

# EUROFAMCARE

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

## The National Survey Report for Germany

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This report reflects the authors' view. It does not necessarily reflect the European Commission's view and in no way anticipates its future policy in this area.

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# 1 Introduction - Aims and structure of the EURO-FAMCARE project and introduction to the German National Survey Report (NASURE)

*Hanneli Döhner, Christopher Kofahl, Giovanni Lamura, Judy Triantafillou*

## 1.1 Aims and structure of the EUROFAMCARE project

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

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

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

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

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

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

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

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

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

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

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

- **23 National Background Reports (NABARES)**, written according to a common Standardised Evaluation Protocol (STEP) and based on secondary analysis of existing materials, expert interviews and/or focus groups (all reports are available online at <http://www.uke.uni-hamburg.de/eurofamcare/publikationen.php?abs=2>).
- A **Pan-European Background Report (PEUBARE)**, based on the pool of information made available by the NABARES, and produced through a synoptic integration of their contents to provide a pan-European overview of the situation of older people's family carers throughout the continent in terms of state of the art in Europe's family care policies, future challenges and necessary prerequisites for good quality integrated family care for older people (this report is available online at <http://www.uke.uni-hamburg.de/eurofamcare/publikationen.php?abs=1>).
- A collection of **Examples of Good and Innovative Practices in Supporting Family Carers in Europe**, based on the examples described in the 23 NABARES (these files are available online at <http://www.uke.uni-hamburg.de/extern/eurofamcare/deli.php#deli7>).

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 (<http://www.uke.uni-hamburg.de/eurofamcare/downloads.php#deli6>).

Finally, an integral part of the EUROFAMCARE project was the Research Action Phase **RE-ACT** implemented by the Trans-European group and AGE throughout the three years of the project, but concentrated in the final year. REACT aimed at the dissemination of the findings at local, national and European levels, with the objective of implementing changes in policy and services for the support of family carers and initiating new partnerships in care for older people. The reactions of the target groups could also provide a feedback to the researchers on the utility of the research. A main result of the REACT discussions was that the planned guidelines for family carers and providers did not find acceptance in the groups. But another deficit arose to be important for further developments: the challenge to develop a national carers' organisation for Germany. The experience in other countries shows that there is a need to lobby on national level for the interests of family carers, to appreciate their work and to support their engagement.

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

A draft of a EUROPEAN CARERS' CHARTER has been completed and the idea of a EUROPEAN CARERS' DAY has been undertaken as one of the tasks of EUROCARERS to inform the public and stimulate better support for family carers.

## 1.2 Introduction to the National Survey Report (NASURE)

In the following section, the main headings and chapters of this German National Survey Report (NASURE) are briefly introduced. The German results presented are based on the baseline survey of 1,003 family carers, the follow-up study conducted with 45 % of them (451) and the service provider study conducted with 35 persons.

**Chapter 2** gives an overview on the state of the art of the literature on support services for family carers of older people in Germany, in particular focussing on the partnership approach. This chapter is based on the German NABARE.

In **chapter 3**, which has been taken from the TEUSURE, the EUROFAMCARE Common Assessment Tool (CAT) as well as the CAT- Follow-Up Questionnaire (CAT-FUQ) are described in detail. The chapter focuses on the development of items and instruments, the piloting of questionnaires, questionnaire item transformation, scale development and the psychometric characteristics of scales used. The additional German specific questions are focussing on the German Long-Term Care Insurance (LTCI) and are described in Chapter 8.

**Chapter 4** deals with the sampling and recruitment procedures and discusses the problem of representativeness. The common procedure agreed for all countries is described as well as the specific German situation.

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

While the earlier chapters are mainly descriptive, **chapter 6** deals with the development of a typology of care-giving situations in Europe, using a cluster analysis approach. After a short outline of the methodology the differences between the European cluster and the specific German distribution of them are described. Then further questions will be analysed, such as the demand for support of the cared-for, informal and formal support available to the carer, the group specific impact of the caring role on the carer and her/his willingness to continue giving care. Thus, a condensed picture of the determinants of family care evolves.

