extremely important. In the Greek context, the research findings about family carers and the older people they care for confirms much of what people experience at a personal level and these results can now be used in a more objective manner to define who family carers are, as well as clarifying some of their characteristics. Participation in a European wide survey with 5 other countries has another advantage; the nature and characteristics of the Greek sample, within the context of the findings from the other country samples, allow a comparison of results illustrating both similarities and differences between the situation of Greek family carers and those in other countries. Research findings reported in the National Background reports from a further 17 countries provide further confirmation of the comparative situation of Greek family carers.

The aims of this chapter are, therefore, to describe the main characteristics of the family carers in the sample, as well as those of the dependent older people they care for. In line with the sequence of questions in the CAT, the characteristics of the older people are reported first.

5.2 Methodology used to collect, analyse and present the data

The selection of the carer sample was designed to be as representative as possible as regards type of locality (metropolitan, urban, rural). The problems involved in this selection have been discussed in Chapter 4 and while the following table refers to the type of locality in which the family carers lived, the close proximity between carers and cared for households (see section 5.3.2.3 below) indicates that there were likely to be no major differences between them in locality.

Table 1. Sample distribution - type of locality in which family carers lived

Locality type	Frequency	%
Metropolitan	163	16.1
Urban	453	44.7
rural	398	39.2
TOTAL	1,014	100

5.3 Main findings

5.3.1 PROFILE OF CARED-FOR OLDER PEOPLE

5.3.1.1 Socio-demographic characteristics

The family carers were asked to provide information about the main dependent person they cared for.

Nearly 2/3 (64.5%) of the dependent older people were women, with only 3 of those cared for being of a different nationality and 4 being from different ethnic origins. The age profile is provided below.

Table 2. Ages of older cared-for persons in 5 year age groups

Age in years	Frequency	%
65-69	126	12.4
70-74	152	15.0
75-79	227	22.4
80-84	229	22.6
85-89	145	14.3
90-94	111	10.9
95-99	22	2.2
100 +	2	0.2

As can be seen, about half the older people being cared for (49.8%) were aged 65-79 years and the rest (50.2%) were over 80 years of age

Table 3. Marital status of cared-for older persons

Marital status	Frequency	%
Married/cohabiting	386	38.3
Widowed	571	56.7
Divorced/separated	18	1.8
Single	32	3.2

The majority of the cared for older people (56.7%) were widowed, with 38.3% being still married and only 1.8% being divorced/separated and a further 3.2% single.

5.3.1.2 Place of residence and household composition

As might be expected in a study of family carers of older dependent people, the great majority of those cared for (98.7%) lived at home. Whilst in Greece, those in residential care represent only approximately 1-2% of the elderly population, in view of the reportedly continued close involvement of family carers with the care process, even within a residential home, it was thought important to include a small sample (1.2%) of family carers of elderly residential home inhabitants in the EUROFAMCARE sample, as long as they were still providing at least 4 hours of care a week to the older person.

Table 4. Place of residence of older person

Place of residence	Frequency	%
At home	1000	98.6
In a care home	12	1.2
Other place	2	0.2

Who does the older person live with?

Which family member provides most care to a dependent older person is strongly influenced by the composition of the household.

50.7% of family carers were living with the person they cared for and a further 15.4% lived in different households in the same building, making a total of **66.1% of family carers who were effectively “co-resident” with the older person; the characteristics of these households are reported in section 5.3.2, Profile of Family Carers.**

As can be seen from Table 5, a quarter of the sample of cared for older people (24.7%) lived alone.

For those older people cohabiting with someone of the same generation, 59.8% lived with their spouse/partner and 11.8% with siblings and their spouses.

For those cohabiting with someone of a younger generation, 53.8% lived with their children, 4.7% with children-in-law and 3.8% with grandchildren or great grandchildren.

A further 14.3% of the older people lived with other relatives, 2% with other non-relatives and 10.9% with a paid carer.

Table 5. Who the older person lives with (multiple responses possible)

Who does older person live with?		Frequency	%
Elder lives alone	yes	250	24.7
Elder lives with spouse/partner	yes	364	59.8
Elder lives with siblings or their spouses	yes	10	11.8
Elder lives with children	yes	394	53.8
Elder lives with children in law	yes	4	4.7
Elder lives with grandchildren, great grandchildren or their spouses	yes	33	3.8
Elder lives with other relatives	yes	12	14.3
Elder lives with other	yes	13	2.0
Elder lives with paid carers	yes	71	10.9
Elder lives in residential care setting	yes	11	1.2

5.3.1.3 Older person's financial situation

Only the most general data are presented here to indicate the numbers receiving state financial support in the nature of pensions and/or benefits.

Table 6. State financial support for older person

Support from state	Frequency	%
NO	79	7.9
YES	918	92.1

As can be seen from the table, the vast majority (92.1%) of the older people were receiving financial support from the state, which was overwhelmingly in the form of pensions.

However, **993 (97.9%) family carers reported that neither they nor the cared for older person received any financial support or allowances as a result of their caring situation.**

For those **older people (49.3%) who were *not* co-resident with the family carer**, carers were asked to report on the net household income of the dependent cared for person; the mean level was 497 euros per month with a maximum of 2,300 euros and a minimum of 100 euros. In comparison, Italian incomes were two thirds larger with a mean of 860 euros, while in Germany the mean amount was 1,276 euros. Since carers were not always sure of the exact household income of the older person, they were given the option of estimating the amount within set income bands.

Table 7. Income distribution amongst older people in the sample

National income band	Frequency	%
0-400 euros per month	43	15.8
400-500 euros	63	23.2
500-700	29	10.7
700-900	31	11.4
900-1,100	40	14.7
1,100-1,300	22	8.1
1,300-1,600	13	4.8
1,600-1,900	9	3.3
1,900- 2,400	8	2.9
2,400 and upwards	14	5.1

For those **older people who were co-resident with the carer**, the older person's income was included in the carer's net household income, reported below in section 5.3.2.3.

5.3.1.4 Older person's health situation and needs for support

Greece has no national data on disability and dependency rates in either the whole population or amongst older people, only estimates based on disability data from other countries (Mestheneou and Triantafillou 2004). Thus, the following data provide an interesting insight into the reasons, physical, mental and social, why care provision was necessary.

In attempting to define the causes for and level of dependency of the older person, the family carers were first asked what they considered to be the main and supplementary reasons why the older person needed care and support.

Table 8. Main reasons for care

Reasons for care	1 st Reason %	2 nd Reason %	3 rd Reason %	4 th Reason %	TOTAL
Physical illness/ disabilities	30.6	8.0	7.9	9.2	55.7
Mobility problems	24.4	14.7	10.4	8.1	57.6
Age related decline	15.9	4.4	4.4	4.6	29.3
Safety/feeling of insecurity	6.4	25.1	22.4	15.3	69.2
Social reasons, loneliness, need for company	5.7	8.2	2.8	4.3	21.0
Memory/cognitive problems/impairments	5.6	4.4	3.7	3.2	16.9
Non self caring	5.5	9.7	16.9	12.1	44.2
Sensory problems	3.2	18.3	24.3	35.4	81.2
Psychological/psychiatric illness/problems	1.9	3.0	2.7	2.3	9.9
Other reason	0.7				0.7

As might be expected, the **main reason for care (1st reason)** reported by the family carers was **physical illness and disabilities (30.6%)**, followed by **mobility problems (24.4%)** and the rather non-specific category of **age-related decline (15.9%)**, although when all reasons for care (2nd, 3rd and 4th reasons) are added, these figures rise to 55.7%, 57.6% and 29.3% respectively.

However, the frequency in the other reported supplementary reasons for care, especially **safety/feelings of insecurity (69.2%)** and **sensory problems (81.2%)**, give an indication of the complexity of causes of dependency amongst older people and the need for comprehensive methods of needs assessment to cover all areas of support for dependent older people and their family carers, as well as giving credence to the increasing trend towards integrated care solutions (Nies H and Berman P, 2004). It also indicates potential areas for intervention to reduce the burden of need for care e.g. in-home and environmental modifications to maintain safety and all possible autonomy of older people, as well as implementation of recent medical advances to improve common visual and hearing problems in older people e.g. cataract surgery, new types of hearing aids etc.

In view of the major age-related predicted increase in the incidence of Alzheimer types of dementia (DAT), questions were specifically asked about any **memory and behaviour problems** in the cared for person. Whilst these types of problem represented the main reported reason for care in 5.6% of the sample and were contributory reasons in 16.9%, it should be noted that the following responses do not represent a systematic assessment of these problems, but simply reflect the opinion of the carers.

Table 9. Older person's memory problems

Has the older person memory problems?	Frequency	%
NO	650	64.2
YES	363	35.8

Table 10. Older person's behavioural problems

Has the older person behaviour problems?	Frequency	%
NO	748	76.2
YES	234	23.8

As can be seen **35.8% of the cared for subjects were reported to have memory problems** and in a further **23.8% behavioural problems** were noted, giving an indication of the higher levels of stress likely to be experienced by carers dealing particularly with the latter type of problem and confirmed by further analysis of the total six-country sample.⁵

Interestingly, **psychological problems and psychiatric illness** e.g. depression, were reported as the main reason for care in only 1.9% of the sample, although their total contribution to the need for care rose to 9.9%; these types of disorder are also a significant cause of behaviour problems and attempts to improve their recognition and treatment at an early stage should help to improve quality of life in both cared for older people and their family carers (Triantafillou, Mestheneou 1994).

5.3.1.5 Older person's level of dependency

As well as the data on different types of care needs, reported in Chapter 7, carers were asked to estimate the level of dependency and need for help of the cared for person, using descriptions⁶ based on the standard instrumental and personal activities of daily living (I-ADL and P-ADL) and their responses are shown below.

⁵ Carers who care for relatives with behaviour problems, compared to those who are only physically disabled or have memory problems, are more burdened, get less support, have a lower quality of life and have both a lower motivation to continue caring and are more willing to consider residential care (TEUSURE 2005).

⁶ **Severely Dependent** – Unable to carry out most activities of daily living, without help (e.g. feeding themselves, or going to the toilet)

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)

Slightly Dependent – Able to carry out most activities of daily living, but requires help with some instrumental activities (e.g., shopping, cooking, housework, etc)

Independent – Able to carry out most activities of daily living, but may need some help occasionally

Table 11. Level of dependency

Level of dependency	Frequency	%
Severely dependent	320	31.6
Moderately dependent	317	31.3
Slightly dependent	246	24.3
Independent	131	12.9

The questionnaire also used a standardised scale (I-ADL and Barthel index) to assess the older person's degree of disability and dependency needs rather more objectively, although the responses were still provided by the carers and not by the older people themselves or by an objective observer. Carers were asked, if the older person were alone, whether they would be able to carry out the following activities. The percentages of those who judged the older person completely unable to carry out the activity have been marked in bold, but activities where the task needed some help from the family carer have been shaded to indicate the total amount of care needed in each category of activity (final column).

Table 12. Carer's assessment of older person's level of dependency (IADL and Barthel scales)

Task		Frequency	%	Total % needing help
Housework (clean floors etc.)	<i>Unable</i>	620	61.3	89.2
	<i>With some help</i>	282	27.9	
	<i>Without help</i>	110	10.9	
Prepare meals	<i>Unable</i>	518	51.3	72.4
	<i>With some help</i>	213	21.1	
	<i>Without help</i>	278	27.6	
Go shopping	<i>Unable</i>	652	64.4	84.6
	<i>With some help</i>	204	20.2	
	<i>Without help</i>	156	15.4	
Handle money	<i>Unable</i>	366	36.3	58.1
	<i>With some help</i>	220	21.8	
	<i>Without help</i>	423	41.9	
Use the telephone	<i>Unable</i>	268	26.5	46.0
	<i>With some help</i>	197	19.5	
	<i>Without help</i>	545	54.0	
Take medicines	<i>Unable</i>	299	29.6	62.9
	<i>With some help</i>	337	33.3	
	<i>Without help</i>	375	37.1	
Walk outside	<i>Unable</i>	337	33.5	63.5

	<i>With some help</i>	302	30.0	
	<i>Without help</i>	366	36.4	
Get around indoors	<i>Unable, no sitting balance</i>	122	12.2	35.3
	<i>Wheelchair without help/ walking with major physical help</i>	75	7.5	
	<i>Walking with some help guided or supervised</i>	156	15.6	
	<i>Without help (may use any aid, e.g. stick)</i>	644	64.6	
Manage stairs	<i>Unable</i>	374	37.4	67.6
	<i>With some help</i>	302	30.2	
	<i>Without help</i>	323	32.3	
Move from bed to chair	<i>Unable</i>	112	11.3	35.8
	<i>With major help (1 or 2 people, physical)</i>	92	9.3	
	<i>With minor help (verbal or physical)</i>	150	15.2	
	<i>Without help</i>	633	64.1	
Use the toilet (or commode)	<i>Unable</i>	168	16.6	33.6
	<i>With some help</i>	172	17.0	
	<i>Without help</i>	670	66.3	
Use the bath or shower	<i>Unable</i>	288	28.6	57.4
	<i>With some help</i>	290	28.8	
	<i>Without help</i>	430	42.7	
Keep up personal appearance	<i>Unable</i>	219	21.7	41.4
	<i>With some help</i>	199	19.7	
	<i>Without help</i>	591	58.6	
Dress self	<i>Unable</i>	221	21.9	43.1
	<i>With some help</i>	214	21.2	
	<i>Without help</i>	574	56.9	
Feed self	<i>Unable</i>	138	13.7	28.8
	<i>With some help</i>	152	15.1	
	<i>Without help</i>	716	71.2	
Does elder have accidents with his/her bladder (incontinence of urine)				
	<i>Yes, frequent accidents (once a day or more or catheter)</i>	197	19.6	40.0
	<i>Yes, occasional accidents (less than once a day)</i>	205	20.4	
	<i>No accidents (continent)</i>	604	60.0	
Does elder have accidents with his/her bowels (incontinence of faeces)				

Yes, frequent accidents (once a week or more or needs enema)	126	12.6	21.1
Yes, occasional accidents (less than once a week)	85	8.5	
No accidents (continent)	789		

These are startling figures, representing the **numbers of cared for older Greeks in the sample who were reported as being dependent on the help of another person** in the performance of the activities of everyday life.

Thus in various **domestic and household tasks**, between **46.0 - 89.2%** need help with housework, shopping, cooking, handling money and telephoning, as well as with **taking their own medicines (62.9%)**. These are the tasks in which help can, theoretically, be most easily be organised and provided by non-cohabitant family carers or care services. Nevertheless, the figures give an indication of the amount of support provided by Greek family carers to their dependent family members, both **before** and after the onset of complete dependency.

Of particular note is that approximately 2/3 of the older people being cared for were **unable to walk outside the home (63.5%) and manage stairs (67.6%)**, either at all or only with help; a further **35.3% were reported unable to get around inside the house** and **35.8% unable to move from bed to chair** without help, leading to speculation on the various factors, environmental and other, that may contribute to Greek older people becoming unnecessarily housebound and dependent on others⁷.

With regard to **personal care tasks** (toileting, bathing, personal appearance, dressing) from **33.6 – 57.4% of the sample could not perform or needed help in the performance of these tasks several times a day and at night**, indicating the heavy and repetitive everyday burden on the carer, which was further exacerbated in the **40% who had at least occasional urinary incontinence and the 21% with some degree of faecal incontinence**.

Furthermore, **28.8% of the cared for sample were unable to feed themselves or were dependent on the help of another person, thus needing time and assistance from the carer at least 3-4 times daily**. This degree of disability and dependency usually necessitates cohabitation between carer and cared for which, in the case of non-spouse carers, frequently leads to the major upheaval of a change of home environment for the older person, as well as overcrowding and stress amongst the other members of the carer's household (Mestheneos and Triantafillou, 1993).

These figures give a clear picture of **what is involved in the practical care of dependent Greek older people at home**, even without taking into account the broader spectrum of care needs documented in chapter 7, including the provision of emotional and psychological support which was reported as a need by 90% of the carers.

The only comparable Greek data on disability come from the WHO population based study on older people in rural areas (Triantafillou et al, 1996). As might be expected, this study reported much lower rates of disability for the general population of older people (although the analyses of data was done separately for men and women and in 5 year cohorts), thus indicating and confirming the high dependency levels of the older people in the current sample and their high needs for care.

⁷ It should be noted that the hosting of the 2004 Olympic Games sensitized Greeks to the need for improved access to public places by people with mobility problems and may have contributed to somewhat better provision of such facilities in the external environment at least.

5.3.2 PROFILE OF FAMILY CARERS

Who are the Family carers?

5.3.2.1 Socio-demographic characteristics of carers

Questions were asked concerning the characteristics of those who were the primary carer for the dependent older person, even if other members in the family helped with care and support. The **characteristics of carers** concerned their age, sex, marital status, educational status, working status, the number of people in the carer's household, ethnic origin and the number of people in the carer's household younger than 14 years of age.

The **mean (average) age of Greek family carers was 51.7 years** though the actual range of carers ages was from 18 - 95 years. This made them slightly younger than family carers in the other 5 countries; in Sweden with many spouse carers the average age of the sample rose to 66 years. This should be born in mind since it has repercussions for their participation in the labour market.

Women were overwhelmingly the main providers of care, representing **80.9% of family carers**. This was the highest proportion in the 6 countries research, even though in all countries women tended to provide three quarters of all care (the lowest was 72% in the Swedish sample where spouse care was often provided by men). Thus the Greek findings are similar to the findings for other countries and from national research reported in the Greek NABARE and PEUBARE.

The **marital status** of the family carers: 76.4% of the sample of family carers were married or cohabiting, of whom 17.1% were spouse carers; 6% were widowed; 5.7% divorced or separated and 12% were single. The data suggest that family carers were disproportionately drawn from those not in a marital arrangement (widows, single, divorced) even though the married were numerically most frequent. In total 20.2% of the carer sample reported having no children, a figure that was close to the average for all the six countries. Of those who had children the mean number was two with a maximum of 8 children, again figures that did not differ from the other countries. Discussion in the international literature (Ch. 2) has mentioned the pressure on the middle generation who have to be carers both for the parental generation and their grandchildren. This situation of potentially being 'squeezed' was faced by 270 respondents (34.2% of those with children) This figure was lower than for most of the other countries (Italy had a similar low proportion 32.7% with grandchildren) reflecting the lower mean age of family carers in Greece but also the very low birthrates in both Greece and Italy.

Of all family carers just 11 (1.1%) were of **non Greek origins**. While such a figure under-represents the proportions of non Greeks in the population, it may accurately reflect the situation concerning the family care of older people where many migrants are younger and their older dependent relatives still in their home country.

Table 13. Relationship between family carer and cared-for older person.

Carer's relationship to older person	Greece		Total EU sample	
	Frequency	%	Frequency	%
Spouse/Partner	173	17.1	1,317	22.2
Sibling	18	1.8	134	2.3
Child	561	55.4	2,896	48.9
Daughter-/Son-In-Law	141	13.9	654	11.0
Nephew/Niece	43	4.2	241	4.1
Uncle/Aunt	10	1.0	72	1.2
Cousin	1	0.1	34	0.6
Grandchild	45	4.4	243	4.1
Close Friend, Family Friend	11	1.1	126	2.1
Neighbour	3	0.3	82	1.4
Volunteer	4	0.4	6	0.1
Other	4	0.4	36	0.6
Total	1,014	100.0	5,920	100.0

As indicated above, **17.1%** were **spouse carers**⁸, and many of the men family carers were in this category and a further **1.8%** were **siblings** of the cared-for older person.

55.4% of carers were **children** and **13.9%** were **daughters-in-law or sons-in-law** of the dependent older person.

4.4% were grandchildren, **4.2%** were **nephews/nieces** and **3.2%** fell into other categories e.g. other relatives, close friends, neighbours and volunteers⁹

As indicated in the table, the Greek sample had a slightly higher percentage of child and child-in-law carers than the total EU sample and, correspondingly, the average age of the Greek sample was also slightly lower

5.3.2.2 Education, personal and employment characteristics of family carers

Education: The educational level of carers was relatively low – 37.4% had a low level of education, 40.6% an intermediate (typically those who had finished High School/Lykeio) and 22.1% had a high level of education. In the other countries the educational level of carers was slightly higher, though this reflects the overall educational standards in each country. Older women in Greece, who form the largest proportion of family carers, are still marked by low levels of education. In the other countries the Swedes had the next lowest level of education, again reflecting the fact that they had a lot of older spouse carers. At the other extreme the Greek sample of family carers also contained a quite high proportion of people who had achieved a high level of education – with

⁸ The PEUBARE study shows that in countries providing directly comparable data it was reported that in Spain 12.4% of family carers were spouse carers; in the Netherlands 14%; in the UK 16%; 21% in the Czech Republic; 29.2% in Poland, while in Finland 43% were spouse carers.

⁹ PEUBARE – comparable figures - Although in many countries children, especially daughters and daughters in law, provide a large percentage of family care e.g. nearly 75% were child carers in Malta, there were large variations. In Hungary daughters constituted only 11.3% and sons 8.7% of all family carers compared to 37.1% daughters and 20.9% sons and 15.5% grandchildren in Poland. See also the PEUBARE report where the difficulties of defining the family carer is apparent when looking at the numbers of spouse versus child carers since both offer different types of care to the dependent older person.