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

The objective of **chapter 8** is a first analysis of the German specific questions integrated in the German baseline questionnaire. It describes the distribution of the cared-for in relation to the LTCI levels of care as well as the kind of benefits utilised. It gives examples of how the main study results from both, the baseline study as well as the follow-up study could be further analysed in relation to the special German social security system.

The topic of **chapter 9** is the service providers' study. The aim is to add the providers' perspectives to the family carer's views. The methodology is initially described, followed by the study results that focus on coverage, usage, access and costs from the providers' perspective. Additionally the importance of quality characteristics and types of service as well as future developments in services are described.

In **Chapter 10** the one-year Follow-up Study provides a time-limited but important longitudinal dimension to the research, given the patterns of change in caregivers' and older people's situation and the need to understand the use and value of services. The present results are based on the preliminary CAT-FU dataset. The common questionnaire has been described in chapter 3. Preliminary findings focus on the changes in the studied population of care-givers and their older cared-for persons after 12 months of caring.

**Chapter 11** summarises the main findings of the German NASUR and the implications of these findings for family carers, service providers and policy makers. The project results are being constantly discussed with a broad audience in different target groups and various regions of Germany. Especially in the last stage – the REACT phase - the EUROFAMCARE research is concerned with this feedback from all those involved or potentially involved in supporting family carers. One of the aims of the project is to identify suggestions for the implementation of strategies to support family carers at the national level. It is hoped that the overall national analyses, mainly described in the National Survey Reports (NASUREs), as well as this European analysis, will lead to further national and European analyses on family care situations and result in Action Plans to promote the partnership approach in family care.

The results of the German NASUR aim at aiding policy and decision-makers - especially in Germany but also in other countries - to understand the critical importance of supporting family carers in the coming decades, of improving their situation and in particular of helping to increase support measures, thus maintaining family carers' high motivation and ensuring that they remain as a valuable resource in the growing work of caring.

The in-depth knowledge from the six systematically chosen countries, covering very different welfare and socio-economic systems, offers the potential to other countries of using the findings as a guide to:

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

Therefore the challenge is to make use of the results not only for carers, providers and politicians in Germany but also for countries under development of better supporting structures for the work of family cares in co-operation with providers and volunteers.

## 2 Literature – State of the art

*Martha Meyer, Christopher Kofahl, Nadine Kubesch*

### 2.1 Introduction

This chapter is providing an overview about research and project activities in Germany dealing with the situation and living conditions of family carers of older people in need of care. For better understanding it seems to be helpful to highlight two German specialties *ex ante*: Firstly, the fact that despite a rather big amount of social research in total, laying the focus on family carers explicitly is rare compared to the research objective of older people themselves. This means that many research results are “side results” of studies on ageing. It has to be argued whether accessing family carers via the dependent older adults means targeting the same group as it would be if family carers were accessed directly and independently of the older family member.

Secondly, the development and introduction of the long-term care insurance (LTCI), which is based on the national law in Sozialgesetzbuch XI – SGB XI – (social code XI), has had a significant effect both on the relationship between carer and cared-for and the definition of dependency. The legal definition of dependency related to “need of care” connected with a legal entitlement to benefits for caring was defined and laid down as an insurable risk with the enactment of the long-term care insurance in 1995 as the last pillar of the social security system. It allows to cover the risks which are associated with the need for care (Döhner & Kofahl, 2001). The political goals were to stabilise domestic care arrangements, reducing individual poverty and public welfare spendings as well as enhancing the infrastructure and improving the quality of social care services (Tesch-Römer, 2001). It also fixed the legal separation of medical treatment and illness, nursing and rehabilitative care, informal and formal care-giving and prevention, rehabilitation and medical care and last but not least the separation of the in-patient and out-patient sector which now belong to different areas of social security benefit (Rothgang, 1997). Because of the enormous relevance of the long term care insurance (LTCI) for the German care arrangements – including family care as the main resource – the German study has added specific questions to the German questionnaire version for family carers (see chapter 8).

### 2.2 Literature on Family Care

#### 2.2.1 Sociodemographic Surveys

The most used socio-demographic information on family carers is taken from two main sources. The first one is a series of representative surveys conducted by Infratest Sozialforschung (1993, 1995, 1998, 2000, 2003) on demand of the “Federal Ministry for Families, Seniors, Women and Youth”. The second is the data collected by the “Medical Advisory Board for the Health and Long-Term-Care Insurance” in the course of their dependency assessments, which everybody has to undertake in order to get any benefits from the LTCI.

In Germany 1.9 million people in need of care, 1.37 million of them living at home, received benefits in accordance with the statutory long-term care insurance and around 1.2 million

people are main care-givers and responsible for persons in need of care and support. Since the introduction of the long-term care insurance there has been a slight increase in the number of informal carers involved in support and care at home. 36 % of all persons in need of care are cared for by one main care-giver, 29 % are cared by 2 persons and 27 % are cared by 3 and more persons. On average 2 persons, including the main family care-giver, are involved in domestic care arrangements and providing regularly care and support (Schneekloth & Müller, 2000, Infratest, 2003, BMGS 2003a, Statistisches Bundesamt, 2003).

According to other data sources from the year 2001 there were about two million persons in need of care in Germany – 70 % (1.44 million) of them living at home. Half a million were cared for exclusively by family carers and 435,000 persons received additional services by formal carers. Moreover, 30 % (604,000 persons) were cared-for in nursing homes (Ziegler & Doblhammer, 2005).

About 32 % of all main family care-givers are older than 65 years and usually belong to the same generation as the person in need of care. Every second carer (54 %) is between 40 and 64 years old, only 11 % of carers are younger than 39 years of age. According to these figures increasingly aged carers must take care of relatives who are ever more advanced in years. As a result there is an increasing risk of the carers themselves becoming dependent on care (Schneekloth & Müller, 2000, Infratest, 2003).

Family care giving still shows a clear gender bias with women carrying the main burden of care and performing 73 % and men with 27 % of all care tasks (Infratest 2003; N = 1,060). While 39 % of men in need of care in the age group 65 to 79 years old are cared for by their spouses only 22 % of the women in need of care in the same age group are cared for by their spouses.

As the persons in need of care become older the support shifts from the spouses to the generation of their children. The amount of support shifts in inverse proportion so that the amount of support given by spouses decreases to the same extent as the amount of support given by the younger generation increases. The change occurs in a relatively continuous manner across the generations (Blinkert & Klie, 1999).

**Table 1: Main carers of individuals in need of care in private homes (%)**

Relationship	Proportion
male / female partner / spouse	28
daughter	26
mother	12
son	10
other relatives	7
neighbours / friends	7
daughter in law	6
father	2
grandchild	2

Source: Infratest Sozialforschung, 2003

With the exception of their spouses men are far more reluctant to look after persons in need of care at home (Gräßel 1998a). Gräßel assumes that this phenomenon is encouraged by traditional social roles which *"favour man's orientation towards activities and acknowledge-*

*ment outside of the home. This is why the son in law as a care-giver is practically non-existent"* (ibid.).

However, the number of male carers is slightly increasing at the moment. Data based on the socio-economic panel (SOEP) show that in the year 2003 about 5 % of adult men and almost 8 % of women of the overall population took over care duties (Schupp & Kühnemund, 2004). In 2001 men spent on average 2.3 hours for care duties whereas it was rising up by the year 2003 to 2.7 hours (ibid.). This increase may be related to unemployment and / or lack of financial resources which partly can be compensated by LTCI-benefits in cash (Infratest, 2003).

However, it has to be taken into consideration that studies concerning family care usually refer to main care-givers – which are predominantly women.