22.1% falling into this category, with the Swedish sample containing the highest proportion of family carers with high levels of education (25.3%.) The UK had the most family carers with an intermediate level of education (69.3%). Only 3.7% of Greek family carers were still in education at the time of the interview, reflecting the age of family carers.

Family carers were also asked about their **religious beliefs** in case this played a major role in their attitudes to care. 36.3% reported that they were very religious and only 12.8% reported not being religious at all¹⁰. Family carers belonging to a religious denomination were overwhelmingly (99.0%) of the Greek Orthodox faith. Yet, as in most countries, the religious denominations were very rarely the source of information to support family carers and, despite the high proportion being religious, when Greek family carers were asked their motives for caring, only 0.7% reported the primary reason to be their religious beliefs, although 40% cited this as a factor influencing their decision to care.

Working and caring

In Greece **47.2% of family carers were still working**, the highest proportion amongst the 6 countries, followed by Italy (43.4%) and Germany (42.3%), reflecting the slightly lower age of the Greek carers' sample compared to the other countries. The high proportion of those who reported that they were self employed (26.9%) is consistent with the norm in Greece^{11,12}. In addition Greek carers worked, on average, longer hours – while the mean for the 6 countries was 35 hours, Greek **working carers' mean average working week was 40 hours**, with a maximum of 140 hours a week! The absence of part time work is evident in these figures compared to for example, the UK where the mean working week for family carers was 29 hours, Although self employment often provides considerable flexibility in terms of the exact hours worked, it may still involve long hours.

Table 14. Employment of family carers

Employment sector	Frequency	%
Private	160	34.7
Public	167	36.2
Self	124	26.9
Other	10	2.2
Total	451	100

¹⁰ The Swedes and Germans were the least religious (47.9% and 37% respectively) while only 5.2% of Poles reported not being religious at all. However in terms of being very religious, this was reported by 20.8% of the Italian sample, with Sweden and Germany having the lowest proportion of very religious family carers. This was reflected in the numbers claiming no religious affiliation – 14.7% in Greece compared to 49.5% for Sweden, 41.6% for Germany and 38.1% for the UK.

¹¹ The SYSDM Report 2002 by D. Karantinos reports that almost half (47%) of the 55-64 age group in employment and 75% of 60 to 64 year olds were self-employed in 1998, partly related to the importance of agriculture which employs a large share of older worker. Around 40% of women aged 55 to 64 in employment were self-employed in 1998 while in the same age group a significant proportion of women (around 40%) was working as unpaid family workers.

¹² Poland had the next highest proportion (18.5%) in self employment, while Sweden had the lowest proportions of carers still in the labour market, reflecting the high levels of elderly spouse carers, as well as the lowest levels (10.2%) in self employment.

Table 15. Employment classification

Type of work	Frequency	%
Armed Forces		
Legislator, senior officials and managers	59	12.8
Professionals	101	22.0
Technicians and associated professionals	16	3.5
Clerks	134	29.1
Service Workers and shop and market sales workers	57	12.4
Skilled agricultural and fishery workers	26	5.7
Craft and related trade workers	23	5.0
Plant and machine operators and assemblers	3	0.7
Elementary occupations	41	8.9
Total	460	100

The figures here do not provide an accurate reflection of the Greek labour market where, for example, a slightly higher proportion are employed in agriculture and elementary occupations. The figures also do not compare easily with the other countries since self definition of one's employment can be culturally specific e.g. defining oneself as a professional or a technician.

Table 16. Status of non working carers

Status of non working carers	Frequency	%
Retired	186	35.2
Unemployed and seeking work	50	9.5
On long term sick leave but intending to return to work	7	1.3
Housewife / househusband	286	54.1
Other, specify		
Total	529	100

The younger age of family carers is reflected in these figures compared to other countries where the number reporting they were retired was higher. They also reflect the low participation rate of Greek older women in the formal labour market, although in reality a larger proportion of women work in the informal labour market e.g. as farmers' wives in agricultural occupations and other forms of unpaid family labour; thus they are unlikely to state they are retired since they continue to be housewives¹³.

¹³ In Sweden with a very high rate of female labour market participation, though carers were on the whole older only 1.4% reported that they were housewives/husbands and 91% reported being retired – as compared to just 35.2% of Greeks. Poles, Germans followed by Greeks, were most likely to say they were unemployed and seeking work.

Family carers were also asked about the implications of caring for their career and what repercussions caring had for their working life or career. 126 carers reported that caring had stopped them developing their career or studies; (12.6% of sample); 122 (12.2%) had felt they could only work occasionally; while other forms of restriction were mentioned by 38 carers (3.8%). 91 (19.2%) had had to reduce the number of working hours by a mean number of 9 hours per week. Family carers reported that this had had an impact on their monthly income by up to 400 euros per month. Overall Greek carers, partly because of their slightly younger age, were far more likely to report such career implications from caring than family carers in other countries. Amongst non working carers 93 (17.7%) were unable to work at all because of their caring responsibilities, again the highest percentage amongst the 6 research countries, while 54 (10.3%) had given up working because of their caring duties. When asked how many hours per week they were working before they gave up work, the mean was 39 hours with a maximum of 84 hours and a minimum of 8 hours, figures that were comparable to those for family carers in the other countries.

5.3.2.3 Carers' family situation

Table 17. Living arrangements of family carers and the dependent older person.

Where do you and elder live?	Greece		Total EU sample	
	Frequency	%	Frequency	%
In the same household	514	50.7	2,824	47.7
In different households, but in the same building	156	15.4	503	8.5
Within walking distance	158	15.6	1,072	18.1
Other, by car/bus/train	185	18.3	1,522	25.7
Total	1,013	100.0	5,921	100.0

The findings showed that family carers and the dependent older person shared the same household in 50.7% of the sample; while 17.1% could be expected to be in the same household as they are spouses, the remainder do so on the basis of another relationship – see below. No question was asked about how long the carer and cared for had lived together, thus it is difficult to know how many started to live together with the onset of dependence. However, a further 15.4% of carers lived in different households, but in the same building as the older person; thus in total **67.1% lived in the same household or the same block of flats** – one of the highest percentages amongst the 6 countries, only exceeded by Poland. A further 15.6% of carers lived within walking distance of the older person while 18.3% had to drive or take a bus or train to get to the cared for person.

The **size of households** reflected the life stage and marital status of family carers, with the mean being 3 co-resident people, though varying from those who lived alone to one household containing 10 people. This compared to Swedish households which were on average smaller (2 people), and Polish households which tended to contain more people (4 people was their mean).

5.3.2.4 Carers' financial situation

Family carers were asked to add up all sources and give an estimate of their total household income per month, with the option of refusing the question. The mean amount was **1,093 euros**, a third less than Italy and almost a half of mean income in German households. However there were huge variations from 40 euros per month to 10,000! For carers who were cohabitant with the cared for older person, this estimation included any contribution made by the latter to the total household income, whereas for older people **not** living with the carer, there was a separate estimation of the older person's household income, reported in section 5.3.1.2 above.

However of the 521 family carers who provided answers to the question concerning the approximate level of their household net monthly income, as a way of understanding the kinds of choices available to them in terms of purchasing help and services, the **income distribution showed the very substantive percentage with very low incomes.**

Table 18. Income Bands of family carers

Income bands	Frequency	%
0-400 euros per month	35	6.7
400-500 euros	37	7.1
500-700	75	14.4
700-900	57	10.9
900-1,100	78	15.0
1,100-1,300	49	9.4
1,300-1,600	39	7.5
1,600-1,900	38	7.3
1,900- 2,400	40	7.7
2,400 and upwards	73	14.0

Those with very low levels of income (less than 500 euros per month), reported by 13.8% family carers, reflects the general low level of incomes of many older people in Greece where 19% of those over 65 live in poverty (Tsakloglou P, 1999, Eurostat 1999), but also the percentage of the sample drawn from rural areas where both pensions and incomes do tend to be lower than in urban areas. It should be recognized that the mean size of household was 3 people (see below) which together with the mean level of income suggests the very limited household budgets of the majority of family carers. As will be seen, this is reflected in Chapter 7 where responses to the main form of help needed by Greek family carers was financial support.

The costs of caring are not only in terms of time but also direct costs, **yet only a tiny minority of carers receive any kind of state financial support or benefit paid either to the dependent older person or to themselves, with just 2% reporting receiving such help.**

5.3.2.5 Carers general caring situation

How many people did family carers care for?

In order to understand the other care obligations that family carers had, they were asked to report on any other people for whom they provided a substantial amount of care. The mean number of children under 14 years of age that family carers had was 2, though one family carer had 8 children! Given the older age of most carers, many had grandchildren for whom they also provided some care, with a total of 270 (34.2% of those with grandchildren) providing such care.

Although the majority of family carers (80.9%) cared for just one dependent older person, 16.8% were caring for 2 older dependent persons while 2.3% were caring for 3 or more dependent older people.

However when one examines the total number of family carers who had responsibility for the care of more than one person, the multi-care role of a substantial number of family carers is evident.

Table 19. Number of other people cared for

Number of cared for other people	Frequency	%
0	410	40.6
1	161	16.0
2	212	21.0
3	142	14.1
4	59	5.8
5 and more	25	2.5

The amount of care given by family carers.

Caring can mean many things, from practical household care, to managing the older person's finances, or complete physical care. Although there were full details given of the kind of care provided, carers were asked to report how many hours they gave per week to the care of the older person as well as to other persons. The **mean number of hours of care given to the main dependent cared for person was 51 hours per week**, the highest (together with the UK) of the 6 countries, with the median being 28 hours.¹⁴

The primacy of this care was evident in that the amount of care given to others was a mean of 31 hours weekly with a median of 15 hours.¹⁵

¹⁴ Data from the National Background Reports show that in Portugal 68.3 % of family carers provided more than 4 hours per day and 56.6 % provided care every day. In Ireland the breakdown of hours provided by family carers showed that 60.3 % worked 1-19 hrs, 13.4 % - 30-49 hrs and 26.7 % more than 50 hrs per week. Luxembourg, which provided detailed breakdown for the hours of care given to dependent people of all ages indicated that the young disabled needed most care followed by the oldest age group (90+) and that overall 35 % of dependent people needed in excess of 24 hours per week. In the Netherlands the average amount of care amounted to 17.9 hours per week, including domestic help, psychosocial support and personal care.

¹⁵ PEUBARE - Few countries provided any estimate of the total amount of 'work' time provided by family carers – Norway reports that care for those over 67 years of age takes approximately 49,000 man years per

Length of time for which care was given.

Care is rarely a brief task for the family carer but tends to extend over a considerable period of time. Family carers reported that the **length of time (in months) for which they had given support to the older dependent person** varied, with the **mean amount, at the time of interview, being 60 months (5 years)** and a median of 36 months i.e. 3 years. Since the interviews took place at different times in the caring process, it should be emphasised that **this does not represent total time spent in caring by Greek carers, many of the caring situations extending for far longer periods** (Triantafillou, Mestheneos 1994, Mestheneos, Triantafillou 1993b)

Help from others in times of need.

Table 20. If you were ill is there anybody who would step in to help with elder?

	Greece		Total EU sample	
	Frequency	%	Frequency	%
Yes, I could find someone quite easily	513	50.6	2,839	48.0
Yes, I could find someone but with some difficulty	332	32.8	1,910	32.3
No	168	16.6	1,171	19.8
Total	1,013	100.0	5,920	100.0

Table 21. If you needed a break from your caring role is there someone who would look after elder for you?

	Greece		Total EU sample	
	Frequency	%	Frequency	%
Yes, I could find someone quite easily	486	48.0	2,787	47.2
Yes, I could find someone but with some difficulty	312	30.8	1,906	32.3
No	215	21.2	1,217	20.6
Total	1,013	100	5,910	100

As can be seen, 16.6% of the Greek sample reported that they had no-one they could count on to take over their caring role even if they were ill, whilst 21.2% gave the same negative response to the question on needing a break from caring.

5.3.2.6 Carers' health status and quality of life

The personal cost to the family carer could be seen in responses to questions on their health and well being.

Family carers were asked to report on their **general health status** using a single item 5-point scale assessment taken from the Short Form-36 (SF-36; Brazier et al., 1992): 31.8% reported their

annum. Yet this involves all kinds of care and rarely in the national reports or literature is sufficient distinction made between 'normal' care and support, and the labour involved when people become very dependent. Nonetheless data on dependent older people shows that in many countries (AT, BE, IT, CZ), 70-80 % of care was given by family carers.

health as excellent, 25% as very good and 35.9% as good (**Total GOOD = 67.7%**), while 26.4% reported it as fair and 5.9% as poor.

These figures need to be compared with figures on self rated health amongst the general Greek population. In a study of health and use of health services in an adult Greek population (Kyriopoulos G et al, 2003), 27.4% of the sample reported their health status as very good, 44.9% as good (Total GOOD =72.3%), 22.1% as moderate, 4.6% as bad and 0.9% as very bad (total BAD = 5.5%)

These results illustrate well the difficulties in trying to compare measures of self-assessed health between different studies, with slightly different response categories. When both sets of responses are grouped into 3 categories of Good, Fair/moderate and Bad/poor an approximate comparison can be made:

Table 22. Comparison of Self-rated health in 2 Greek survey samples

	% "Good"	% "Fair/moderate"	% "Bad/Poor"
Family carers	67.7	26.4	5.9
General pop.	72.3	22.1	5.5

Source: EUROFAMCARE Greek National Survey 2004 and Daniilidou et al 2004

These 2 samples of course are not directly comparable in terms of gender (80.9% of the carers' were women compared with only 39% of the general population) and other factors associated with the self-rating of health status such as age, income and education (Daniilidou et al, 2004).

Nevertheless, what is striking about these results is that there appear to be only small variations between the responses from the family carers and from those of the general population regarding their self-assessed health status, surprising findings in view of the high levels of care they were providing and the frequently reported finding in other (non-Greek) studies of poor physical and mental health status in family carers (Dwyer et al. 1994, Fink 1995, Jutras et al.1995).

Compared with family carers in the other countries, amongst those reporting "good" and "poor" health, Greek family carers are intermediate between the Poles with the lowest levels of good health (49.4%) and highest levels of poor health (11.4%), and the Germans with the highest levels of good health (75.4%) and the lowest levels of poor health (3%).

In terms of what **forms of support** carers felt were available to them as caregivers, as well as their **feelings about and attitudes to caregiving**, responses to the COPE Index questions are given below:

Table 23. COPE Index

	never		sometimes		often		always	
	No.	%	No.	%	No.	%	No.	%
do you feel you cope well as caregiver?	6	0.6	164	16.2	408	40.3	434	42.9
do you find caregiving too demanding?	183	18.1	271	26.8	231	22.8	327	32.3
does caregiving cause difficulties in your relationship with your friends?	503	49.7	278	27.5	146	14.4	85	8.4
does caregiving have negative effect on your physical health?	424	41.9	310	30.6	170	16.8	109	10.8
does caregiving cause difficulties in your relationship with your family?	578	57.1	299	29.5	95	9.4	40	4.0
does caregiving cause financial difficulties?	483	47.9	245	24.3	127	12.6	153	15.2
do you feel trapped in your role as caregiver?	373	37.0	327	32.4	164	16.3	145	14.4
do you feel supported by friends/neighbours?	182	18.1	296	29.4	241	24	287	28.5
do you feel caregiving worthwhile?	10	1.0	83	8.2	194	19.2	721	71.5
do you feel supported by family?	88	8.0	162	16.2	272	27.1	481	48.0
do you have a good relationship with elder?	12	1.2	72	7.1	182	18.0	744	73.7
do you feel supported by services?	348	34.4	298	29.4	266	26.3	101	10.0
do you feel appreciated as caregiver?	39	3.9	158	15.7	323	32.1	486	48.3
does caregiving have negative effect on your emotional well-being?	289	28.6	378	37.5	213	21.1	129	12.8
overall, do you feel well supported in your role of caregiver?	136	13.5	333	33.2	305	30.4	230	22.9

Details of the scoring of this instrument in terms of Negative Impact, Positive value and Perceived level of formal and informal support are reported in Chapter 3.

Whilst these figures merit comparison with the other country samples, what is perhaps initially surprising about the Greek carer responses is their overall positive evaluation of their caregiving role. With responses “**often or always**”, 90.7% rated caregiving worthwhile, 80.4% felt appreciated as caregivers, 83.2% estimated that they cope well as caregivers and 91.7% reported their relationship with the older person to be good. Regarding support in their role as caregivers, 53.3% felt well supported overall, with 75.1% supported by family, 50.5% by friends and neighbours, but only 36.3% being supported by services.

However, 55.5% felt caregiving too demanding and 33.9% felt it had a negative effect on their emotional well-being, although only 27.6% felt it had a negative effect on their physical health.

30.7% felt trapped in their role as caregiver and 22.8% believed caregiving caused difficulties with relationships with friends, but only 13.4% reported that caregiving caused difficulties in their relationships with other family members.

Finally, caregiving often or always caused financial difficulties for only 27.8% of the carers, a surprisingly low rate considering the lack of public financial support for family carers and the older people they care for and the high percentage on low incomes, reported above. Despite this, it should be noted that in Chapter 7, 52.5% of older people were reported to need at least some financial support, the highest rate amongst the six countries participating in the national surveys and these costs being born overwhelmingly by the interviewed carer and by other informal carers. Additionally, financial support was rated by the majority of family carers in Greece as the help they would most appreciate in caring for their older person.

Psychological well being was measured in terms of responses to questions on how family carers felt generally over the past 2 weeks, using the World Health Organisation-5 Well-being Index (WHO, 1998), and overall **Quality of Life** during the past 2 weeks was measured using a single item 5-point scale assessment taken from the Short Form-36 (SF-36; Brazier et al., 1992).

Table 24. General Assessment of family carers' psychological well being

	I have felt cheerful and in good spirits		I have felt calm and relaxed		I have felt active and vigorous		I woke up feeling fresh and rested		My daily life has been filled with things that interest me	
	No.	%	No.	%	No.	%	No.	%	No.	%
At no time or some of the time	280	27.6	350	33.5	223	22.0	399	39.4	369	36.4
Approximately half of the time	480	47.3	473	46.6	442	43.7	442	43.7	379	27.4
Most or all of the time	254	25.1	191	18.9	348	34.4	171	16.9	266	25.5

Thus, only approximately 1/3 of the sample (22% - 39.9%) responded negatively (at no time or some of the time) to these questions with the majority of responses (27.4% – 47.3%) being in the middle range and less than 1/3 in the higher range (most or all of the time, 18.9% - 34.4%). While these figures need further analysis, what is initially striking is that despite the demands of their caring role, most family carers did not seem to report a very heavy burden in their life.

Correspondingly, in the past 2 weeks **only 10% reported a poor or very poor quality of life, while 50.2% reported a good or very good quality of life** and the remaining **39.9% reported neither good nor poor**.

Table 25. Quality of life in the last two weeks

QOL in the last 2 weeks	Frequency	%
Very good	112	11.1
Good	396	39.1
Neither good nor poor	403	39.8
Poor	85	8.4
Very poor	16	1.6

However, when these figures are compared with the scores of carers in other countries, **Greek family carers scored the highest levels of “poor” quality of life (10% cf. 6.5% Germany) and the lowest levels of “good” quality of life (50.2% cf. 66.6% UK).**

5.3.2.7 Factors influencing decision to care and main reason for caring

Carers were asked what factors influenced their decision to care and which of these was their principle reason for caring. **Emotional bonds** were the most commonly reported reason overall (96.8%) with 57.1% saying this was the primary reason. **Duty** (total 89.3%) and **obligation** (total 91.4%), in combination accounted for just over 30% of the primary reasons given for caring. Despite the parlous state of many family carers income, the financial benefits of care were the main reported motive for caring in only one case (0.1%), although it was reported as a factor in the decision to care by 8% of the sample. The possible role of financial contributions by the old person to willingness to provide care, especially amongst low income families, is explored further in the discussion.

Table 26. Factors affecting decision to care and principle reason for caring

	All factors		Principle reason	
	Frequency	%	Frequency	%
A sense of duty	906	89.3	160	15.8
There was no alternative	539	53.2	48	4.7
The cost of professional care too high	444	43.8	6	0.6
Emotional bonds	982	96.8	578	57.1
Caring makes me feel good	826	81.5	26	2.6
Elder would not wish any one else to care	441	43.5	19	1.9
Religious beliefs	406	40.0	7	0.7
I started caring by chance	383	37.8	21	2.1
Economic benefits for both	81	8.0	1	0.1
A personal sense of obligation	927	91.4	146	14.4
other	7	0.7	0	0

5.3.2.8 Carers’ opinions on future care

However a more searching question asked family carers if they were **willing to continue to provide care over the next year**, depending on various changes in the older person’s health situation. A total of 91.1% felt they would be prepared to continue to care if the situation remained the same or even if the older person required more help for a limited or longer period of time; 8.2% were prepared to continue only if more help was received and only 0.7% said they were not prepared to continue to care no matter how much extra support they received.

Regarding the decision to transfer the older person to a **care home**, 81% of the sample would not consider it under any circumstances, whereas 17.7% would consider this option only if the older person’s health worsened and just 1.3% were prepared to consider this possibility, even if the older person’s condition remained the same.

Despite the lack of accurate data on numbers of older people in residential care homes (Μονάδες Φροντίδας Ηλικιωμένων), these figures reflect current estimates of between 1-2% of Greek >65 year-olds in such units. .