There is a high interest to know whether carers' earnings are directly connected to the question of to what extent paid employment is compatible with caring tasks or to what extent a loss of income is caused by a reduction of paid employment. Married women between 41 and 50 years of age are particularly hard hit by this compatibility problem – although this should not distract from the fact that an increasing number of men will become involved in family care giving in general in the future (Reichert & Naegele, 1997).

The question of income is also closely associated with school education and occupational qualifications of the mostly female main carers on the one hand and with their extent labour participation (e.g. part-time, full-time) and the resulting earnings on the other hand (Schneekloth et al., 1996).

As a rule family care giving is a full-time job: an average of 64 % of all main carers are available to the person in need of care round the clock, about 26 % by several hours daily, about 8 % by several hours weekly and 2 % are rarely available. About 76 % of all carers must interrupt their nightly sleep more than once (Gräßel, 1998a). Family carers are actually engaged in care giving and supportive tasks for an average of 36.6 hours a week. The care-givers assist with many activities of daily living, most of them several times daily. From their point of view the most frequently daily task carried out is personal care (e.g. conversation) which is received by 68 % of the persons in need of care several times daily and 14 % at least once a day.

About 62 % of the persons in need of care live in the same household with their care-givers. About 8 % of family carers live in the same house or very nearby, about 14 % live less than 10 minutes away, about 8 % live more than 10 minutes away whereas the remaining 8 % of persons in need of care don't receive any regular family care-giving or support.

Living in their own private homes is as well from the older persons' as from the family carers' point of view the clearly preferred kind of living and housing. Only 4 % of the family carers (N = 1,060) considered the move of the older person in need of care into residential care being possible. Every second family carer stated that a move into residential care will be "out of the question" (Infratest, 2003).

### **2.2.2 Family Ethics and Expectations**

The family is still the central institution providing instrumental and emotional support to older people in Germany. And also in the 21<sup>st</sup> century family care giving is still often considered to be a private matter dealt with by the closest members (Runde et al., 1999, 2002).

Based on the results of quantitative data analysis Runde et al. (1999) have observed a retreat of the daughters from family care giving and attribute this phenomenon to the long-term care insurance which brings about a social "normalisation" by opening up new possibilities for action to women. Prior to the introduction of the long-term care insurance daughters in particular felt compelled to take on family care duties in accordance with their moral codes and in the absence of alternatives. However, these results are not compatible with other research data which show that the daughters still hold the second place (26 %) in care-giving (Infratest, 2003).

Domestic care takes principally a higher priority than in-patient care as well as medical rehabilitation before care. The long-term care insurance motto "out-patient care before in-patient care" expresses the intention of the legislative to promote the willingness to provide family care for persons in need of care. It is a reflection of the fact that the German welfare state still reckons on the stability of family networks of informal carers (Daatland et al., 2003).

Based on their research outcomes Runde et al. (1999) assume that social expectations, attitudes and the emergence of "family ethics" related to family care-giving depend on the internalisation of social norms and are independent of the individual care-givers situation.

Representative data (Runde et al., 1999, 2002) on the influence of the long-term care insurance on expectations and behaviour towards family care-giving show that two thirds (N = 2,130) of all interviewees have attitudes towards family care-giving which are influenced by social-normative expectations. The results confirm the hypothesis that family care-giving is not so much something that can be legally recovered but is rather a culturally influenced and a regulative model for social relationships within the family.

A comparison of the generations 30-50 years old, 50-70 years old and > 70 years old showed that older people (> 70) are more often of the opinion that relatives are morally obliged to take care of family members (67,5 %) than the younger generation in the age group 30-49 years. Only 58 % of this age group were of the same opinion. An analysis of the data set "Eurobarometer 1998" affirms that persons over 45 years take family care duties for more granted than persons aged 18 to 44 years (Berger-Schmitt 2003).