Only the Poles were even less willing than Greek carers to transfer their older person to a care home under any condition (86.9%) while the Swedes were most likely to consider this an option if the health of their older person got worse (70.2%) and 16.5% would consider it even if the health of the dependent person they cared for stayed the same. However this should not be read sentimentally as the “goodness” of the Greek or Polish family versus the “uncaring” Scandinavians¹⁶. On the contrary Sweden has a well developed network of good care homes, carefully integrated into the community, supervised and paid for out of public taxation. In contrast Greek care homes are often private, inadequately registered and supervised whether in the private, public or NGO sector, and, given the average income of Greek families’ as well as the doubtful status of many homes, the choice of using such a care home may not really be available. Those carers who had reported using residential homes, for which they had had to pay, did however respond positively in terms of satisfaction. This issue of family carers in all countries being unwilling to use care services that are not of adequate quality is discussed further in chapter 7.

Table 27. Willingness to continue to provide care over the next year

		Frequency	%
In the next year, are you willing to continue caring for the older person?	Yes, and I would even increase	690	68.5
	Yes, and I would increase for a limited time	28	2.8
	Yes, if the situation remains the same	200	19.8
	Yes, but only with more support	83	8.2
	No, no matter what extra support I receive	7	0.7

Table 28. Willingness to consider the older person’s placement in a care home

		Frequency	%
Would you be prepared to consider the older person’s placement in a care home?	No	805	81.0
	Yes, but only if the older person’s condition gets worse	176	17.7
	Yes, even if the older person’s condition remains the same	13	1.3

5.4 Discussion

The general estimations of the level of dependency of those being cared for in the Greek sample (approximately 1/3 highly dependent, 1/3 moderately dependent and 1/3 slightly dependent) mask the true situation of the amount of help provided by family carers in meeting the everyday needs of

¹⁶ Findings from the OASIS study underlined this point. Norwegian families provided a lot of care but with the support of good community based support services, The care received by older people was judged to be superior to that received by Spanish dependent older people even though they got more hours of family care, but fewer services.

their older people, as detailed in the I-ADL and Barthel analyses of their actual functional ability. This is further confirmed by the **high mean number of hours of care reported (51 hours per week)**, yet even the median of 28 hours suggests the weight that care represents. In view of these high levels of dependency and disability, the most surprising finding is that only 2% of the sample reported receiving any state benefit either for the dependent older person or themselves, reflecting the out-dated assessment procedures and bureaucratic obstacles that need to be overcome in order to qualify for the available benefits.

The long and tiring hours spent on the care of a dependent older person also had **implications for family carers in the labour market**. Many had had to limit their hours, cut back on their career, leave their job entirely or not seek work because of their care duties. As discussed in Chapter 7, given the preoccupation of the national government with increasing the numbers active in the labour market, especially women, the absence of services to support family carers is a serious obstacle in achieving this objective.

As in other countries, the **heavy reliance on women as family carers**, has long-term implications for them in terms of their employment. The numbers of family carers who had not been able to get on satisfactorily in their career, both men and women and who had had to reduce their working hours or withdraw from the labour market, is striking. **The data here provides a justification for policies that seek to support family carers on economic grounds alone.**

Whilst there is a strong tendency for people to be self-satisfied about the Greek family situation, they do not see the real cost for family carers. In all countries, the emotional bond between the dependent older person and the family carer is the decisive factor in the reasons why people care; love in all its forms is the main motivator. However while in many other countries family carers receive some support and help in their caring role, both in the form of services and financial benefits to older dependent people or to family carers themselves, the amount of any type of formal support received in Greece is low. Again, this is explored further in Chapter 7.

The picture that emerges of family care in Greece is that **people are supporting their older family members with inadequate resources**. While the primary lack of resources is reflected in the family carers' difficult financial position, the lack of services has other impacts. It should also be noted that which types of support and services are most needed may vary according to different categories of carers, or by the relationship of the carer to the older person, as well as varying over time. For example, finance may be a very large issue for carers of the same generation who live on small pensions, while for the working child carer, having services which will help them with some of the weight of care may be critical. What services actually help family carers is explored in Chapter 7.

The role of **financial contributions** by the older person, either to the household income in the case of co-residence, or as direct payments to the family carer, or as indirect support to other family members e.g. grandchildren, or even as bequests, may be a factor contributing to the willingness of the family carer to provide care, particularly in low income households. This could at least partly account for the relatively high well-being amongst Greek and Polish carers, despite high levels of care provision and deserves further analysis within the EFC study.

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6 Different care situations

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6.1 Aims of chapter 6

The aim of this chapter is to show different family care situations in Greece. It is based on chapter 6 in the Trans-European report (TEUSURE)¹⁷ where a common cluster analysis on data from all the six countries is presented.

6.2 Method

The use of clusters allows – despite the marginal distribution – a comparison of the care situation in the six countries. However, the distribution of the individual clusters in the countries does not necessarily represent the statistical distributions in these countries since different recruiting strategies were used.

6.2.1 Procedure

The following procedure was used for the analysis of all the six countries data. For clustering caregiving situations the following variables were taken into consideration: Variables related to family carers: Carer's demographics as indicated by carer's gender, educational level, working status and generation with respect to elder, and the characteristics of the carer's place of residence.

Variables related to the caregiving situation: duration of caregiving, availability of help if ill and availability of help in case of necessity. As for the carer's well-being the perceived burden associated with caregiving was included as indicated by the Cope Index's negative impact subscale; and measures of carer's reported state of health and quality of life.

As for the elder-related variables: elder's age and gender, elder/carer 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.

The correlations between the variables were produced in order to exclude those with high correlations. The variables used are presented in table 1.

¹⁷ EUROFAMCARE. 2005. Trans-european report (TEUSURE). <http://www.uke.uni-hamburg.de/extern/eurofamcare/>

Table 1. Variables for the cluster analysis

ELDER	
Elders age	0 = 65-79 1 = 80- highest
Elders sex	0 = male 1 = female
Where do elder and carer live	0 = different houses 1 = same house
Cognitive status	0 = no cognitive disorder or age associated 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
Time of caregiving	0 = up to two years 1 = more than two years
Working conditions	0 = non working 1 = working
Neg impact	0 = lower impact_7 to 10 1 = higher impact_11 to 28
Quality of life	0 = worse quality of life_0 to 14 1 = better quality of life_15 to 25
Carers sex	0 = male 1 = female
Help if ill	0 = yes I could find someone 1 = no or I could find someone with difficulties
Generation	0 = not the same generation 1 = same generation
Locality	0 = rural 1 = urban
Not included	
Help if break needed (because of high correlations with "help if ill")	0 = yes I could find someone 1 = no or I could find someone with difficulties
Health (because of high correlations with "quality of life")	0 = better health_1 to 3 1 = worse health_4 to 5

To explore the possible number of clusters, a cluster fusion procedure (Ward procedure) was carried out. It resulted in 6 clusters which represented the limit of simplification possibilities.

A discriminate-analysis was used to verify the selectivity between the clusters. The present cluster solution resulted in a rate of 81% correctly classified cases.

However, to reach the necessary flexibility, a non-hierarchical cluster-approach (quick cluster in SPSS) was added to the ones previously found in order to be able to "re-sort" cases. The optimizing algorithm of quick cluster checked for each case whether the previous assignment from the hierarchical analysis was the best available or whether, with another assignment, the homogeneity of the new target cluster was less affected than with the previous one.

The newly arranged clusters provided 92% correctly classified cases with the discriminate analysis based on the new classification, and the corresponding value in each individual cluster reached at least 85%.

6.2.2 Description of clusters

The description of the different caregiving situations was at first performed with few characteristics and then, step by step, with the entire list of characteristics used for this clustering. In the first step, sorting was performed using "objective burden" (measured by functional IADL abilities and the cognitive status of the cared for) and "subjective burden" that indicates the caregivers' perceived situation (measured using reported burden and the quality of life) in a sequence from "relatively high" to "relatively low" burden. Table 2 gives an overview of the cluster characteristics.

In cluster 1 and 2 the reported objective as well as the subjective perceived burden of the carer, dominate. As compared to group 1, in group 2 most caregiving women are working and they mostly have a higher education.

Clusters 3 and 4 mainly include couples, in the third cluster women give care to their male partners with this reversed in the fourth group where men care for a female partner. Here, the family carers are members of the same generation and live in the same household.

Cluster 5 displays those whose subjective burden is perceived as relatively low, with a small group of carers reporting a higher negative impact from caregiving, while in the majority of cases a better quality of life is reported. This appears in contrast to the higher objective burden with high IADL disability among the elders in this cluster.

Cluster 6 includes those cases in which the cared for does not show any severe IADL disability and they represent the lowest percent of reported cognitive impairment. Only a minority of caregivers in this cluster show a higher negative impact from caregiving while the majority report a better quality of life. In this group, most of the caregivers are able to combine caregiving with work.

The variable that concerns financial support generally varies with the subjective perceived burden of the carer. The fusion steps showed that before using the non-hierarchical cluster-approach, cluster 2 consisted of two subgroups that could be differentiated only with this variable. Thus, it has to be taken into consideration when characterizing this caregiving situation that financial need was only voiced by a subgroup.

In cluster 3 and 4 the older cared for are usually younger. Older cared for persons can be found more often in the caregiving situation within the more problematic first groups.

The availability of someone else to take over caregiving in case of sickness of the family carer is reported by caregivers in cluster 5 and 6. In all other clusters the majority (from 57% to 73%) do not have such possibility.

Table 2 . Main characteristics of the clusters in the six-country sample

Cluster	Objective burden	Subjective burden	Generation	Working
1	high	high		
2	high	high		yes
3	high	high	same	
4	high	high	same	
5	high			
6				

6.3 Findings

Examining the distribution¹⁸ of clusters in the six countries, it becomes apparent that care-giving couples occur almost twice as often in the Swedish sample than in the other national samples (cluster 3: SW= 30.7% vs. GR=13.8%, I=9.2%, UK=14.5%, PI=12.8%, GE=14.8%; cluster 4: SW=16% vs. GR=5.0%, I=5.3%, UK=10.0%, PI=7.2%, GE=6.2%) This is the biggest country-specific characteristic. In the Polish sample, a focus lies on those two care-giving situations that feature the least subjectively perceived burden (i.e. cluster 5=24.5% and cluster 6=32.2%). The distribution in the UK sample looks similar to the Polish, and the cluster with relatively low subjective and objective burdens occurs most often (cluster 6=30.7%).

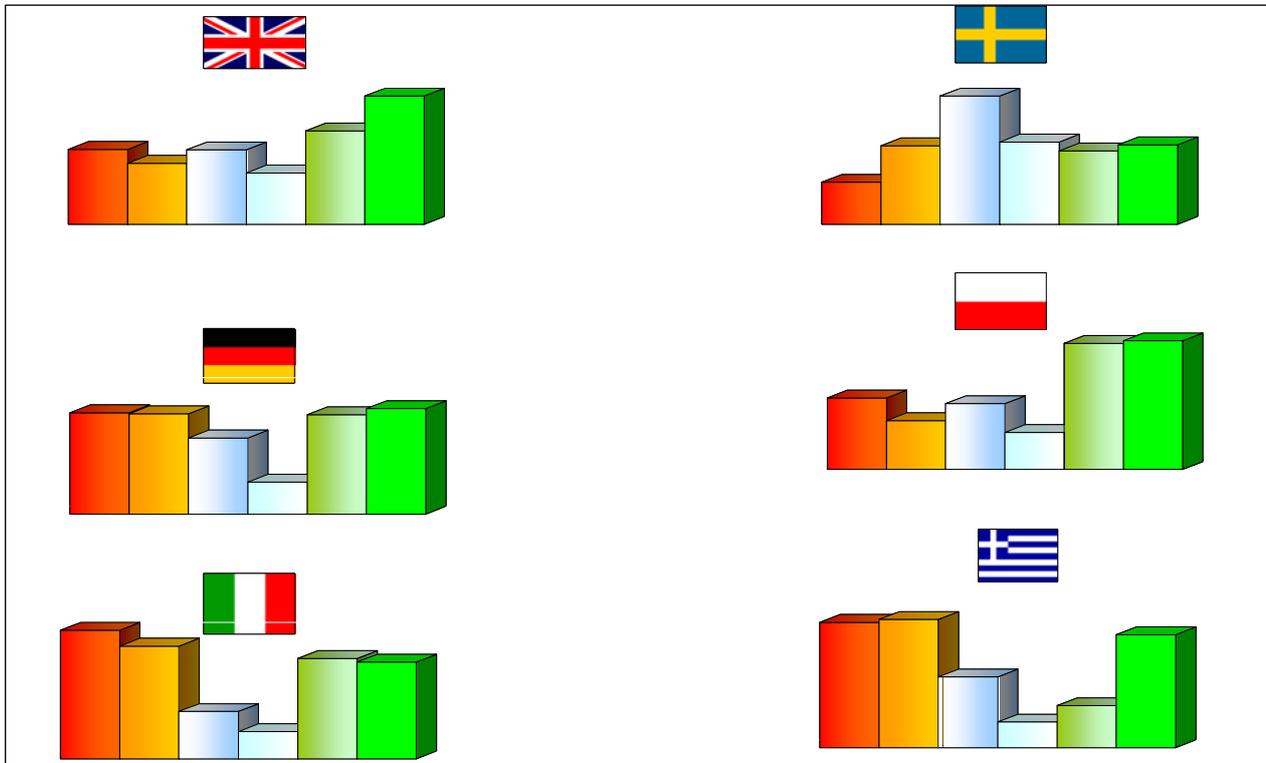
Southern Europe, represented here by Greece and Italy, shows a high percentage in the first two groups in which both the objective and the subjective burdens are above average (cluster 1: GR=24.4%, I=25.4% vs. UK=14.6%, SW=8.2%, PI=13.9%, GE=19.7%; cluster 2: GR=26.5%, I=21.9% vs. UK=11.9%, SE=15.3%,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

Table 3. Care situation and motives for caregiving

Cluster	Cluster characteristics	Motive
1	High subjective and objective burden	Strong emotional ties
2	High subjective and objective burden, working	No alternative
3	Wives(women), high subjective and objective burden	Strong emotional ties Financial advantages
4	Husbands (men), high subjective and objective burden	Strong emotional ties Financial advantages
5	Low subjective and high objective burden	Strong emotional bounds
6	Low subjective and objective burden	Strong emotional bounds

¹⁸ Again, it is to be noted that the distribution of the individual clusters in the countries does not necessarily represent the actual distributions in these countries due to different recruiting strategies and representation. However, these clusters allow – independently of the marginal distribution – comparison between countries.

Figure 2: Care situations in the six countries



6.3.1 Care situations, motivations for caring and views on future care

The question about motivation for care-giving was used to show how the clusters could work in a cross country comparison. In table 5, the distribution of motives by country is shown. Emotional bonds or a sense of duty are mentioned in all countries from a high number of carers. In general, 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%) are dominant and extrinsic motives are mentioned less. As most intrinsic motives are, generally speaking, positive statements, one has to expect considerable effects of social desirability that contribute to the dominance of intrinsic motives over possible extrinsic motives. To avoid social desirability bias, only one motive dimension will be used thus obtaining useful information for the country comparison.

Table 4. Distribution of family carers in the clusters

Cluster	The six-country sample	
	n	%
1	964	17.9
2	937	17.4
3	838	15.6
4	436	8.1
5	943	17.5
6	1266	23.5
Total used cases	5384	100

Care situations, motivations for caring and views on future care

Five different dimensions of motivation for family caregiving have been identified at European level using a factor analysis to explore the underlying dimensions of the original 10 reasons that were given as responses (Table 4).

Table 5. Factor analysis of motives for caregiving by the family carers

Dimension	Motive for caregiving
A sense of duty	A sense of duty Personal sense of obligation towards elder as a family member
No alternative	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	The cost of professional care would be too high There were economic benefits for me (carer) and / or elder

Strong emotional ties is the most frequent reason for family caregiving in the Greek sample.

Table 6. Future care: % of answers

- 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?*

Care situation		Total	Greece	Poland	Italy	UK	Germany	Sweden
1	a) - Yes and I would even increase	53	61	53	61	55	37	35
	- 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
	- 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
	- 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
	- 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
	- 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
	- 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 elder's condition" in this table

Both the German and the Swedish sample diverge from this general pattern. In the German sample, the willingness to expand 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 carers (cluster 2). In the Swedish sample, as well, the possibility to continue care

is seen by a below average number of carers 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, at approximately 40% for married couples and about 50% if the carer is working (cluster 2). The most pronounced differences can be found when comparing national samples. In Sweden, it is an option that is considered most 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 amongst 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 the 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 amongst carers in group 2 (high objective and 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 clusters .

6.4 Final comments

A method of analysis was selected that identified a relatively low number of types of family care situation while using comparatively detailed information regarding the individual care situation. As a result, the core burden differences for the individual carer are presented. Also, intra and intergenerational care relationships are shown more clearly. From the analysis, a group forms where the carers, even though the elder is more functionally impaired, perceives care as less of a burden. At the same time, this group is characterised by the fact that it can more easily find help for the care (in the sense of replacement when they cannot do it themselves) than other groups.

The use of this typology allows "control" (as a statistical strategy) of the different distribution in these groups in inter country comparisons, e.g. more less burdened carers in Poland and the UK, more intra-generational care in Sweden and higher number of burdened carers in Greece and Italy. This is done by performing country comparisons within the individual clusters. Country-specific structures regarding motivation, for example, are taken more seriously if they don't 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 the emphasise of characteristics of a subgroup in a country which were not revealed from the descriptive statistics.

As expected, the religious motive (in combination with a stronger "sense of duty") plays a more important part in Poland in comparison with other countries, but it is also important in Greece with wives who are in an intra-generational care situation and amongst group of women with a low level of education (as in Germany, though there it is more pronounced with caring husbands). In the UK, care is comparatively often motivated by "externally determined" factors if the stated burdens are higher. Swedish carers refer more often than others to "strong emotional ties", which is also true for subjectively lesser burdened carers in Greece. Italy does not show specific structures in this cross country comparison, while in Germany financial reasons are named more often than in other countries in intergenerational care situations (with one exception). All in all, the cross country comparison shows that in case of motives the cultural specific aspects of the countries have an greater impact than actual care situations on motives for care giving.

Finally, a cautious look (carers' statements of intent) was taken into the possible future developments in family care in the participating countries. They clearly fall – aside from the subgroups – into two 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 (physical,

financial and qualitative) of these institutions in the different countries or due to cultural particularities remains to be discussed.

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7 Need for Support, Service Use, Service Satisfaction and Services paid for

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7.1 Aims of chapter 7

The central focus of the EuroFamCare research project was to assess the contribution currently made by a variety of health and social services in supporting family carers, both directly and, indirectly, through supporting the older dependent person.

In Greece, as was known and as the survey research showed, there are few services that are primarily intended for or oriented to the direct support of family carers. Family carers were asked to report on their experiences of how far health and social services of all types helped them and the older dependent person; since the main responsibility for the care of dependent older people in Greece is undertaken by family members, any services which help the older person to maintain a degree of independence are potentially of significant benefit to the family carer.

7.2. Methodology used to collect, analyse and present the data

Since the level of dependency of the older person is directly related to needs for care, the EFC questionnaire had several groups of questions which attempted to address this issue in detail. These results are mainly presented in chapter 5, related to the profile of the cared for older person.

However since this section examines the role of services the results are presented here (7.3.1.) from questions referring to **different types of care needs** (health, physical/personal care, mobility, emotional /psychological /social, domestic, financial management, financial support and organising and managing care and support) and who, at the time of the interview, currently helped with or undertook these activities (7.3.2.), as well as data on the activities with which family carers felt they would appreciate more help.

Finally, sections 7.3.3 to 7.3.9 present the data on services used by the family carers and the older dependent people they cared for, together with the views of the family carers on their use and non-use of services and the importance and quality characteristics of such types of support.

7.3 Main Findings

7.3.1 Older peoples' needs for support

Table 1 (below) indicates for each type of care need whether the older person was independent, or partly or completely dependent on the help of another person to meet this need.

Table 1: Older persons relying on others' help, by areas of need			
<i>Does Elder have a need for help in any of these areas (thus relying partially or completely on others to meet it)? ("YES" answers only)</i>			
DOMESTIC CARE	(N= 1,012)	% relying on others	86.3
partially			30.6
completely			55.7
EMOTIONAL/PSYCHOLOGICAL/SOCIAL	(N=1,013)	% relying on others	90.0
partially			36.0
completely			5.0
HEALTH CARE	(N=1,013)	% relying on others	88.3
partially			36.9
completely			51.4
MOBILITY	(N=1,014)	% relying on others	71.8
partially			40.8
completely			3.0
FINANCIAL MANAGEMENT	(N= 1,014)	% relying on others	79.2
partially			2.3
completely			58.9
CARE ORGANISATION & MANAGEMENT	(N= 1,014)	% relying on others	73.0
partially			25.9
completely			47.1
PERSONAL CARE	(N= 1,013)	% relying on others	65.9
partially			3.0
completely			32.9
FINANCIAL SUPPORT	(N= 1,014)	% relying on others	52.5
partially			3.4
completely			2.1

The **highest frequency** reported in the type of dependency of the older person and need for support, was for **emotional, psychological and social support**; here 90% needed help and 54% of these older people were considered to need total support, results which were similar to those for the other countries. It may be appropriate to note that carers of the same generation, such as

spouses and siblings, usually find this form of care less problematic than family carers of a different generation since they have been keeping company with the dependent older person for much of their lives (Mestheneos, Triantafillou 1993)

The **heaviest form of dependency** is where the older person needs **physical or personal care**, defined here as **needing help with washing, dressing, feeding, toileting**; in this category **65.9% needed some form of help**, but **32.9% were completely dependent**. These results compare well with the specific individual responses for the ADL (Barthel scale), reported in Chapter 5, and represent an overall estimate of the sum of the older person's need for help in the performance of all of these tasks.

This aspect of the need for care is by far the most exhausting for the family carers since the dependency is the most extreme, often requiring 24 hour care and needing additional skills in the performance of tasks e.g. lifting, in such a way that carers do not damage their own health. In two countries (Italy and Germany) older people were reported as having the need for more personal care, reflecting the heavier levels of dependency in the older people in these samples according to the Barthel scores, though in Greece and Poland, family carers provided the highest levels of personal care.

The issue of **finance** was an important one for family carers: in the Greek sample complete dependency in the need for the **financial management** of the older person's affairs was reported by 58.9% and a further 20.3% needed partial help. The reasons for this are not clear, yet Greece is not exceptional in this result since in all the 6 countries the numbers needing help with their financial affairs is similarly high or even higher, possibly reflecting low educational levels, memory and mobility problems. In 90.9% of the Greek sample, this help was supplied by the interviewed family carer, again a rate similar to that in the other countries, although 36.9% of the Greek carers requested help in this area, a much higher rate than in the rest of the European sample.

Financial support was needed by a significant proportion of the older people; 21.1% were completely financially dependent and a further 31.4% partially dependent, giving in total 52.5% who needed some financial aid. In 87.6% of these cases, the financial support was provided by the interviewed carer and in a further 26.9% by other informal carers; again, 74.2% of Greek carers requested more help in this area, the highest rate amongst the 6 countries. This reflects both the fact that many older people have totally inadequate incomes that need to be supplemented by members of their family, while at the same time the additional costs involved for medical and health care (see below) also strain financial budgets. The proportion of older dependent people in Greece needing financial support was by far the highest amongst the six countries participating in the national surveys.

Domestic care was also needed by a high proportion of the older people with 55.7% being completely dependent and 30.6% partially dependent on the help of another person to meet this need. Domestic care includes shopping, cleaning, cooking and washing, tasks which are essential for the comfort and survival of the older person. For those family carers who are cohabitant, this work may be difficult to distinguish from that undertaken for their own and the rest of the family's benefit, but represents a special set of additional tasks for those who are non cohabitant. The percentage offering such care was the lowest among the 6 countries though the variation was not large, possibly associated with higher levels of co-habitation in the Greek sample.

Health care needs, defined as needing assistance with medication, medical treatment, rehabilitation, therapy etc, were also mentioned as an area of substantial need with 88.4% of the older people being cared for needing help of whom 51.4% were completely dependent, more than in the other countries. In 93% of cases this assistance was given by the interviewed carer and in a further 32.8% by other informal carers, with only 14.1% reporting support from services in this area, the lowest rate in all the countries except Poland. Since the reported levels of moderate and severe

dependency in the Greek sample were not higher than the overall sample average, whereas 55.3% of carers requested more help in this area (the highest rate in all the countries), possible explanations may be found in the inflexibility of the health system in responding to the needs of disabled and housebound patients, as well as the traditional habit of families accompanying and supporting an older person in their encounters with the health service (Triantafillou and Mestheneos, 1994).

Nevertheless, the lack of comprehensive home care services to support dependent older people and the services available being necessarily targeted mainly at older people without family carers (Amira et al. 2002) means that Greek family carers have to provide the vast majority of support to their older people in this area.

Mobility, both in and outside the home, was another area of dependency for the older person with 71.8% needing help, a slightly lower rate than for the other countries.

The onset of dependency requires new arrangements as to how the needs of the older person will be met.

Help in **organizing and managing care** was needed by 73% of the older people, a figure that was similar to the other countries.

7.3.2 Who provides the support?

Table 2 indicates **who currently provides help** to the dependent older person in meeting their needs. The **family carer** was the main provider of help, whether the need was for emotional support, personal care or financial support, with percentages varying from the lowest level of 88.1% for domestic care to 95.8% for emotional and social support. However, a significant amount of help was also provided by other informal carers, with rates varying from 25.3% to 48.85% for different areas of need, with the exception of personal care (see below).

Table 2: Who helps the older person to meet their needs?

Type of help	N =	The interviewed carer (%)	Other informal carers (%)	Service / Support organisations (%)
DOMESTIC CARE	875	86.1	33.3	8.1
EMOTIONAL/PSYCHOLOGICAL/SOCIAL	912	95.8	48.8	8.1
HEALTH CARE	896	93.0	32.8	14.1
MOBILITY	728	92.9	35.7	6.9
FINANCIAL MANAGEMENT	803	90.9	25.3	1.7
CARE ORGANISATION & MANAGEMENT	741	88.0	25.8	5.3
PERSONAL CARE	667	92.2	8.1	6.9
FINANCIAL SUPPORT	532	87.6	26.9	2.4

* more than one answer was possible, so percentage values (which are calculated on the total number of subjects who reported the specific need and answered this question) do not sum up to 100.

If one examines those family carers who received **help and support from services** in meeting the care needs of the older person, the highest level of help from services was in meeting health

care needs, although, as already discussed, this is still a surprisingly low rate, at only 14.1%, compared with other countries.

All figures need to be compared with the figures in Table 1 where the family carer reports what they perceive as the need for care; 51% of the cared for older people were considered completely dependent in terms of health care. Even more startling is that of the 32.9% of older people who were completely dependent for their personal care, just 6.9% received help from services. Again, while 55.7% were completely dependent in terms of their need for help with domestic tasks, only 8.1% of the dependent older people currently received help with domestic work from services, while 33.3% received help from other informal carers. Similarly 54% needed complete social and emotional/ psychological support; but only 8.1% received such help from services. Other informal carers were particularly important in providing emotional and social support to the older person with 48.8% of family carers reporting that the older person received such support. Between a quarter and a third of informal carers, other than the main family carer, were mentioned as being important in a variety of tasks where the older person needed support. This was least forthcoming for personal care where only 8.1% helped fulfil such needs, figures which indicate that Greek family carers follow the pattern reported in other countries, where the main family carer frequently undertakes the main burden of provision of personal care tasks without assistance (Dwyer et al 1993, Fink, 1995) although levels of informal support recorded by Greek carers in other areas of need were higher than those in some other countries, with the exception of Italy and Poland, where higher levels of informal support were recorded.

Family carers were asked **what help they would most appreciate in caring for their older person**. For the majority of family carers in Greece the top priority was **financial support**, reflecting the high level of dependency of the older people on the family carer for this need. This percentage was the highest in the 6 countries in the research. In general family carers in Greece were most likely to respond that they wanted help in all areas to support the older dependent person. While this may be the result of the current low levels of support they receive, it is only part of the explanation since, for example, Polish carers received even less support from other informal carers or service and support organizations, yet expected or wanted less help. Help was particularly wanted for emotional and social support, for mobility and for care organization and management.

Table 3: For which areas of need would family carers like to have more help for the cared for older person?

	No.	%*
DOMESTIC CARE	855	55.7
EMOTIONAL/PSYCHOLOGICAL/SOCIAL	896	63.8
HEALTH CARE	892	55.3
MOBILITY	716	60.1
FINANCIAL MANAGEMENT	795	36.9
CARE ORGANISATION & MANAGEMENT	733	62.5
PERSONAL CARE	660	55.3
FINANCIAL SUPPORT	528	74.2

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

The need for financial support to meet the additional costs of care for Greek family carers is further illustrated by the responses in the following table.

Table 4: Has caring resulted in any additional financial costs?

	Yes	Greece		Total EU sample	
		No.	%	No.	%
Special food		346	34.3	962	16.3
Medicines		739	73.3	2844	48.2
Other		136	13.5	731	12.4

Thus, in contrast to the findings from the other country samples where there is often state coverage of essential drugs and special dietary requirements, these additional costs of care are of necessity met by Greek family carers, given the low incomes of the older people themselves.

7.3.3 Services supporting family carers – use, satisfaction and cost

Family carers were asked to report on both any specific services they used to support them in their work of caring as well as general support services which could help. They were also asked about the frequency of use, their satisfaction with the service and the cost to them of using these services. Only **21.6% of Greek family carers reported using any specific or generic service** at all; this was also the case for other countries in the research where the absence or paucity of any kind of support services for family carers in Italy, Sweden and Germany was reflected in the low percentage (20-24%) accessing them.

What **specific services** did family carers use to help them in their work? The very small percentages reflect the very tiny minority of family carers who had accessed any specific service. 0.1% used information services, 0.2% had used socio-emotional support ; 0.3% used respite care to take a break from the care of the older person; none had received any training and there was no help in assessing the caring situation from professionals. Compared with the other countries in the research programme, Greek family carers are poorly supported¹⁹. Socio-emotional support for family carers was also far more available in the other countries – in the UK 7.9% received such support, 10.7% in Sweden and 8.1% in Germany. Respite care, where the family carer can be relieved from the responsibilities of care for shorter or longer periods, was far more frequent in Sweden (6.1% of family carers) and the UK (2.3%). Training which is a very useful tool in helping family carers learn how to care and protect their own health, was also rare in other countries. The highest percentage who had received training was in Germany (2.1%) followed by the UK (1.8%) .

Overall the frequency of use was very low and no-one used such a special service on a regular weekly basis. Thus there were no details on the costs of such services. In other countries the majority of such services, with the exception of respite services, were free.

However there were other more **general services** which Greek family carers resorted to, particularly health services. 17.8% (180 carers) visited a **general doctor**, 3.1% on a weekly basis, 92.8% of them were satisfied with the service (167 people) and 28.3% of those that visited a GP paid for the service (51 people).

13.3% used a **specialist doctor** in the 6 months prior to the research (135 carers), and 4.1% of these on a weekly basis. 91.1% of them were satisfied with the service (123 people) and 48.9% of them paid for the service (66 people).

¹⁹ Thus in Germany 16.2%.obtained information

In interpreting these results, it should be noted that general practice is a newly developing specialty in Greece, with high numbers of and relatively easy access to specialist services in both the primary and secondary/hospital health care sectors.

6% had used the services of a **general hospital** (61 respondents), 86.9% of them were satisfied with the service (53 people) and 19.7% (12 people) paid for the service, although there was no clear distinction between inpatient and outpatient services.

These figures tell us little until we compare them to the figures for other countries. The UK also reports high use of health services by family carers yet when examining the use by Swedish family carers, who tend to be older spouse carers where one might expect increased health problems, there is a much lower reference by the family carers to health services with 5.9% using a GP, 2% a specialist doctor and 0.1% a hospital.

Other generic services used by more than 1% of family carers also included the publicly provided **home help service** for cleaning the home environment, used by 17 respondents (1.7% of the sample), 16 of them (94.1%) were satisfied with the service and 76.5% of them (13 people) paid for the service. **Recreational social centres** were used by 24 family carers (2.4% of the sample), all were satisfied with the service and 16.7% paid for the service. **Specialised diagnostic services** were used by 10 people (1.0% of the sample) with 80% of them were satisfied (8 cases) and 2 (20% of the users) paying for the service.

Table 5: Services used by family carers, costs, frequency of use (% values)*

Services used by family carers	Services used % values (N=1014)	Frequency of service use (% of carers using service at least weekly)	% of carers <u>not paying</u> for services used	Costs paid by carers for services used in past 6 months (in euros)
<i>Total % of carers using at least one service</i>	21.6			
<i>Mean number of services used by carers</i>	0.3			
Specific support services for carers				
Information (about disease, caring, available services and benefits,, help lines, internet)	0.1	*	*	*
Socio-emotional support (counselling, social work, support or self help groups etc.)	0.2	*	*	*
Respite care (including supervision of elder)	0.3	*	*	*
Training for caring	-	*	*	*
Assessment of caring situation	-	*	*	*
Other specific services for carers	0.1	*	*	*
Generic services used by family carers				
GP	17.8	3.1	71.5	26
Specialist doctor	13.3	4.1	51.1	83
General hospital	6.0	0.0	80.0	75
Other generic services used by carers	7.5	49.2	56.6	268
<i>Total amount paid on average by carers for generic services</i>				118
Overview of costs paid by carers for all services used in the last six months (N=335)				%
No costs				60.6
Between 1 and 120 Euros				22.7
121-300 Euros				7.5
301-600 Euros				4.8
601-3,000 Euros				3.9
Over 3,000 Euros				0.6

Family carers were asked about **costs** and of the 335 family carers who had used services in the past 6 months approximately 60% had incurred no costs. At the other extreme were 4.5% of carers who had paid from 600 to over 3000 euros. Those who did pay reported an average 118 euros

overall for health and other general costs in the previous 6 months for their own needs, including 26 euros for a GP, 83 for a specialist doctor, and 75 euros for a general hospital visit.

7.3.4 Services for older people - use, satisfaction and cost

Family carers were also asked to report on services used by the older person they cared for, as well as on their satisfaction with the service and whether or not they had paid for it. The services reported here were those used by more than 1% of the total sample of the elderly participants (1,014 respondents).

General doctors were used by 556 respondents (54.8% of the total sample) and of these 7.7 % (43 respondents) visited a GP more than once in the previous six months. 497 respondents (89.4% of those using the service) were satisfied by the service and 229 respondents (41.2% of the ones that used the service) paid for the service.

Specialist doctors were also widely used by the older dependent people with 494 respondents (48.7% of the sample) using the service in the past six months and 28% of these (138 people) visiting the specialist more than once. 466 respondents (94.3% of those using the service) were satisfied by the service and 64.5% (319 respondents) had paid for the service.

Again, given the dependent status of the older persons cared for, a considerable number, 357 persons (35.2%) had used **general hospital** services in the previous 6 months. 85.7 % of them (306 respondents) were satisfied by the service and just 14.6% of them (52 respondents) had paid for the service

Home rehabilitation services, which primarily concerns physiotherapy, had been used by 40 respondents (3.9% of the sample) of whom 87.5% were satisfied with the service (35 respondents) while 75% of those that used the service paid for it (30 respondents). A further 0.9% used ambulatory rehabilitation services.

Home nursing services had been used by 27 older people (2.7% of the sample) ; 85.2% (23) of the family carers responding said they were satisfied with the service while 77.8 % paid for the service (21 respondents).

Laboratory or diagnostic tests at home, important for the dependent older person who cannot easily get to medical centres, had been used by 82 respondents (8.1% of the sample) with 77 of the respondents (93.9% of those using the service) being satisfied; 45 respondents (54.9% of those that used the service) had paid for the service.

Another health related service for older people concerns **specialised diagnostic** examinations: 36 people used the service (3.6% of the sample); 94.4% of them were satisfied with the service (34 people) and 61.1% of them had paid for this service (22 people).

The services of a **psychologist**, had been used by just 13 older people (1.3% of the sample). Given the large number of older people with problems related to memory, Alzheimer, depression, the limited use of professional psychologists is surprising, although some of these may have reported visits to a neuro-psychiatrist in the specialist medical services section. Of those using a psychologist, 11 respondents were satisfied (84.6% of the users) and 8 respondents (61.5 % of the users) had paid for the service.

As indicated, nearly a third of the older people being cared for needed personal care and many of these can be presumed to be heavily dependent. Thus the use of a **nursing home or residential care** on a temporary base (recuperation, rehabilitation and respite care) might be expected. In the sample just 10 respondents (1%) of the sample had used or were using a permanent nursing home, all of them were satisfied and all of them had paid for the service. In view of the unclear distinction between residential and clinic/nursing home care for dependent older people in Greece, a

separate category was used which combined both types of care: thus a total of 18 respondents had used residential and nursing homes (1.8% of the sample), with all users being satisfied with the service and 66.67 % of the users had paid for the service (12 respondents).

Inadequate nurse staffing levels and high expectations concerning personal care and support, have led to the development of the use of additional privately paid “**practical nurse**” carers in hospitals and clinics. 23 family carers (2.3%) reported that they had used such a service for their older person, 18 (78.3% of the users) were satisfied with the service and 19 of them (82.6%) paid for the service (in the remaining cases it has to be presumed that they were reimbursed by the social insurance fund of the older person). In an attempt to regulate the supply and registration of this sector of health care workers, many of whom are immigrants both legal and illegal, 1 and 2 year government training programmes have been instituted, with an expected increase in the numbers of registered nurses in Greece and a rise in the currently inadequate levels of nursing personnel, which are amongst the lowest in Europe (Kyriopoulos et al, 2003).

Mobility problems are often associated with poor foot care. Though chiropody is not a specialty in Greece 10 respondents (1%) had used the services of a **Podiatrist**, all of them being satisfied with the service and 7 having paid for the service (70%).

The dependent status of so many of the older people might indicate their need for various forms of **technical aids** to support them e.g. in walking, domestic tasks, and is of interest given the stress in Europe on developing modern technologies which will support independent living. Yet just 25 people used such a service (2.5% of the respondents), all of them were satisfied with the service and 84% had paid for the service (21 users).

Again the mobility problems of the older person are helped with suitable **home adaptations and the removal or architectural barriers**. 12 people claimed they had used such a service (1.2%); 9 of them were satisfied with the service (75%) while 9 of the people using the service paid for it. (75%).

Another aspect of mobility concerns the availability and use of **transport services** for older people. 10 respondents (1%) stated they had used such a service; 6 of the users were satisfied with the service (60%) and 3 of them paid for the service (25%). In the absence of a comprehensive programme of transport arrangements for older people, these reports probably relate to the initiatives of individual Municipalities which have made public transport arrangements to serve older people in their areas, either within the context of general transport services or associated with KAPIs and other social service programmes. Additionally, many private taxis will make financially agreeable arrangements to pick up older people for transport to and from health services on a regular basis.

In the past few years local authorities and the Ministry have extended the work and service provided by **social workers**. 15 people had accessed social workers (1.5%), all had been satisfied with the service, and 2 of them (13.3%) paid for the service.

The **public sector** has also expanded its services for older people, many of which indirectly help the family carer. Amongst such services are **recreational social centres** such as the Open Care Centres for Older People (KAPI) and Friendly Clubs (Leski Filias) mentioned as being used by 56 people (5.5% of the sample); 94.6% of the family carers said they were satisfied with the service (53 people) and 37.5% of them paid for the service (21 people).²⁰

Publicly provided and funded **home help services** have been expanding steadily in the past ten years in many local authority areas. In total 97 people had used this service (9.6% of the respondents) with 94.8% of them being satisfied with the service (92 users) and 78.4% of the users (76

²⁰ Although the local authority centres are basically free i.e. heavily subsidized, there is a minimal annual membership fee which can be waived at the discretion of the Social Worker.

people) paid for the service. Another publicly provided service for older people was Help-at-Home for home support including **personal care** of dependent older people. 65 people used this service (6.4% of the respondents); 93.8% of them were satisfied with the service (61 people) and 9.2% of them paid for the service (6 cases).²¹ It should be noted that due to financial restrictions, this newly developing programme has, until recently, given priority to dependent older people without financial and family resources to help in their support and thus was less likely to be used by family carers in this research sample. However, a recent small study of services for older people and family carers indicated that in some areas, Local Authorities were becoming sensitised to the needs of family carers, especially women, to work outside the home and were modifying their criteria for acceptance into such programmes accordingly²².

The past 10-15 years has seen a substantial expansion in the numbers of **migrants** who undertake caring work in the home of older dependent people. The sample in this research concerned older people who had a primary family carer. However in this sample 30 respondents (3%) used **cohabitant private carers** with 86.7% of them being satisfied with the service (26 respondents) and all of them paying for the service. A further 36 respondents (3.6%) used **day-time private carers** for their older person's personal care needs. 83.3% of the users were satisfied with the service (30 users) and all users paid for the service. While there would appear to be higher percentages of older people being cared for by migrant care workers in the general population, the study focused on family carers, and this may explain why the percentage is lower than that estimated overall. (See NABAREs report)

Given the poor mobility of the older person in many cases, other home services were also used. Amongst such services, very important for maintaining the older person's morale, was that of a **hairstylist** at home with 4.6% of the respondents using such a service (47 people), all being satisfied with the service and 95.7% paying for the service (45 people)

Other services were used by less than 1% of the respondents for and by the older person and thus have not been detailed further.

7.3.5 Reasons for not using or stopping using services

Family carers were asked if there were **any services that they or the older person being cared for still needed but had stopped using**. Respondents could give up to three answers. While 92 said there were no services they had stopped using, 81 people had stopped using a service. (8.1%). Specialist doctors was listed both as the first service they had stopped using and overall represented a service that people were most likely to have stopped using. Home rehabilitation (physiotherapy) was the next in frequency (11 listing this as of first importance and 14 overall).

²¹ Some payments were nominal while others, especially in the private sector, would cover the real cost of the service. Thus for the publicly provided services respondents refer to the contribution to the costs of the service and not full payment.

²² Interviews carried out by students of the Dept. of Health Services Management, National School of Public Health, Athens, 2004, as part of their special projects.

Table 6: Services no longer used

Service	First listed			Overall (multiple responses)		
	Frequency	%	Valid %.	Frequency	%	Valid %
Specialist doctor	13	1.28	15.85	19	1.87	23.17
Home rehabilitation services	11	1.08	13.41	14	1.38	17.07
Recreational social centre	11	1.08	13.41	13	1.28	15.85
Laboratory or diagnostic tests at home	6	0.59	7.32	6	0.59	7.32
Psychologist	5	0.49	6.10	6	0.59	7.32
Government provided home help for elder's personal care	5	0.49	6.10	6	0.59	7.32
General doctor	4	0.39	4.88	5	0.49	6.10
General hospital	4	0.39	4.88	4	0.39	4.88
Private care in hospital or nursing home	4	0.39	4.88	4	0.39	4.88
Cohabitant private carer	3	0.30	3.66	4	0.39	4.88
Day-time private care for elder's personal care	3	0.30	3.66	3	0.30	3.66
Physiotherapy at hospital or special centre	3	0.30	3.66	3	0.30	3.66
Integrated planning of care for elderly and families	2	0.20	2.44	2	0.20	2.44
Home nursing services	1	0.10	1.22	1	0.10	1.22
Respite-care home/ Temporary nursing home	1	0.10	1.22	1	0.10	1.22
Meals delivered at home	1	0.10	1.22	1	0.10	1.22
Internet services	1	0.10	1.22	1	0.10	1.22
Care attendant /sitter for the elder	0	0.00	0.00	2	0.20	2.44
Specialised diagnostic examinations	0	0.00	0.00	2	0.20	2.44
Long term residential health care	0	0.00	0.00	1	0.10	1.22
Day hospital	0	0.00	0.00	1	0.10	1.22

Social worker	0	0.00	0.00	1	0.10	1.22
Night-time private care for elder's personal care	0	0.00	0.00	1	0.10	1.22
Government provided home help for cleaning home environment	0	0.00	0.00	1	0.10	1.22
TOTALS	78	7.69	95.12	102	10.06	124.39

Family carers who had used services were also asked the **reason why they had stopped using them**; again they could give up to three answers²³. This data is important for planners of services in allowing them to understand the barriers to usage by the public. Not surprisingly the most important one listed was **finance** with 2.9% of the total sample who were 36.71% of the group who had stopped using services, mentioning this as the main reason. Overall 40 people (38.46% of the group that stopped using services) complained about cost. Given the initial comment that financing the older person and his/her care was a particular burden for family carers in Greece, the role of payment for services is critical in their use.

The **poor quality of service**, was mentioned as the most important reason for stopping its use by 19 carers (1.9% of the overall sample who made up 24.05% of the group who had stopped using services; in total 25 persons mentioned this issue making up 24.04% of those who had stopped using a service). These responses were based on individual experiences but also reflect the lack of evaluation and control in many health and social services.

Access and mobility problems accounted overall for 15 people who had stopped using a service. Sometimes this was the inappropriateness and poor access in public buildings or from the older person's residence to the service and sometimes a matter of transport, or the lack of it.

Non-availability of a service e.g. home help, was mentioned overall by 12 people; although home help services have developed in many local authority areas in the past few years, there are still many areas and communities that are not served by such a service. Non-availability also occurred when the older person no longer had the right to continue using the service e.g. physiotherapist; this was mentioned by 7 people. Social Insurance Funds like IKA, often provide a limited number of hours for rehabilitation through a physiotherapist.

Finally, an issue mentioned by family carers and service providers in a different context, was the **attitudes of older people** themselves who may be quite unwilling to let 'strangers' perform a service for them e.g. domestic work, personal care. This issue is also mentioned in the following chapter by service providers.

²³ OECD figures show that the costs to patients of using health services in Greece are among the highest in Europe despite the existence of a National Health Service since 1986.

Table 7: Reasons for stopping using a service.

Reason	First listed			Overall (multiple responses)	
	Frequency	%	Valid %	Frequency	Valid %
Financial reasons, high costs	29	2.9	36.71	40	38.46
Poor quality of services	19	1.9	24.05	25	24.04
Difficult access, mobility problems, barriers	11	1.1	13.92	15	14.42
Not available	10	1	12.66	12	11.54
No right to use	5	0.5	6.33	7	6.73
Social/attitudinal reasons by elderly or carer	5	0.5	6.33	5	4.81
Total	79	7.9	100.00	104	100.00

Despite the low level of service use, and thus public experience of using services, when family carers were asked **what services they and the older person needed but had not yet used**, 259 carers of the 1011 respondents (25.5%) said they needed services but had had no access to them so far. The dependent state of nearly a third of the older people who need personal care, inevitably puts pressure on family carers and accounts for the many who need support in caring (home help for personal care and for cleaning, home nursing, home diagnostic tests, and permanent or day private carers). The need for help in the social and emotional tasks of caring is also evident in responses where the main support takes this form (psychologist, recreational centres, care sitter and cohabitant private carers.)

Though family carers were asked if they would like and needed **services that would support them as carers**, few were able to imagine what such services would consist of, judging by the low level of response. Only as services develop and knowledge of them is passed round the society are people able to imagine using such a service. (Note Table 9 which suggests the main sources of information). Nonetheless 12 people could understand the benefit of belonging to a self help family carers group, suggesting that being able to talk about their difficulties in a safe and supportive environment of people sharing the same problems, would be as valuable in Greece as in other countries.

Table 8: Services needed but not accessed.

Service	First listed		Overall	
	Frequency	%	Frequency	%
Government provided home help for elder's personal care	25	2.47	40	3.94
Laboratory or diagnostic tests at home	21	2.07	36	3.55
Cohabitant private carer	21	2.07	26	2.56
Government provided home help for cleaning home environment	20	1.97	26	2.56
Home nursing services	17	1.68	21	2.07
Psychologist	15	1.48	23	2.27
Care attendant/sitter for the elder	14	1.38	21	2.07
Recreational social centre	13	1.28	22	2.17
Specialist doctor	10	0.99	17	1.68
Day-time private care for elder's personal care	10	0.99	15	1.48
Counselling services used by the elder	8	0.79	13	1.28
Transport services for older people	7	0.69	16	1.58
Private care in hospital or nursing home	7	0.69	12	1.18
Counselling services used by the carer	7	0.69	11	1.08
Social worker	6	0.59	15	1.48
GP	4	0.39	4	0.39
Home rehabilitation services	4	0.39	11	1.08
Night-time private care for elder's personal care	4	0.39	11	1.08
Permanent nursing home	3	0.30	3	0.30
Laundry service	3	0.30	5	0.49
Security alarm systems for older people and relatives	3	0.30	6	0.59
Technical aides (sanitary towel, walker, arm-chair, false teeth, stick, hearing aid, catheters, etc.)	3	0.30	10	0.99
Integrated planning of care for elderly and families	3	0.30	4	0.39
Relative support groups or self-help groups	3	0.30	12	1.18
Formal standardised assessment of the caring situation	3	0.30	3	0.30
Home health care for terminally ill patients	2	0.20	3	0.30

Hairdresser at home	2	0.20	3	0.30
Day care centre	2	0.20	4	0.39
Physiotherapy at hospital or special centre	2	0.20	2	0.20
Internet services	2	0.20	5	0.49
Regular respite service at home, supervision of the elder person at home for some hours per day, each week	2	0.20	9	0.89
General hospital	1	0.10	3	0.30
Long term residential health care	1	0.10	2	0.20
Day hospital	1	0.10	2	0.20
Telemedicine for monitory purposes	1	0.10	2	0.20
Respite care home/Temporary nursing home	1	0.10	2	0.20
Removal of architectural barriers	1	0.10	3	0.30
Nail care	1	0.10	1	0.10
Specialised diagnostic examinations	1	0.10	2	0.20
Help lines provided by charities addressed to family carers	1	0.10	3	0.30
Management of crises	1	0.10	2	0.20
Podiatrist	0	0.00	3	0.30
Help lines provided by charities addressed to elderly people	0	0.00	1	0.10
Other services for carers	0	0.00	1	0.10
TOTAL	256	25.25		

When family carers were asked why, despite the fact of needing the service for themselves or for the older person they cared for, they did not use it, (see Table 8) the outstanding initial response was the **cost of the service**, and indeed in answers throughout the questionnaire the cost of providing care and supporting the older person was strongly evident. Nonetheless perhaps the most serious issue was the **lack of information** about services, their availability and criteria for use; 190 of the 259 respondents stating that a lack of knowledge and information was the main reason why they had not accessed the service. Greece is far behind in developing the electronic information society, while public information concerning the rights of citizens, the availability of public services, eligibility and costs, is now being made more widely available through such services as the Citizen's Advice Centres, dedicated information centres, publications or web sites for family carers or older people are, as yet, not available.

Access and mobility remain issues for 35 respondents while 28 again mention the **poor quality of services**.

Lack of access in terms of **not having the right to use the service** – presumably without payment – was mentioned by a total 33 family carers. Again the social attitudes of the older person were mentioned by 2 family carers, as being the main barrier to usage.

Table 9: Reasons for family carer and older person not accessing services*(up to 3 responses)*

Reasons	First listed		Overall	
	Absolute Value	%	Absolute Value	%
financial reasons, high costs	108	41.70	162	36.00
lack of knowledge/information	96	37.07	190	42.22
difficult access, mobility problems, barriers	19	7.34	35	7.78
poor quality of services	19	7.34	28	6.22
no right to use	17	6.56	33	7.33
social/attitudinal reasons by elderly or carer	0	0.00	2	0.44
Total	259	100.00	450	100.00

7.3.6 Sources of information and help in accessing services

Family carers were asked how they **found out about and accessed services**. Despite the actually very low rate of service usage, many family carers answered about how in general they found out and accessed services. As Table 9 indicates, the role of an individual's **personal networks** in learning about and using services is particularly strong in Greece, partly because of the poor development of other sources of information.

Health professionals are by far the next most important source of information about services. The next most important source is the **family carer's own knowledge and experience**. The very limited role of counselling agencies, local authorities, and voluntary organizations is also apparent. Interestingly the potential of the social insurance agencies to inform their beneficiaries is also poorly exploited, perhaps partly reflecting the tradition of public services trying to reduce workload and contain costs by the non-provision of information and limitation of outreach services.

Although the TV and radio plays a large part in many family carers' lives, it is rarely used systematically as a source of information. The role of public service broadcasting by the state and private channels needs to be far more explored and ways developed to help advise the public about caring. Advice and information and good examples of care services and would not only raise the profile of family care but provide emotional and practical support.

Table 10: Greatest help in accessing services

Greatest help in accessing services /support	First Listed		Overall (Multiple responses)	
	Frequency	%	Frequency	%
family, friends and neighbours	254	25.05	341	33.63
medical/nursing professionals	164	16.17	244	24.06
carer's personal experience and knowledge	123	0.13	167	16.47
financial resources/savings	55	5.42	58	5.72
counselling agencies, centre of information	37	3.65	41	4.04
local authorities	33	3.25	55	5.42
information/advertisement in mass media, leaflets	33	3.25	57	5.62
health and social insurance	29	2.86	40	3.94
social services	21	2.07	34	3.35
NGOs, voluntary organisations, support groups	16	1.58	28	2.76
good transport (to and from the service)	5	0.49	6	0.59
don't know, never tried to access services	4	0.39	5	0.49
religious organisations	3	0.30	12	1.18
availability of services nearby	3	0.30	3	0.30
no one, nothing	1	0.10	3	0.30
Total	781	77.02		

7.3.7 Barriers to service use

Finally family carers were asked what were their **experiences and greatest difficulties in accessing existing services** (see Table 11) ; up to three responses were possible. Interestingly new issues were brought up in this question that underline the particular needs that family carers have for support in ways that are often not currently met by existing services. One of the most important, with a total of 191 family carers mentioning the issue, is that **care is a 24 hour business** for the more dependent older person and thus services which limit themselves to the needs only of the personnel or the service and do not consider the needs for support at any time over the 24 hours, including weekends, are failing to provide a practically useful service. A further 29 carers mentioned the **inflexible time schedules of services**. Thus service planners and providers need to consider how to manage services that cover the real needs of carers and dependent older people.

In particular public services will have to consider their priorities and reorient their attitudes in order to meet some of these needs (Nies H and Berman P, 2004).

The **bureaucratic and complicated proceedings** involved in accessing a service were mentioned by many family carers (in total by 128 carers). While bureaucratic impediments are familiar problems in Greece, given the particular strains on family carers that caring for a dependent older person implies, this further barrier to the use of a service is a strong disincentive. While this may be one method of rationing service use, it is likely to be a way of increasing inequalities between family carers. Those who have the resources can pay for help, while the majority cannot and have to suffer the consequences unsupported, with however potential short and long-term implications for their own physical, mental and social health.

Since family carers were interviewed from many regions and areas of Greece, some lived in areas without services nearby and distance proved a major barrier for them in accessing services.

The **costs of accessing services** was the fourth most important barrier specifically mentioned by 147 carers. Other problems included long waiting lists and the poor quality of the service.

Table 11: Barriers to Service Use

Barrier	First listed		Overall (multiple responses)	
	Frequency	%	Frequency	%
No one, nothing	151	14.9	151	14.9
Few available 24-hours a day services	132	13.0	191	18.8
Distance	111	11.0	167	16.5
Bureaucratic/complicated procedures	94	9.3	128	12.6
Financial/economic reasons, high costs	76	7.5	147	14.5
Other	65	6.4	118	11.6
Long waiting lists	50	4.9	70	6.9
Poor quality of services	42	4.1	82	8.1
Few available services (with no other specification)	34	3.4	50	4.9
Not accepted by the elderly	22	2.2	36	3.6
Fixed/inflexible time schedules from the service side	20	2.0	29	2.9
Restricted acceptance criteria	13	1.3	16	1.6
architectural barriers	1	0.1	1	0.1
Total	811	80.0		

7.3.8 Importance of different types of support

Regardless of whether or not services were used, family carers were asked about the importance to them of **different types of support** for themselves and the older person, and whether they currently received such support.

Table 12: The importance of different types of support to family carers and if these types of support are currently received?

Type of Support	Importance		Currently received	
	Number	%	Number	%
Information and advice about the type of help and support that is available and how to access it	1009	70.3	953	40.5
Information about the disease that the older person has	1009	74.4	944	68.0
Training to help family carers develop the skills they need to care	1009	41.6	901	28.5
Opportunities to enjoy activities outside of caring	1005	52.5	929	37.9
Opportunities to have a holiday or take a break from caring	1002	60.3	932	36.7
Opportunities for the older person's to undertake activities they enjoy	1005	60.9	937	28.8
Help with planning future care	1005	55.4	926	19.9
The possibility to combine care giving with paid employment**	809	49.3	700	19.6
The opportunity to talk over their problems as a carer	1006	44.2	921	27.3
Opportunities to attend a carer support group	1002	30.1	874	8.8
More money to help provide things they need to give good care	1007	64.2	916	16.3
Opportunities to spend more time with their family**	896	60.0	817	49.4
Help to deal with family disagreements**	764	32.5	665	34.7
Help to make the older person's environment more suitable for caring	999	50.2	889	34.8

(%values*: percentage values refer to the positive answers "mostly yes" on the reported total number of valid answers to this question.)

The need for **information**, both about the older person's health problems (74.4%, currently available to 68.0%) and about the type of help and support that is available and how to access it (70.3%, currently available to only 40.5%), were ranked most important by family carers, with the

latter response indicating the extent of unmet need in this area. Even more striking is the importance of **financial support in the provision of good care**, noted by 65.2% of carers, but currently received by only 16.3%.

7.3.9 Importance of different service quality characteristics

Regardless of the support family carers were or were not currently receiving, they were asked what service characteristics they valued.

Table 12: The importance of quality characteristics of services to family carers and whether existing services mostly meet these quality characteristics?

Service Quality characteristic	Importance		Mostly met	
	Number	%	Number	%
Help is available at the time they need it most	1011	93.6	974	49.3
The help provided fits in with carers own routines	1011	73.0	948	37.3
Help arrives at the time it is promised	1010	90.6	968	50.0
Care workers have the skills and training they require	1007	88.1	948	48.8
Care workers treat older person with dignity and respect	1005	94.6	960	61.0
Care workers treat carers with dignity and respect	1005	88.0	944	62.5
Carers views and opinions are listened to	1007	67.4	944	54.3
The help provided improves the quality of life of the older person	1005	90.6	947	59.8
The help provided improves the carers' quality of life	1004	75.9	955	42.6
The help provided is not too expensive	1004	83.3	948	35.8
Help is provided by the same care worker each time	1004	59.9	950	46.7
Help focuses on the carers' needs as well as those of the older person	1006	81.9	953	49.9

(% values*: percentage values refer to the positive answers "mostly yes" on the reported total number of valid answers to this question.)

The importance given to the need for both professional and humane attitudes of care workers towards the older people they care for was emphasized by carers, as well as the necessity for the help provided to improve the older person's quality of life.

7.4 Discussion

This chapter on the use of services by Greek family carers is necessarily limited by the fact that so few have used services. The narrow range of services used e.g. doctors, hospitals, reflects

- the lack of diversity in service provision,
- the lack of comprehensive provision especially of social services,

both for older dependent people and for family carers, which can be summarised as a lack of “person-centred care.” (Nies and Berman, 2004)

However, what also emerges from this chapter is a picture of the older persons’ needs as perceived by the family carers. The findings on the current use of services as well as the perceived importance of different forms of support, provide a stimulus to policy makers and practitioners on what is really needed if family carers are to be enabled to continue to provide good care. Though finance is an important issue and influences the choices family carers have both in accessing services and paying for extra help, it is by no means the only issue. Even higher priority was given to the need for and current lack of information, reflecting carers’ feelings of being unsupported in this area.

Remembering that the levels of dependency as assessed by the carers using the Barthel Index show that a third of all the cared for older people are highly dependent (see Chapter 5), some of the figures reflecting the older person’s needs for support are not surprising e.g. the need for total personal care. Needs assessment, used as a criteria for service allocation, has the known difficulty of trying to present a summary of complex and dynamic dependency and needs for care from the viewpoint of the family carer and/or older person and/or any service provider, which cannot be totally objective and may alter rapidly. Nevertheless, the implementation of any form of support to family carers, whether in the form of services for the older person and/or the carer or as financial benefits, has as a necessary prerequisite some form of needs assessment. Current methods of disability assessment carried out by committees of the different Health Insurance Funds for the allocation of disability pensions and benefits, need to be radically revised to meet the current needs for care of an ageing population, needs which are not limited to rigid medical criteria regarding categories of disability.

The value of asking carers about the needs of older people for support is that it shows the wide range of types of help some older people need. Of interest is that some forms of dependency are perceived as heavy and stressful by the carer, yet an objective observer would give these a lower priority. The obvious example is psychological and emotional needs for support where 90% of the cared for older people were reported to have this need, although it can be argued that this is a universal human need. The question is when the provision of such support is perceived as a burden rather than part of normal human intimacy normally shared amongst a range of close friends, family and neighbours. The reduction of the life world of the older dependent person inevitably makes the weight of social interaction fall on fewer individuals, and sometimes only on the family carer. This emphasises the importance of supplementary forms of social support such as volunteer visitors, transport to get the older person out of the home, social day care centres, all of which help to reduce loneliness, isolation and social exclusion of dependent older people and also reduces the perceived burden on the carer.

The lack of specific services to support family carers is a reflection of the lack of recognition of their role in Greece. Respite care, information and training appear to be services that have developed in other countries as a response to demands for support by NGOs of older people and family carers, or by social policy planners who have become aware that without supporting family carers the increasing numbers of older dependent people will have negative implications for future social and health care services. In Greece phenomena such as an increase in bed blocking in hospitals and total or relative abandonment of older people will inevitably become more frequent as family carers become more burdened by increasing numbers of older dependent people. At the moment families bear the burden of dependency associated with longevity unsupported by public policy and associated services, either for older people or for themselves as carers. It should be noted that existing services to support older people in their homes are non comprehensive and of necessity focus currently on supporting older people without families to care for them.

Reflecting on all the reasons why family carers did not use services provides an insight into the problems with existing services. Cost remains a significant barrier to use of many services; lack of accessibility reflects both the carer's personal difficulties in moving the older person, but also the placement and facilities of each service; the lack of information on the availability and scope of services was stressed in different contexts; and finally an important aspect of services is their quality. Family carers will not avail themselves of services of inferior quality to the care which they themselves can provide. Overall the weakness in providing adequate evaluation and monitoring of services, including quality evaluation, is a serious problem in most Greek services both public and private which needs addressing as a matter of urgency if the objective of "person centred care" is to be realised in practice.

Final comments on the use of services in a European perspective

Usage of support services by family carers

Comparative data in the field of care service provisions should always to be interpreted with caution, since the contents and meaning of single services are very much nationally defined, thus not always completely corresponding across countries and different care systems. Keeping this in mind, the illustrated findings seem however to reveal with enough 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 caregivers find support often in rather more traditional, "**generic" services**, i.e. in services which have not been created to specifically address family carers' needs, but play a sort of **substitution role** in this respect to relieve and sustain family carers in their everyday tasks. This is primarily true for **General Practitioners** or their equivalent in Greece, who seem also to play a relevant key role in the UK. Especially where no other services are available, they appear to be key figures in ensuring, the information necessary to access the 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 is instead the recourse to **generic services**, thus revealing that their use, although very widespread, remains usually a very "irregular" or "mild" one.

Care allowances

Support to family carers is in the UK and Poland provided, to a certain extent (i.e. in about one tenth of cases), also in 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, remaining a quite residual form of support in Sweden and Greece, although for very different reasons. Again, Polish recipients can count in this respect too on much lower average amounts than their Italian, British and, above all, German counterparts.

Carers' experience in using services

A 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** – as a consequence of the fact that they are funded by public agencies – so that only a very small minority of carers has to pay for using them. However, in some countries the need for some kinds of support services is evidently higher than their availability (on a public, free 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, quit 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 reveal to be the “gatekeepers” of the overall service care system in all analysed countries (and especially Germany and Italy), with the only exception of 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 the **family, friends and neighbours** (i.e. other informal support networks) 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), **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 an overall perception of **poor service quality** (relatively high in Greece and in the UK). The latter (to be found also in Sweden), together with the high cost of services (in this case relevant 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 result **no longer available** (mainly in UK and Italy). The **lack of adequate information** proves to be the major reason for **not using needed but never used services** in country characterised by a generally lower educational level of their older population (mainly Greece, Italy and Poland), while in the remaining countries (Sweden, Germany and UK) the relatively more frequent non 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.

Carers' opinion about most important 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 the attendance of 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 almost all types of support are currently provided to family carers to an extent which can be judged as insufficient, since they reach only part of those retaining them important. **Sweden and the UK** are characterised by a more balanced situation between demand and provision of most types of support, although in Sweden a certain lack can be observed in some specific areas (information, recreational activities for the elderly, help in planning future care and attendance of carer groups), while in the UK even some situations of “support abundance” seem to occur (with regard to the availability of carer support groups and counselling on carers’ problems and family disagreements). The latter phenomenon of “support abundance” is even more accentuated in **Poland and Germany**, where many of the support types retained as most relevant by carers are currently met to an even higher degree, thus revealing a situation of overall satisfaction. This can probably be explained by different reasons in the two countries: in Poland to be searched in the prevailing lower 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 mostly 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 retained by carers as “very important” are on the whole 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 show cross-national differences which reflect and even accentuate the pattern already described above for the preferred types of support: **Greece** and (but this time to a lesser extent) **Italy** as mainly characterised by carers not being satisfied about the crucial service characteristics; **Sweden and the UK** in an intermediate, more balanced position (this time 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.

Service effectiveness

A preliminary analysis on the **determinants of the negative impact of caring** on family carers shows that this is associated mainly with main 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, temporary residential social/respite care, home based domestic services, cohabiting non-family paid carer, training for caring and emotional/psychological/social support services) is connected with a more negative impact of caring, probably explained by the fact that the **usage of these services is higher for more frail elderly-carers dyads**. With regard to cross-national differences, carers tended to show a **more negative impact of caring in Greece and less negative in Poland** than carers in other countries. In order to be fully comprehensible and to prove the direction of the detected associations, these findings

will need to be integrated by those derived from the analysis of the follow-up survey focusing on determinants of change in carers' outcome and service use, which are preliminarily discussed in chapter 9.

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8 Service providers' views on services for family caregivers and older people in Greece

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8.1 Aims of chapter 8

One of the main issues and aims in the EUROFAMCARE project was to understand how services can and do help family carers, with some perspective on how services may be able to help in the future. Thus interviews with current service providers were important as a way of understanding their perspectives, values and current difficulties in reaching out to support family carers. The aim of this primarily qualitative study was to gather information about services provided for carers and the older people they care for, and specifically to gauge some of the

- 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
- service provider perspectives on current and future developments

8.2. Method and sample

8.2.1. Sample

The lack of systematic national data on the availability, distribution and coverage of services for older people and for family carers led the Greek team to undertake a pilot study in the autumn of 2003 with post graduate students from the Department of Health Services Management, the National School of Public Health, who were asked to find out what support services for older people and family carers were available in different areas of Greece to which they had access. Questions were similar to those used in the subsequent common Service Providers' Questionnaire. Students contacted over 28 services and interviewed²⁴ many of the service providers, all but two being in the public sector. This background study helped in the formation of an understanding of the situation of service providers in Greece and in an understanding of the main issues in the Greek context.. No service specifically for family carers was identified. Confirmation was provided that there were similarities throughout the country in the structure of services for older people, though not necessarily in their operation and funding.

Subsequently the SPQ was developed for use by all 6 countries and this was used with selected service providers. The aim was to interview at least 5 service providers per area and in total 20-25 interviews: in the end 21 interviews were completed. The SPQ consisted of questions providing basic data on the service, comparable data concerning the values they held about their service, as

²⁴ 5 ΚΑΠΙ; 2 Κοινωνική Αλληλεγγύη 7 Βοήθεια στο Σπίτι 1 Κέντρο Κοινωνικής Πολιτικής 2 Μονάδα Κοινωνικής Μέριμνας 1 Γραφείο Κοινωνικής Μέριμνας 1 Οργανισμός Πρόνοιας και Πολιτικής Προστασίας 1 Δημοτικό Πολυϊατρείο 3 Κοινωνική Προστασία Ηλικιωμένων 1 Κέντρο Ημερήσιας Φροντίδας Ηλικιωμένων 1 Λέσχη Φιλίας 1 Υπηρεσία Κατ' οίκον Νοσηλεία 1 Συμβουλευτική Υπηρεσία Ηλικιωμένων ΜΚΟ

well as open-ended questions about family carers. The questionnaire had four sections in addition to the initial description of the service and basic information about the respondents.

- A. semi-structured questions about services for family carers
- B. semi-structured questions about services for older people that might relieve family carers
- C. structured questions about service types and quality characteristics of support that family carers needs and prefer
- D. 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, primarily through the original research co-ordinators and interviewers from the prior family caregiver interviews as well as through interviewed service providers.

- The second part of the Service Providers Questionnaire had more open questions to those service providers giving services and support directly to family carers
- The third section asked the same questions of services provided primarily for the older person.

The geographical sampling for the service provider interviews was within the original sampling areas for the interviews with family caregivers; Attiki, (Athens) Macedonia (Thessaloniki), Crete (Herakleion), Peloponnesus (Patras) and NW Greece (Corfu) and included, with the exception of Athens and Thessaloniki, examples of services in urban and rural areas. Interviewed in total were :

- 12 local branches of public services;
- 5 local branches but part of national organizations,
- 4 Regional services.

The sampling attempted to be diverse by finding management representatives from the voluntary sector, faith based organisations, social and health services and commercial companies.;

Given the centralisation of **health services**, there were few regional and organizational differences in service provision in the state health sector, helping to explain the similar responses from the different regions. Variations in the provision of health care that impacted on family carers had far more to do with the staffing levels, demand for the service and personal sensitivities of the staff. Few services are primarily offered within the older person's home; older people and their family carers are expected to come and find the service rather than receiving primary health care at home.

A majority of health services are provided by the National Health Service and administratively implemented in health districts. In addition there are private health services (e.g. private doctors, private nursing services – one was interviewed, specialist services and public primary health services provided through IKA (Urban Workers' Fund). Municipalities may also provide some primary health care services if they run KAPIs (Open Community Care Centres).

Social services, however, showed considerable regional variations both in levels of provision and in their capacity to reach out to family carers. Social care is provided at the level of municipalities, but is non comprehensive. Services depend on national legislation and funding as well as municipal resources and programming. There is no explicit legislation nor recommendations that covers

support for family caregivers; in practice this is left to the sensitivities of managers and professionals running services. In particular structural facilities, location and staffing levels accounted for their outreach ability within their communities, rather than substantive variations in local policy. Nonetheless, the sensitivities of local politicians and social workers organizing services lead to variations in their attitudes towards supporting family carers. While nowhere is the support of the latter part of their official administrative brief – since both KAPIs, Help at Home and Nursing at Home services are designed for older people - many social workers make efforts to find out the needs of all older people and their family carers in their community:

“We do more than is required because it is in the nature of our work.”

Private business, voluntary and religious organisations serving family carers are very few. Private business that have an impact on older people and family carers are mainly residential homes and, more recently, a few organised private health services that provide care at home. Migrant carers, used by some family carers, may be recruited privately, by word of mouth, or through private employment offices though these do not in themselves offer a direct support service to family carers.

There is no national supervision and licensing of services, and even residential homes are mainly supervised in terms of their physical facilities, with many being unregistered.

In the private sector the ability to pay, or to have appropriate insurance that will pay for a service, is critical; if family carers are pleased with the service and can afford the price, they continue to use it. Although there are few private services²⁵, they are available for family carers with money.

Voluntary and religious organisations exist throughout Greece. A traditional religious philanthropic body, and a ‘newer’ form of self help organization, as well as an association funded by the state to operate a specific service were interviewed.

8.2.2. Recruitment

The six interviewers used for the administration of the Service Providers Questionnaire, had been involved in the previous data collection interviews with family carers in their regions. Each interviewer in consultation with the research team was asked to select and contact a sample of services for older people and/or family carers in their area, according to the study guidelines, and interview the senior manager or service provider who was in the best position to give the required information. Interviews took a varying length of time, but all comments were carefully noted and transcribed directly afterwards. Content analysis was used to analyse the open questions.

²⁵ A private residential home and a private nursing agency were interviewed. In addition there are hospital nursing agencies, typically used if someone needs to go into hospital, to care for the older person while in hospital, and agencies providing domestic and care workers, mainly foreigners.

Table 1. Profile of service providers by type of organisation, area, size, type and provision of services for family carers and/or older people, n=21

	GR
Total sample	21
Respondents' role	
Head	4
Manager	7
Practitioner	9
Other (volunteer running a service)	1
Type of area	
Metropolitan	3
Urban	12
Rural	6
Type of organisation	
Public social care	12
Public health care	4
Religious denomination	0
Voluntary organisation	2
Private business	2
Other	1
Number of employed people	
Small (10 or less people)	10
Medium (11-50)	8
Large (more than 50) – as part of the National Health Service	3
Portion of the services intended for older people	
Less than 50%	2
More than 50%	7
100% or nearly 100%	12
Portion of the services intended for family carers	
No service	13
Less than 50%	3
More than 50%	3
100% or nearly 100%	5
Number of carers using the services	100 to 500

8.2.3. Method of analysis

The interview data were analysed using both qualitative and semi-quantitative methods, according to the type of questions and following a common protocol. Content analysis was used on the open answers from the semi-structured questions in section B and C. The protocol for the data analysis used the following main categories:

- goals and benefit
- usage and access
- coverage, quality
- attitude towards family carers
- costs
- future development

Quantitative data from section A and D and E were entered into SPSS a statistical package for descriptive analysis to be undertaken.

8.3. Representativeness

There are few organizational differences in services and few regional variations throughout Greece as the Greek state continues to be highly centralised, particularly reflected in the Nation Health Service. In recent years there have been efforts towards de-centralisation, with the development of services at regional and local community levels. This has included the setting up of Regional Health Authorities, Health Centres in rural areas, IKA (Urban Workers Health Insurance Fund) primary health care centres, Mental Health centres, and some primary and preventive health care provision in the over 900 KAPIs (Open Care Community Centres for Older People). Social services, in contrast, though following a similar centralised model, are planned, organised and implemented at the local level by the Prefecture or Local Authority, leading to considerable differences in type and level of provision of services in the various regions.

Despite the variations in the levels and completeness of local health and social services, they maRegional Hinly have identical forms of centralised legal and administrative organization. The pilot study consistently showed the similarities, confirmed in the 21 interviews conducted using the Service Providers' Questionnaire.

8.4. Main findings

8.4.1. Service providers' views on services for family caregivers - goals, benefit, quality, attitude, future development

In fact few of the service providers, with the exception of one of the Associations, provided a service primarily focused on the needs of the family carer. Thus the responses from service providers described here reflect on services primarily given to older people and only incidentally to family carers²⁶. Few service providers, even where less sensitive or proactive to the needs of family carers, entirely ignored them since the needs of one older person can often not be separated from the needs of an older couple, an older child or sibling carer.

²⁶ In the responses to the questionnaire, service providers often stated they gave no services to family carers and then responded in a subsequent question that they served x number of family carers. This conflict is because few services primarily consider family carers yet inevitably do serve many of them.

Apart from the descriptive data concerning the structure and size of the service, there were two lists of closed questions which asked service providers firstly about how important they considered each type of service support they offered for the family carers; the second list of questions asked about the characteristics that were important in any service for a family carer. In summary the most important services mentioned by service providers for family carers were training family carers in caring skills; attending family carers support groups; and ensuring alterations in the home that helped family carers in their tasks.

Service providers were also asked about the service characteristics that were important in any service for family carers: they believed that of most significance was that the care worker (professional) treated the older person with respect; that the service improved the quality of life of the older person; and that they focused on the needs of both the older person and the family carer.

These responses will be compared to both the replies and perceptions of family carers themselves (in the Family Carer's Questionnaire and in the Follow up questionnaire), as well as in the qualitative elaborations made by managers and staff in the Service Providers Questionnaire and discussed below.

Services for family carers and services for older people that might relieve family carers

The only service exclusively designed for family carers was that of the Garda Association providing help and support primarily for family carers. For this reason the analyses of responses concerning usage and access, coverage, quality, goals and benefits, costs, attitudes and future developments have been consolidated into one.

8.4.2 Usage and Access

o Lack of knowledge and information

Community services and NGOs shared a common problem, namely that family carers are frequently unaware of the availability or even existence of the service, the eligibility criteria for using the service, the kind and range of support it might offer them and the quality of this service. Although service providers agreed on the networks by which people learn about services including membership of their local community, social networks, doctors, pharmacists, neighbours, the community centre (KAPI), rural and urban health centres, other family carers, pamphlets, local authorities, it is worth pointing out that each family carer normally comes without much preparation to their caring role and needs to have readily accessible information on what the service consists of and how they may access it. However information tends to be provided only locally and spasmodically and, since most of the services have a relatively short history, rather vague ideas remain about the services on offer. It was also evident that some services were far more proactive than others in seeking out those people that might need help and support from their service;

"We do house to house research."

"The first job is to find out their needs."

"We use the COPE Index²⁷ to analyse the needs of family carers."

²⁷ COPE Index is a standardized measuring tool developed in the EU to examine carers' health and well being – see chapter 3.

Two different service providers used standardised tests:

“The needs of the person are evaluated through psychometric tests and discussion.”

In some cases the older person had been directly referred to the service and then staff contacted family carers, usually the children, to tell them of the programme and try to develop personal cooperation. Interestingly several services made similar comments about why family carers did not try to access or use their services.

“They think they will solve their problems by themselves, that the state is not interested in them and that any help would not correspond to their needs.”

“It isn’t easy since they are not as informed as much as they should be. They are not aware of the services to which they are entitled.”

“They don’t realise that the KAPI is for them and they don’t ask for help.”

Lack of knowledge about the service sometimes had consequences in terms of both older people and their family carers being ignorant of the nature of the service.

“Does it only do cleaning, or does it just measure blood pressure?”

“The population does not have a clear understanding of what the programme offers. This is because those served and the family carers just talk about the specific services they get and thus there are many different versions going around. For example, someone says, ‘They measured my blood sugar and sent me to the doctor’ – which then makes everyone think it is a health service. Again, though information is critical, it has not been emphasised enough because we are short of time. Before Help-at-Home there was another programme, so there is a misunderstanding about what each programme offers.”

○ **Attitudes**

Service providers reported that many family carers were unwilling or unable to talk about their problems to them; thus the main difficulty of family carers accessing and using the service involved getting over this reluctance and making the initial decision to approach the service²⁸. The Help at Home service mentioned some of the attitudes that made it difficult for family carers to use their services and meant it was sometimes less utilised than it could have been:

“The main thing that stops people accessing it however, is shame that they have to ask for help to look after an older person, since traditionally this was the role of the family. There are some cases where they don’t believe the programme can help since the older person needs full time care. There are some services which are not even used 50% of the time, but when they get to know us they use more of the services”

“Family carers are ashamed; they don’t have all the information and believe they are begging.”

The service provider from the Mental Health Centre pointed out that:

“People only ask for help when they get to zero point, but they don’t ask for help before because they feel guilty, they come only when they feel very worn out or desperate”

Indicative of some of the attitudes of family carers was the under-use of some services, including laundry and housecleaning; some family carers also could not accept group psychological support and counseling.

²⁸ Older people were also part of the problem; as 2 service providers in the pilot study commented; older people sometimes thought it was a curse to have to rely on care from non-family members – strangers. The traditional reliance on the family is part of a strong ideological belief and the weakening of this relationship with changing social conditions is making many older people unhappy.

In contrast, a group of volunteers who form the basis for a new voluntary association such as an Alzheimer support group, had to be more proactive in reaching out to the community and family carers. While traditional Church based voluntary associations typically serve a parish of known constituents, more modern secular forms of associations dealing with family carers have to be far more proactive in both setting up working relations with other bodies and agencies, including the University, the Church, the Municipality and other NGOs. They learnt to reach out to the community by holding events such as scientific meetings and weekly talks, by producing pamphlets and scientific brochures and by participating in media events or spots. Though members form the core of the association, family carers may still be reluctant to access it:

“The main barrier is fear and the hesitation of the family carer concerning whether his real needs will be recognised, especially his difficulties with the cared for person with Alzheimer. Some use the service fully and we have a lot of members who participate actively in the activities and work of the Association. For the rest of the family carers there is a lot of effort to get them to participate and offer what they can to our work.” However this Association also provided many traditional and social occasions that brought family carers together out of their isolation:

“We organize various events such as the Alzheimer café, with the aim of developing links between members of the Association. And we have a Christmas Fair, New Year Pitta cutting, Easter Egg bashing...”

- **Physical access**

Access also depends on the ability of family carers to get to the service; service providers commented on the fact that family carers are faced by the serious difficulty of a lack of time – it is not always easy to leave the person needing care, or to combine care with work or the maintenance of a household.

8.4.3 Coverage

The only estimate concerning coverage by one community based Help-a-Home service for older people was that it covered approximately 10% of the older people in the area. It is not clear if this means 10% of those with needs or of all residents 65+. However, with respect to family carers, there was agreement that none of the services offered support when they needed to be relieved from 24hour care. Despite some support through the Social Care programme, the primary focus was on the older person.

“The Programme does not cover the family carer for a full day – even if they need just a day off.”

“The time we devote to family carers is just not enough, because they are numerous and we are overworked. There are no family carer groups. The programme does not cover transport to hospital, or repairs and the painting of houses especially in the winter, which is really important.”

The bureaucratic difficulties faced by family carers such as in obtaining prescription drugs for the older person through the latter’s insurance fund and in dealing with the public administration, were mentioned as areas where some of the services were able to help e.g. in purchasing medication, giving injections, measuring blood and sugar levels and personal cleanliness.

Examining the needs of both family carer and the older person helped some services undertake their long term planning.

“In the evaluation of needs we frequently work with the doctor in the regional clinic or the attending doctor and the physiotherapist. The monitoring of needs occurs mainly through continuous follow up of the cooperation between the family carer, who tells us about changes occurring, and the doctors. Generally the evaluation of needs and their subsequent coverage is an important part of the

programmes' activities; frequently we notice needs that the individual ignores or does not express and these are difficult for us to deal with e.g. mental illness, or house cleaning."

For those offering private services, coverage depended not only on the size of the enterprise but on people's ability and willingness to pay: one residential home owner said:

"It is limited to those can pay and we have very little spare bed capacity. We deal with some family emergencies e.g. business, holidays, but only a few. We need more space for respite care."

Service providers in the community, both public and NGO, recognised that they had an enormous remit: this included the sensitization of the neighbourhood, links and cooperation with agencies and resources in the local community, research in cooperation with university centres and investigating needs.

Yet the general absence of support services for family carers was noted by service providers:

"The basic benefit for a family carer is that if there were an organized service which could offer moral and economic support and strengthen the work of the family carer, then older people would also get better care and live with dignity in their last years of life."

One health service mentioned their inability to cover the needs of older people with mental problems and learning difficulties, while the Mental Health service was aware that it was unable to provide practical help for family carers looking after older people with mental health problems.

8.4.4 Quality

The measurement of the quality of a service is a complex matter: growing demand by family carers and older people and expressed satisfaction with the service offered were mentioned as ways in which the service could judge its success. No service mentioned the introduction of ISO standards or any other form of systematic and objective quality control. In a country where services are new and people do not take them for granted, then one might expect there to be considerable satisfaction when a service does help.

"People are positive since they think we give them whatever we can, though still we don't have an objective evaluation."

"Satisfaction with the service? Yes they are satisfied, since the person they care for is not suffering. Both they and the older person feel safe. The psychological support they feel is most important."

The quality of the service was affected by limited resources: thus family carers who needed help with the care of someone early in the morning or late in the evening were not satisfied since there was no staff on duty at these times.

"Their needs have increased and they are not satisfied because the service does not respond adequately."

"Family carers are generally happy except for those who are generally ungrateful!"

The rather limited hours during which Greek public services are open to the public should be noted in the general context of understanding problems in service quality. Although not mentioned in the context of these interviews, a very important limitation on the development of quality standards is the lack of secure and adequate resources for many of the community based services. Thus not only are there inadequate numbers of staff but even they are often unsure about when their salaries will get paid and whether they have a short or permanent contract. There are very few substantive mechanisms in place in any sector of the Greek public service to review the quality of that service from the perspective of the user.

Service providers mentioned some of the elements in developing a good quality service: these included regularity, respect for the family carer and older person, direct communication, good and immediate information, coordination with other services, effectiveness and ability to help the family carer. Although many reported they had such elements in their service, there was no objective and regular assessment by the service of their actual practices. One community based service interviewed had tried to develop better coverage and quality in their service by using trainee students and forming them into working groups of ten volunteers, both to provide help *and also to visit isolated older persons living in the community, on a weekly basis.*

“They learn, and what is important is the relief they offer to the family of the dependent older person, which is very important since so many are themselves older and have a lot to discuss and understand with these volunteers.”

Service providers pointed out that though evaluating the service was important it was not always easy:

“From what is said to us and within the KAPI most seem happy with the services. There have been cases of omission and mistakes, but we could not be effective because of our work loads and inexperience. Objectively we don’t know whether they are happy or not since our relationships are direct and they don’t want to talk to us about these difficulties. There are cases where the workers are kin, neighbours and friends and thus the older person and family carer cannot express themselves freely. We would like there to be an external evaluation so we can see our mistakes and omissions and to see how effective we really are.”

“We think the cooperation between staff is very good and the communication with the older people and their family carers too. There is an immediacy in our relationship, and of course one issue is keeping the necessary distance between us so that they don’t take us over. “

○ **Training**

An important element in the quality of the service was training. As was pointed out there is no specialised training available in Greece in gerontology or geriatrics and thus the need for staff to receive special training was noted.

○ **Existing problems in quality**

Several important issues affecting service quality were mentioned. The first was flexibility, so that alternative ways of dealing with problems, of helping family carers and older people, are available. Many of the difficulties came from state and local authority bureaucratic problems and rigidities:

“Characteristically we are not permitted to transport an older person in the mini-bus belonging to the service.”

“The service Help-a-Home, needs to see quite a few changes at the institutional level, as well as others. Programmes need to be more flexible and to provide alternative solutions for the care of older persons since the needs are many and various. A completely dependent older person and his/her family carer have quite different needs from someone who is more or less independent.”

The Association helping family carers of people with Alzheimer disease pointed out that quality in their service depended on the attitudes of family carers and the use they made of the association.

“We can only understand the family carer when we use a holistic approach, and make an effort towards integrated care. One needs to look at the behaviour of the family carer in the context of a complex network of mutually influential forces which meet in time and space and change over the period of time where and as the form of the disease changes.

We have a building and suitable infrastructural support. Relationships are very good and there is a good atmosphere of cooperation between members, they feel they are active partners in an attempt to deal with their problems in many different dimensions."

The owner of a residential home was very concerned with the development of national standards in residential care and good quality control; to this end he was working closely with the Ministry for quality standards. Although recognising that residential care was likely to be used by few, part of the problem for the private service provider of a residential unit was the lack of a national system of evaluation, certification and quality control for all residential care units.

"At the moment there is no correct evaluation of residential care homes and we are pressing for this in cooperation with the Ministry."

With respect to his own nursing homes he suggested that an element of quality lay in:

"A high ratio of staff and thus the family feels safe. They see the cleanliness. We have no face control at the door so anyone from the family can come in and see their resident member whenever they like. So there are no special preparations – this is part of our success and the quality. Other homes have face control – so when a family visitor comes the staff rush to the patient and this gives a false picture. An open door policy is the only way. Yes, we have quite a few with Alzheimer – but with enough care and the correct medication they stop wandering and stay in the building."

The lack of quality control was also something that other service providers hoped would change:

"The basic gain for the older person is they feel security in the services provided, in their quality and continuity. For them it is important to know that, for example, on Thursday we will measure their blood pressure, etc..... Also they feel that the services stop them being a weight on their children and don't stop the latter from working."

8.4.5 Goals and Benefits

As stated initially, almost no services have been designed primarily for family carers²⁹:

"The central goal of the organization, unfortunately for family carers, is actually about the older person themselves."

Nonetheless several of the services see their role as encompassing family carers:

"Goals are concerned with the preservation of the health of the older person, keeping the family together and the support of family carers."

"What is positive is that the link between family carer and the older person is not severed. The user feels safe and thus accepts the service and there is continuity and follow up."

Nearly all the services that provided any kind of support to family carers mentioned the importance of psychological and emotional support; security; being relieved from some of their everyday tasks and thus having some time to themselves; obtaining primary health care advice about caring for the older person; obtaining advice and counselling; sharing their anxieties and problems and some relief from the weight of the care for the older person. Other benefits for family carers is that they get support, help in coordinating their work and in obtaining support from other programmes run by the municipalities e.g. Help-at-Home. Other services stressed that the service enabled some-

²⁹ The Hellenic Red Cross is one service provider that is sensitive to family carers' needs. It does run Counselling and support services for family carers and older people in a number of areas, and though not interviewed in the framework of this study, the central Athens service was interviewed in the pilot study.

one to stay in their own home and environment, provided specialised support services and an improvement in the quality of care.

“Emotional recognition is one of the main benefits for family carers, relief, improvement in their self confidence, decrease in their feelings of guilt, to be more logical and objective. “

A rather larger aim was stressed by one service provider who thought their organization should be researching into the needs in the community and expanding in accordance.

“The service should not be directed only at older people but at all the community.

We need trained personnel, a staffed office which will work with the Municipality and with all the programmes.”

The church based association pointed out that one of their goals was to provide counselling and some economic help and advice.

Given that frequently the stay of a dependent older person in hospital constitutes an additional burden for family carers who have still to provide psychological, nursing and practical support, both private and public services offering nursing at home were important in improving the family carer's knowledge, conditions of work and quality of life.

The Association helping family carers of those with Alzheimer had larger goals:

“Our general goals are to sensitize the community, to fight stigmatization and social exclusion as well as providing much better knowledge to family carers about how to react to those with Alzheimer.”

They provided a wide range of support as part of their central goals including education, psychological, moral and legal support as well as a 24 hour telephone service.

8.4.6 Costs

As indicated, the use of private services is dictated by the willingness and ability of either the older person or the family to pay. Capital resources can be liquidated or payments made out of current income. In contrast, both the Greek National Health Service and even more the limited social services available are supposed to be or are free to users. Access to public hospitals and health services is dictated in great part by the state of health of the older person and there are real monetary and time costs involved in using the 'free' national health system for family carers, from having to transport the dependent older person to the health service, extra payments made to staff, the cost of prescription medicines and other health needs not easily covered under health insurance. The social services, if allocated to an older person, are actually free. Associations and NGOs normally provide their services free or rely on voluntary support from other family carers.

8.4.7 Attitudes

The staff in nursing and health services recognised that part of their function was to help the family carer be more informed and learn a few skills. Many service professionals commented that they perceived them as partners, that they encouraged them to communicate with the programme and that their opinions were carefully listened to since they were far more aware of the problems:

“And if they don't agree with the programme we cannot have a good outcome.”

Nonetheless there were differences between family carers: as one service provider said:

“In the evaluation and implementation of the service, what is important is whether the family carer is the spouse or the child, where they live, and their age. Where the family carer is the spouse, s/he is also served by the programme. In this case we support the stronger of the two but it is diffi-

cult for them to be very active. If the children live in the same village, their reluctance to accept help with respect to cleanliness etc is high, even if they themselves can't respond to the need. They cooperate much better on matters of health since we discuss more openly the difficulties and if we are worried about early signs of dementia we can discuss it more easily with the child than the spouse – though of course that does not mean it does not occur. In the case where the older person is an uncle or aunt, or sibling, cooperation is more difficult, though there are only a few cases where there is not much interest and difficulties in getting them involved. In these cases when we mention services they are all reluctant. When we say there have to be changes to the house, it needs painting etc, or we need to transport the older person to a doctor, they are much less active than children would be.”

“We see family carers as a critical part of the community who, if they get proper support, would be better carers”

“Initially there is some emotional conflict; when a specific difficulty has to be confronted we try and discuss with the family carer as to the best way of dealing with it. We make the programme/plan in common, separate our roles and responsibilities and always ask ‘what can we do? What is your opinion?’ We look together for alternative solutions. “

“If the family carers are indifferent or negative, we don't just stop, we try to find other approaches. At the end of each action we complete with them we have a discussion with them as to what else we might have done. We keep them informed about all our actions, at regular intervals, even if there is no immediate reason and we discuss with the family carer about the older person. In the situation where an older person has no immediate family carer in the area, their children live far away for example, we try to telephone them and communicate with them and they do the same with us.”

“We try to involve family carers since the programme does not aim to replace them nor can it replace the importance of the family environment in the care of older people.”

“Characteristic is the story of a daughter who asked us after a time to help with the personal hygiene of her mother, a need that she had from the start but had refused. Then when she had to be away for two weeks, she asked us to take on the care of her mother for breakfast. She said “Now I need the help – when I am here it isn't any trouble, but now I need to feel secure that the old lady will eat and that someone will go into her house twice a day and check that she is OK.”

Many stressed that family carers were treated as partners in the programming of care for the older person, though –

“Family carers cannot be treated as partners in care when there is indifference, abandonment, or if they have crazy ideas. The kin are then a part of the problem. What is significant is the particular relationship, whether they live near or together especially for subsequent care.”

“Family carers are a critical part of the community who, if they get proper support and cooperation with the services would be better carers of the older persons.”

One of the original goals of the Greek Alzheimer Association was the development of other branches in Northern Greece for family carers to have better access – this has already been achieved in Volos, Larissa and Xanthi and elsewhere with a total of 22 branches (2006).

8.4.8 Future Developments

As discussed, the future development of services in Greece is very unclear. Thus when asked about future developments few were able to be specific about what was actually planned and tended to respond in terms of what would be desirable. Several services were so new that they felt unable to discuss likely future developments as they still tried to fulfil their original brief. Others

were pessimistic about the likelihood of them providing services for family carers in the near future and many services reported that there was no strategic plan to develop services for family carers in the future. Public service providers were not optimistic about how far they would be able to extend their services to help family carers, particularly those looking after the heavily dependent, the immobile, bedridden and demented, who need continuous care.

Many recognised both the increasing needs for support services for the growing number of older people, as well as the needs of family carers for support. Changes in residence patterns, with older people remaining in rural areas, and the trend for women to enter the labour market, were already leaving some questions in the minds of service providers as to what needed to be done. Thus they underlined the need for existing programmes to be strengthened or expanded with coverage from new staff e.g. a psychiatrist, a permanent doctor, occupational therapist, physiotherapist, gerontologist, GP, home helps. More nursing services and health promotion in the home of the older person and the family carer was also thought to be a development that was needed.

Service providers recognised the many gaps in service provision and thought there needed to be a more systematic approach, with a special service dealing with the issue of family care. The need to give more time to family carers and to sensitize the administration of this need was a goal of more than one public service provider. One suggestion was the setting up of an office with staff exclusively for family carers. Increased staffing levels were mentioned as developments to be hoped for in the future, though this was considered very uncertain. An important subject was extending the hours of operation of the service to cover the afternoon, weekends or periods when the family carer had to be away. However not all services could expand without adequate accommodation and equipment:

“Equally essential is that this team has permanent equipment (medical equipment etc, washing machine, cooker), so it can organise its time better. For example, if the home help has to cook meals for 2 houses, she could do it once for the two households – the same goes for washing. These solutions are being examined by the service so we can be more effective.”

New services were felt to be important for family carers and several service providers in the private and public sectors thought that an important future development was that of Day Care Centres, a few of which are already in existence (though not found in the areas where family carers were interviewed in the EUROFAMCARE National Surveys) and some were being planned:

“We are setting up here a Day Care Centre where Family carers can leave their person for 5-6 hours or as long as they wish when they go to work.” (Residential home owner)

The extension of services, by employing more staff and providing a 24 hour service to cover needs around the clock and if necessary substitute for the family carer, was needed in order to help family carers. A service for family carers that would provide respite relief for families at regular intervals was also needed.

In the health field the creation of more specialist help was underlined, including psychological support and physiotherapy at home.

An unresolved problem that bedeviled both current service usage and future developments and mentioned by service providers in both the health and social service fields was that of suitable transport e.g. a mini-bus or ambulance, enabling older people and their family carers to get to health and social facilities.

Several mentioned the critical importance of training for family carers as well as professionals, since they were aware that many carers had insufficient skills in caring, including a lack of awareness of the need of the dependent elderly for psychological support and inadequate communication skills. Support units and the supervision of those working in the services were also needed.

Information about how services worked elsewhere was also thought to be important for the staff, so they had some vision of what could be done.

Supporting the formation of self help groups was mentioned as a necessary innovation in the coming years, supported by the service professionals. These could be used both for advocacy e.g. to demand financial help or recognition, but also importantly for psychological support. As one service provider said:

“A challenge for us is to learn how to develop better cooperation with family carers and to push them to network and work together.”

The development of support groups of volunteers was mentioned by one Association, though they felt a greater dynamism was needed so that they could offer help and relief to family carers³⁰.

The future role to be played by new technologies for family carers was discussed by more than one service provider as useful in the provision of advice and information, systems for making appointments, home alarms etc. Such technology is understood to help both older people remain independent and safe and aid the family carer. Suggestions were made as to how family carers should be supported e.g. payment for care from the insurance fund of the older person for as long as they offer their service.

The need for additional hands-on carers was mentioned by service providers; noticing that many people were unemployed, they suggested that some could be employed and trained within a coordinated service providing care at home, either through the KAPI or the Social Work department of the Municipality.

The social changes occurring led to some suggesting the need for research and investigation into the needs of family carers, so that appropriate services could be created and run at local and regional levels.

“Finding resources to undertake such research at the local level is problematic and we try to activate the local authority so it moves in this direction. “

Other specialist services that would help family carers were mentioned, including community care nursing for terminal patients and specialist services for those needing help when caring for those with learning difficulties or mental health problems.

Although the church based association made considerable efforts to recruit volunteers, comments were made on how difficult it was to get enough helpers to work with older people and family carers.

In addition in the health services many professionals see their role as that of the expert to whom the older person and family carers refer themselves; as suggested initially, a proactive stance to reach out to the community, and specifically family carers and older dependent people is rare.

³⁰ The comments from service providers in the pilot study suggested that the use of volunteers was not without problems. Relying on them to provide regular support for family carers and older people requires a considerable investment of time and effort. e.g. in their training, recruitment, management.

8. 5. Discussion

The results of the Service Providers Questionnaire showed that despite the availability of highly trained and motivated staff in some services, the current operation and mission of existing services does not suggest that there will be any immediate move from their current service orientation towards older people, towards an orientation that also supports family carers. It is also dubious as to whether family carers would be a political priority for local policy makers, though at the national level the wish to increase labour market participation may mean that funding of the planned Day Care Centres becomes a necessity.

In addition it is evident that the mere existence of services to support, directly or indirectly, family carers, is not enough to ensure their use. Consistent and long term information about the availability and the provisions of a service is vital. Ideologies concerning women's position as family carers, family life and care, and intergenerational support are coming into conflict with the demands of modern employment, contemporary expectations about life choices, as well as the huge increase in longevity. Service providers cannot expect family carers and older people to always understand what they might be able to gain from the use of services; those that have active outreach policies begin to be a part of the solution rather than an additional problem for family carers. The results from the SPQ also suggest that training is a key element for both the staff of services and the family carers so that they can both work towards the goal of improving the quality of life of both the older person and the family carer.

9 The one-year follow-up study

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9.1 Introduction

As is evident from the present report, Europe presents a rich cultural context for examining family caregiving, with the six countries representing very different European contexts, 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 of 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; Gräsel 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 TEUSURE 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. The addition of a longitudinal element to the original cross-sectional study, should enable analyses indicating 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 clarifying the interdependency between costs and the effects of supportive networks and family well-being.

9.2 Aims of chapter 9

The present chapter aims to extend the prior cross-sectional reported data on the family caregiving situation in Greece to include an examination of longitudinal patterns of change over one year, by addressing the questions:

- What are the changes over time in the selected older person and carer characteristics?
- What are the positive and negative predictors of these changes?

9.3 Methodology

9.3.1. Follow-up Study design and procedure

As already described, the baseline data (T1) were collected during face to face interviews using a Common Assessment Tool [CAT], between November 2003 and June 2004., resulting in a final sample of 1014 completed questionnaires from family carers who were giving support or care to their older relatives (age 65 or over) for more than four hours a week.

The follow-up [FU] data (T2), were collected after approximately 12 months (+/- 6 weeks) from the baseline study, between December 2004 and July 2005 from the same original sample subjects and using the FU questionnaire, which consisted of items selected from the baseline questionnaire [CAT], supplemented with several new ones.

9.3.2. The Follow-up Questionnaire and the implementation of the FU study

The FU questionnaire was designed 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 situation of the family carer and their cared-for person. It consisted of several sections:

- Identifying data (number of questionnaire as in the initial study, interviewer's details, date of interviewing);
- Mode of FU questionnaire administration;
- Filter question identifying "present carers" who were still caring for their older relatives, where the full version of the FU questionnaire was used, and "ex-carers" who had stopped caring after the initial study, 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 had questions concerning:

- Living arrangements;
- Occupational status and the economic consequences of caring;
- Restrictions on carers and on their professional career;
- Level of physical and mental 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. The same wording of questions used in the CAT baseline study was used in the FU questionnaire.

The FU Study was carried out both with baseline carers who had given up caring for different reasons, e.g. older person's death, etc., as well as with family carers still caring for the same older relative. Those carers who had given up caring for the older persons in the previous year were asked to complete a short version of the FU questionnaire, with a special paragraph focusing on reasons and circumstances related to this fact. Those amongst the initial respondents who were still continuing caring for their relatives were asked to answer the full version of the FU questionnaire.

9.3.3 Specific problems of the Greek FU survey

The original design of the EUROFAMCARE study had not foreseen, or included a budget for, the follow-up survey. Consequently, whilst a common FU questionnaire was designed and used by all 6 countries, each of the 6 countries used a different methodology for conducting the FU survey, with the main variations being in the size of the targeted follow-up samples (full or partial resurvey attempted) and the mode of FU interview (face-to-face, postal or telephone). Due to severe financial constraints, Greece had to limit the size of the targeted FU sample to approximately 1/3 of the baseline sample subjects, excluding those who had originally refused to be contacted after a year. Furthermore, the follow-up interviews were conducted by telephone, not by face-to-face interviews as in the baseline survey and used only 2 of the original 70 interviewers. A random sampling pro-

cedure was **not** used and the FU interviewers were instructed to attempt to contact the listed baseline sample carers in sequence, but after 2 unsuccessful attempts to move on to the next subject.

All of these factors led to a number of problems both with the planning and implementation of the Greek FU survey, discussed below.

9.4 Results of the Greek FU survey

9.4.1 Subjects, sample size, response rates and reasons for non response

The final number of completed FU questionnaires for Greece was 282 (28% of the baseline survey sample), 88 with the short version and 194 with the full version of the FU questionnaire.

Details of the Follow-up Study are shown in **Table 1**.

Table 1: Size of T1 and T2 samples: Reasons for non response, and response rates

COUNTRY	T1: Sample Size	A priori excluded from ⁽¹⁾ resurvey (Germany, Greece)	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					
Greece	1014	396 ⁽¹⁾	0	0	0	61	1	38	236	88	194	45.6	282
Total:	5923	796	4	1	4	119	15	296	1319	914	2448	65.6	3362

(1) Due to shortage of funding, Germany and Greece had to limit *a priori* the size of the FU samples.

(2) The number of cases excluded from resurvey was not included in the calculation of the response rate

The reasons reported by the FU interviewers for non-successful contact, including refusals, were: reported wrong telephone number or address; automatic answering machine or mobile service; number out of service; an absence of carer at home; lack of memory about the first interview and refusal to be re-interviewed; refused re-interview (no time, busy, wanted to speak only to original interviewer, negative attitude to interviewer); moved away; lack of cooperation between older person and their husband/wife as carer, illness of carer, lack of belief in the effectiveness of the study for the carer's situation.

Very specific difficulties were encountered during the resurvey, which may partly explain the high rate of non-contacts and refusals. The interviewers noted the particular problem caused by the fact that whereas the first interviews were face-to-face and allowed the interviewers to establish a personal relationship with the subject, the second interview was conducted via a phone call and only in a few cases, by chance, were they conducted by the original interviewer. The length of time needed for the FU interview may have affected some responses in particular, such as those to the question on the "usefulness of a service", which were note by the interviewers to be poorly addressed by the respondents, since they had little relevance to their own caring situation and it was felt that frequently any answer was given, rather than a considered response. Moreover, due to the proliferation over recent years of "marketing" types of phone calls, visits and correspondence, many people have no patience with contacts or calls from an unknown person; there is also con-

siderable suspicion generated by requests for personal data and the easiest response was often just to say no.

9.4.2 Representativeness of the FU sample (T2) in relation to the initial samples (T1)

Despite the non-random selection of subjects for the FU survey, the demographic characteristics of the Greek FU sample (T2) are similar to T1, although caregivers of more severely dependent older people, those with higher impacts on negative outcomes from caring, and a worse quality of life were more often willing to enter the FU study.

9.5 Main findings of the Greek follow-up survey

9.5.1 Continuity versus discontinuity in care: Reasons for discontinuity in care

In the Greek sample 68.8% of the original family caregivers were continuing the caregiving process after one year, compared with 72.7% in the total European FU sample.

Table 2: "Continuity" versus "discontinuity" in caregiving for the older relatives over one year

	Greece N=282	Total EU sample N=3362
Still caring	194	2446
% by country	68.8%	72.7%
Stopped caring*	88	916
% by country	31.2%	27.3%
Due to:		
Elder's death	62	577
% by country	22%	17.2%
Other family member provides care now	13	100
% by country	4,6%	3%
Professional carer provides care now	3	41
% by country	1.1%	1.2%
Transferred to nursing home	1	153
% by country	0.3%	4.6%
Lack of data, or other reason	9	45
% by country	3,2%	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 (22% of re-surveyed carers) and the second most common reason for withdrawal was the transfer of caring to another family member (4.6% of resurveyed carers).

9.5.2 Mortality in the sample of cared-for older people

The death rate for the Greek sample after 1 year was 22% compared with 17.2% for the total European sample.

Higher mortality was evident especially amongst the older group of cared-for elders and those in metropolitan and urban localities, with the lowest mortality in rural areas.

Also, as expected, more severe physical and to a lesser extent mental disability predicted a higher probability of death as shown in Table 3.

Table 3: Mortality rates per year and per country [% by category & by country]

	Greece	Total EU sample
	N=282	N=3362
In whole sample n=3362	62 22,0 %	577 17,2%
Age		
Age <80 n=1459	27 20,0	194 13,3
Age >=80 n=1885	35 23,8%	378 20,0%
Type of locality [g4loca]		
Metropolitan n=704	9 28,1%	144 20,5%
Urban n=1603	34 25,4%	274 17,1%
Rural n=1044	19 16,4%	156 14,9%
I-ADL dependency [iadl_t_r]		
Low to moderate n=1011	10 12,2%	98 9,7%
More severe n=2324	51 25,9%	473 20,4%
Cognitive disorders [cogn_r]		
Intellectually able n=1235	19 17,9%	162 13,1%
Probable/suspected n=2109	40 23,5%	409 19,4

9.5.3 Discontinuity of care - possible predictors

Analyses and statistics

Due to the small numbers of subjects in the Greek FU survey, statistical analyses aiming to identify the factors associated with the changes in the selected characteristics of the FU sample and the predictors of these changes, were not possible; therefore, individual country data relating to the Greek FU sample, as for most of the individual country samples, is not available.

Details of the total sample analyses are available in Chapter 9 of the TEUSURE report and this report of the Greek FU survey will present only a brief summary of the results of these analyses for the **total FU sample**.

Excluding those carers who stopped caring because of the death of the cared-for person, possible predictors of withdrawal from the caring process for the total European FU sample are summarised as follows:

- 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, demanding more physical or personal carer's help. On the other hand, cohabitation with carer in the same household and cohabitation with own child/children, especially with those having their own children aged <14 years, predicted continuity of care by the same carer. 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 a year.
- Amongst **carer dependent variables predicting withdrawal** from care were 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 carer, lower investment 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 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.

9.5.4 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 their cared-for person's place of living may be strongly connected with reciprocal support, help, and the elders' level of dependency. It may facilitate the caring process, although it may also be a result of other factors e.g. a shortage of apartments, carers' or elders' financial situation, better access to service networks, etc.

The change in living arrangements between time T1 and T2 of the FU study is presented in **table 4**, which shows the changes between categories of initial carers' and elders' place of living, recorded into two modalities: those living in the same household or building versus those living in another place at least within walking distance. As can be seen, of those living initially in different houses 19.2% had moved into the same house during the past year, 3.6% of those initially living together had moved into separate accommodation but the vast majority (77.2% had not changed their living arrangements.

Table 4: Changes in the place of living between time T1 and T2.

	Greece	Total EU sample
No of valid	N=193	N=2,420
Moved from different to the same houses (n)	37	253
% of initial residents of different houses within countries	47.4	23.6
(% column)	19.2	10.4
Moved from the same to different houses (n)	7	45
% of initial residents of the same houses within countries	6.1	3.3
(% column)	3.6	1.9
Without change (n)	149	2,122
(% column)	77.2	87.7

9.5.5 Changes in carers' occupational status, restrictions on professional career and other restrictions due to care

84.2% of the Greek carers did not change their employment status during the previous year. However, 9% of the Greek sample became employed, and 6.8% became unemployed during the same period.

Table 5. Transition of employment status between time T1 and T2

	Greece	Total EU sample
No of valid	N=190	N=2400
Began work between T1 and T2	17 9%	135 5.6%
<i>% of initial non-workers within country</i>	1.2%	9.2%
Stopped working between T1 and T2	13 6.8%	124 5.2%
<i>% of initial workers within country</i>	1.6%	13.4%
No change (% of country)	160 84.2%	2141 89.2%

Being employed and caring for an older person may generate 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 6** shows carers' opinions on possible restrictions due to caring on

professional life amongst the sub-groups of carers currently working and currently not working (at T2).

Table 6. Restrictions on carer's professional career in the groups of "current workers" and "current non-workers" (at T2)

	Greece	Total EU sample
Currently working (at T2)		
No of valid cases	N=49	N=860
Despite caring, my working hours are unchanged	44 89.8%	758 88.1%
Because of caring I had to reduce my working hours	5 10.2%	82 9.6%
I had to reduce my working hours for another reason than caring	0	20 2.3%
Currently not working (at T2)		
No of valid cases	N=80	N=1,092
Because of caring I could not carry out my job at all	48 60%	314 28.7%
Because of caring I had to give up my job	1 1.2%	42 3.9%
I stopped work for another reason than caring	31 38.8%	736 67.4%

The vast majority of currently (at T2 time) working carers (89.8% of the Greek sample), was struggling with caring responsibilities without any reduction in working hours, with only 10.2% reporting having to reduce their working hours because of caring.

Amongst currently non working Greek carers, 38.8% had stopped work for a reason other than caring, but 61.2% reported restrictions on work due to caring, the highest proportion in all the study countries.

Table 7. Other restrictions from caring (at T2)

	Greece	Total EU sample
I can/could not develop my professional career or studies due to caring (at T2)		
No of valid cases	189	2,280
YES	38 20.1%	188 8.3%
I can/could work only occasionally (at T2)		
No of valid cases	189	2,186
YES	30	174

	15.9%	8%
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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	192	2395
Yes, quite easily	87 45.3%	997 41.6%
Yes, I could find someone, but with difficulty	38 19.8%	917 38.3%
No, there is no one	67 34.9%	481 20.1%

Other restrictions on professional life, such as difficulties in developing professional careers or studies, were declared by 20% of the followed-up Greek carers and 16% could work only occasionally.

The burden of care undertaken by a single carer unsupported, is illustrated by the 35% of the followed-up Greek carers who reported that there was no-one to look after their cared for older person if they needed a break from caring, a marked increase from the 21.2% who gave this response in the Greek baseline sample and a much higher percentage than the 20% in the total European FU sample who replied in this way.

9.5.6 Changes in the level of the older people's physical and mental condition

9.5.6.1. Physical disability after a year

Table 8 presents changes after 1 year in instrumental activities of daily living (I-ADL) and personal activities of daily living (P-ADL) functioning, measured in terms of the number of carer-reported dysfunctions, which were defined as the older person being "not able" or "able only with help" to perform one of six I-ADL or ten P-ADL activities.

I-ADL activities were defined as ability to: do housework, prepare their own meals, go shopping, handle their own money, use the telephone, take their own medicines (questions 43-48 in the baseline EUROFAMCARE questionnaire)

P-ADL activities (Barthel scale) were defined as ability to: get around indoors, manage stairs, move themselves from bed to chair if next to each other, use the toilet (or commode), use the bath or shower, keep up their personal appearance (brush hair, shave, make up etc.), dress themselves, feed themselves, incontinence of urine, incontinence of faeces.

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 8. Changes in I-ADL and P-ADL dependency between T1 and T2 [in % from columns]

	I-ADL	P-ADL	Total I-ADL	Total P-ADL
No of valid cases	N=188	N=173	N=2,339	N=2,277
Less dysfunctions IMPROVEMENT	19.2%	36.4%	19.3%	23.7%
The same as in T1 NO CHANGE	48.9%	20.8%	48.6%	27.6%
More dysfunctions WORSENING	31.9	42.8%	32.1%	48.7%
DECREASE on '0 -100 Barthel-Index Scale' (T1 - T2)				
		-8.9		-5.5

Regarding I-ADL function after a year, 19% of the follow-up sample showed improvement and approximately half were reported to be unchanged, whereas 32% were worse. Perhaps more surprisingly, for P-ADL function 36% were actually improved after one year and only 21% were unchanged, whereas 43% were worse.

These figures should be interpreted with caution, firstly because they are based on the responses of the carers, not on the older people themselves, and secondly because, whilst the baseline data was collected during face-to-face interviews, the follow-up data was given via a telephone interview, with all the attendant problems discussed earlier in this chapter.

What emerges clearly, however, is that even amongst a sample of initially moderately to highly dependent older people, their functional status does not inevitably undergo a steady decline over time, but may demonstrate both declines and improvements. This illustrates the potential for the implementation of interventions aimed to improve the physical status of older people, thus reducing their dependency on the support of another person and reducing overall needs for care both at the individual and at the population level (Mestheneos, Triantafillou et al. 1999).

Whilst at the European level the implications of this have been understood and incorporated into an emphasis on the importance of preventive health and active ageing programmes in planning for long-term care needs (Spidla V., 2006), there is little evidence that Greek governments have so far realised the need for and supported the implementation of such programmes in an attempt to reduce disability in an increasingly ageing population.

Nevertheless, the majority of Greek carers (54.1%) reported an increase in the intensity of care after one year, measured in terms of the number of hours for care, as shown in Table 9

Table 9: Distribution of caregivers by changes in intensity of care after a year (T2)

	Greece	Total EU sample
No of valid	192	2,364
Less hours per week than at T1	70 36,5%	948 40,1%
The same hours per week as at T1	18 9,4%	395 16,7%
More hours per week than in T1	104 54,1%	1021 43,2%

9.5.6.2. Mental disability after a year

In addition to physical disability, mental abilities are usually susceptible to change over time.

Table 10. Changes in memory problems [MP] between time T1 and T2

	Greece	Total EU sample
No of valid	N=193	N=2,409
Without MP at T1 & T2	41.4%	41.8%
MP retreated	11.4%	10.6%
MP newly appeared	19.2%	11.9%
MP persisted up to T2	28%	35.7%

41.4% of the older people in the follow-up sample had no memory problems in either the baseline or the follow-up survey, whereas 28% were reported to have memory problems in both surveys. However, 19.2% of the cared-for older people began to show memory problems during the FU year, while in 11.4% of the sample family carers reported that memory problems had decreased. These results support other findings that memory problems alone, without other cognitive dysfunctions, may be ascribed to a mild memory impairment syndrome, which can show progress to dementia but also recovery over time (Jacoby and Oppenheimer, 1997).

Behavioural disorders, co-existing with memory impairment, usually indicate a dementia if other cognitive functions are impaired. The proxy assessment of the older persons applied in the study, based only on one face-to-face and one FU telephone interview with the carer, makes it difficult to provide precise judgement about the presence or absence of disease. Nevertheless, it is interesting to recognise the dynamics of changes amongst the re-surveyed, even with these limitations.

Table 11 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 an average scores' numbers based on T2 results.

Table 11. Changes on the Behavioural Disorder Scale [BDS] between time T1 and T2; average scoring on the BDS (T2) per category

	Greece	Total EU sample
No of valid	N=191	N=2,333
Less BD	37.2%	23.5%
Mean scoring	0.8	1.7
No change	32.5%	42.7%
Mean scoring	0.9	0.8
More BD	30.4%	33.8%
Mean scoring	3.9	4.0

33% of the follow-up sample of cared for older people were reported not to have changed their behavioural status after one year, whereas 37% were reported to have less disorders and 30% to have more disorders than at the baseline study.

Whilst acknowledging the limitations of these results, as discussed above, it is interesting to observe that over 1/3 of the FU sample of older people were reported to have fewer behavioural problems than one year previously, indicating that behaviour problems in older people do not inevitably deteriorate and can be effectively managed. This has important implications for reducing the burden on family carers caring for older people with the most difficult problems of behaviour disorders and co-existing behaviour and memory disorders.

The results also emphasize the **urgent necessity for the provision of formal support to these families by the Greek government, including training family carers and health care personnel in how to manage behaviour disorders**, in order to **prevent** both the development of physical and mental health problems in the individual family carers, as well as the otherwise inevitable breakdown in the long Greek social tradition of good family care for dependent older people. These topics are discussed further in chapter 10.

9.6 Summary remarks:

- 1) 69% of the initial Greek sample of family caregivers were still caring for the same older person after a year.
- 2) Mortality amongst the cared-for persons was the main reason for carers' withdrawing from care over the year (22%), but the second cause was the transfer of the cared-for person to another family member (nearly 5% of the Greek FU sample, the highest proportion amongst the 6 countries), whereas transfer to a nursing home was reported by only one Greek family carer (0.3% of the Greek FU sample) but represented 4.6% of the total European sample, being highest in Sweden, Germany and UK.
- 3) Regarding changes in the living arrangements of the family carers and cared-for older people with respect to cohabitation, nearly one in five of those originally living separately had moved into the same household or building after a year.
- 4) Whilst the vast majority (90%) of the Greek FU sample of currently working carers was struggling with caring responsibilities without any reduction in working hours, caring for an older person also **negatively affected the caregiver's professional career**; 61.2% of the

Greek sample of non working caregivers reported restrictions on work due to caring, the highest proportion in all the study countries.

- 5) Caring for an older people also negatively influenced everyday life with the finding of **increasing isolation of family carers** in the FU study, illustrated by the markedly higher proportion of Greek family carers reporting that they had no-one to replace them if they wanted or needed to make a break from their caring duties.
- 6) The fluctuations in the reported functional status of the cared for older people during the FU year illustrate that **physical decline in old age is not inevitable**, with more than 1/3 of the FU sample reporting an improved functional status as measured by the Barthel scale and 1/5 improved I-ADL function after one year. These findings have implications for the reduction of age-related disability amongst older Greeks, as discussed earlier in this chapter.
- 7) Similarly, the finding of improved memory (11.4%) and behavioural disorder (37%) status in the FU sample indicates that memory and behavioural decline in old age is not inevitable, with implications for interventions to maintain and improve cognitive function and training of family carers in the effective management of their older person's difficult behaviour .

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10 Summary of main findings, conclusions and recommendations

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10.1 Summary of main findings from the Greek NASUR

This study provides important and unique data on family carers of dependent older people in Greece, together with equally interesting findings on the older people they care for, their informal support networks and the formal services they do and do not use to help them in the provision of good quality care.

As Ch. 4 indicated, although there are no national statistics on those providing family care to dependent older people in Greece, in a comparative perspective the sampling and data results suggest that the Greek sample does not differ in most significant respects from the other countries participating in the national surveys. One possible difference is that the Greek sample of family carers included a rather higher proportion of people still working and who were slightly younger than the average for the 6 countries.

The results from Chapter 5 provide a **profile of the Greek family carer** as well as descriptive data on the older dependent person. There were no surprises as to who was caring; everywhere women provide most care and indeed 80,9% of the sample of Greek family carers were women, although spouse care was more likely to involve men as carers. What is important is the short and long term consequences for the female carers of providing this care. Many will earn less over their life time as a result of family care duties (for children as well as older persons) and enter old age with an inadequate pension and income. This has significant implications for family policy, for equality and the promotion of women's labour market participation³¹.

In view of the reported high levels of disability of the older people in the sample, an even more startling finding was that **only 2% of family carers responded that either they or the older person currently received any form of financial support for the essential daily care they provided**. The costs of care have been well documented in the study, ranging from the additional costs of basic equipment, drugs and service expenses to the reduction in career opportunities for family carers and loss of earnings due to heavy caring responsibilities and the study findings show clearly that these costs are currently being met entirely by family carers out of their own pockets. One immediate action by the Greek government to redress this imbalance would be the implementation of the proposed new disability assessment process which would ensure that those older people in need of care receive some essential financial support as a right.

One pleasant surprise was the general well being of carers and good self-rated health, results that were not unique to Greece. However, despite these results, an outstanding finding was that Greek family carers reported feeling the most burdened by their care work and, although managing well on the whole, tended to experience a **more negative impact** from their caring work than in the other 5 countries. (see Chs 6 and 7) Similarly, the findings on quality of life, when compared with those from the other country samples, showed that Greek family carers report the lowest levels of quality of life within the EUROFAMCARE study sample, an important finding that merits further analysis.

³¹ IKA statistics for 2004 indicate that by age 55 average earnings for women are almost a half those of men; this suggests another reason why many women find it difficult to pay for outside care and may have to leave the labour market.

Financial incentives to care do not appear to be a major factor for Greek family carers in the decision to undertake care, Services specifically for family carers are very few, while even those for older people rarely fully extend themselves to support the family carers. (see Ch.8) The lack of statutory social services to support either family carers or older people, marks the Greek situation, whilst the additional costs of using the supposedly free national health services emerged clearly in the findings.

What has to be understood from such a primary research study is that the interview with the family carer presents a snapshot of a particular moment of time in the caring process, yet caring is a dynamic situation, with periods of decline, improvement and stasis in the health of the dependent older person. In chapter 9, the Follow Up study indicated that 22% of those resurveyed no longer provided care because of the death of the older person, but of those still caring, the majority (54.1%) were providing an increased amount of care, whereas 36.5% were providing less care than a year earlier and 9.4% the same amount of care. This indicates the need for support services for both older people and family carers to be flexible and person centred, in order to respond rapidly to changes in the care situation.

The study findings point to the existence of an "army" of Greek family carers who are mostly willing and able to undertake the major part of caring for their dependent relatives BUT with increasing needs for support to provide good quality care. What types of support do they ask for?

- Information about services and support available
- Advice about the disease suffered by the older person
- Financial help – The care of an older person causes extra costs for Greek family carers: 56% said they needed financial help, the highest figure amongst the 6 countries.
- Good quality services for their older person and, to a lesser extent, for themselves, that provide trustworthy, responsive, 24-hour care
- Respite care at home and in institutions; related to this is the need for holiday or care break opportunities for carers, including the possibility to spend more time with the family
- The removal of bureaucratic and complicated procedures stopping family carers using services, and the reduction of long waiting lists
- Opportunities for the older person to undertake activities they enjoy
- Help in better combining caregiving and paid employment
- Training in caring techniques

This invaluable resource of family carers needs to be acknowledged, documented and provided with the support they need in order to be able to continue to provide good quality care for the increasing numbers of dependent older people in Greece.

10.2 Conclusions and recommendations from the Greek NASUR

The inequalities in Greek society are nowhere more apparent than in this study of family carers.

As will increasingly be the case, many of the family carers are themselves older people and a very large proportion have a low average income (1,100 euros was the average for a household of 3 persons). Probably the most striking finding is that little has been done by politicians who, being

amongst the fortunate percentage with a higher than average income, are part of a self satisfied middle class who can afford to pay for help and services. Yet there is still a cost for the many individuals with inadequate incomes to meet the extra financial demands of care, again costs which in some part should not have to be met on a personal basis or by out-of-pocket payments e.g. costs in using a national health service.

The study has shown that Greek family carers are still trying to meet the ever increasing demands of providing long-term care to dependent older people within a traditional framework, a framework however, which was based on the long and radically changed previous demographic profile of the Greek population, characterised by large numbers of children sharing the care of dependent parents for relatively short periods before their very much earlier death.

What emerges from the EUROFAMCARE survey is that Greek family carers are still trying to cope within this traditional value system based on the family, respect for older people, and the role of women, all factors which probably contribute to their relatively positive response to their role as carers, despite their lack of formal support. But the reality is that the quality of hands on daily care may eventually suffer from this lack of state support to families providing care and equally importantly, there are long term negative consequences for many family carers in the form of loss of income, inadequate pension contributions and poverty in old age and negative effects on their physical and mental health as they themselves become older.

This section seeks to put forward some unified proposals based not only on the findings from the Greek National Survey but also from the Greek National and pan-European Background Reports, as a way of providing a clear 'map' or **Action Plan** against which progress can be marked in achieving the essential better support for family carers.

1. **Information** – on services, rights and the diseases of the older person
2. **Financial help** to either the dependent older person or to the family carer, to cover some of the extra costs arising from caring and to ensure family carers do not end up uninsured, and with inadequate pension coverage later in their life.
3. **More services** with comprehensive coverage throughout Greece and which are additionally far more responsive to the needs of both dependent older people and their family carers, provide outreach services and realise that coverage needs to be over 24 hours.
4. **New services** and forms of support e.g. genuine respite care for family carers both for programmed holidays and emergencies, support for working carers, support especially, though not exclusively, targeted on those with behavioural problems.
5. **Integrated care** - social and health services need to work together as partners to provide real quality help to family carers. This is born out by other studies in Greece and Europe e.g. PROCARE, the CARMEN Network
6. **Workforce/formal care providers** – Finding and developing an adequate care workforce is essential. Thus maximising the potential of the current workforce e.g. migrant care workers to be fully trained and certified, ergotherapists to be trained in comprehensive needs assessment, needs to be examined and specific proposals defined and implemented as an urgent necessity.
7. **Comprehensive needs assessment** is essential for correct resource distribution (disability benefits and pensions) and service allocation . The reorganization of assessment processes for disability benefits and pensions is being proposed by IKPA and needs to be implemented . Recognition has to be given to the increasing and complex dependency needs of current and future generations of Greek older people, which includes systematic quality evaluation and monitoring of services.

One question which deserves further analysis in the EUROFAMCARE survey data, is whether the approximately 1/3 of family carers looking after the most heavily dependent older people have any specific social characteristics e.g level of education, age income, gender, self reported health and well being, use of services, costs etc.

Additionally, the EUROFAMCARE survey data provides a rich resource for further analysis of the situation of family carers in Greece and an opportunity to rectify the current deficiencies in their support by the state, an opportunity which it is sincerely hoped will not be missed.

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