No significant differences in the normative attitudes towards taking care of relatives were found between different occupational milieus specific to certain social strata. The importance ascribed to moral obligation is a general attitude independent of social strata. However the proportion of those who feel morally obliged and who at the same time also expect financial compensation is 10 % higher in workers households than in academic households (Runde et al., 1999, 2002). The willingness to take on family care-giving is in the foreground in low class milieus whereas residential care is least accepted. In middle class milieus among people with a high social status the willingness to take on family care-giving is minimal whereas residential care is widely accepted (Klie & Blaumeister, 2002).

According to comparative data (Runde et al., 2002) from 1997 and 2002 the authors assume, that the willingness to take on the family care-giving is decreasing: It is noticeable that only 45 % of all interviewees asked in 2002 were of the opinion that parents have a right to be cared for by their children. This represents a decrease of 10 % since 1997. The decrease concerning the care of marital partners from 71.1 % in 1997 to 62.3 % in 2002 is also conspicuous. Fewer and fewer people see the statutory long-term care insurance as a measure which promotes solidarity between the generations and which encourages people to take care of their relatives.

Solidarity between the generations continues to be a cultural model and is still important within society. However it is losing its meaning to be a societal norm in the sense of a moral obligation to take on family care-giving. The social normative attitudes concerning moral obligations are losing ground and at the same time rational calculations are on the increase due to the fact that resources provided by the Long-term care insurance law puts at the disposal of family members which can be used according to rational choices. The sum of benefits available and a norm which is orientated towards individual preferences and needs will be gradually pushed through as motivation to take on family care-giving.

The research data confirm the trend seen in 1997 when 40 % of interviewees were of the opinion that the state was exclusively responsible for the provision of concrete support concerning family care-giving and quality control of the care given. Runde et al. assume that the socio-political aim of the long-term care insurance to promote the willingness of family members – or other informal carers – to take on family care-giving must be called into question due to a decrease in acceptance of this insurance (Runde et al., 2002).

The recent research data of the Freiburg carers study ("Freiburger Pflegestudie", N = 1,432) show how the effects of the long-term care insurance have been integrated into arrangements for domestic care under very different social and biographical conditions. According to Klie and Blaumeister (2002) future generations will be involved to a much lesser degree in family care-giving, not only as a result of demographic developments but also due to shifts in the social milieus. The traditional reliance on care resources within the family will become less and less relevant in a "cultural" sense and the moral orientation will also lose its meaning regarding the decision to take on family care-giving as the costs involved begin to play a central role in decision-making.

Experts' opinion differ in assessing the further development of domestic care. Klie (1999), Runde et al. (2002) and Rothgang (2003a) reckon that the willingness to family care giving will decrease as a result of changing social normative attitudes, increasing costs and shifts in social milieus and that formal forms of support will become more important. On the other side, the LTCI-benefits allow people to stick to the role of a family carer – especially in the context of high unemployment rates (Mnich & Döhner, 2005).

### **2.2.3 The Relationship between Carers' and Older People's Interests**

Family care-giving can affect the intra-familial relationships and the role allocation because family carers as well as the older person cared-for have different needs which have to be brought in line: Older people in need of care want to be cared for in their own home as long as possible and more or less expect being cared by a family member; family carers often have to balance between their own psychosocial or economic needs (employment, social participation, leisure interests, the own partnership) and the older persons' needs and often are afflicted by a feeling of guilty not being able to please everybody.

Research data revealed that tensions and the emotional burden of care between the person in need of care and the carer will increase if the role of family care-giving is taken over under a high social pressure. In particular the lack of time-autonomy in order to structure the day is experienced to be seriously burdening (Wahl & Wetzler 1998, pp. 191-194).

From an economical point of view and according to Beckers (1974) "rotten-kid-theorem" financial incentives (Bergstrom, 1989, Kritikos & Bolle, 2002), e.g. the settlement of heritage, should not be underestimated in order to secure family care-giving and to avoid tensions be-

tween children and their parents. The point is how to guarantee family care-giving by negotiating appropriate contracts.

It's also important that in Germany benefits in cash paid through the long-term care insurance are allocated to the person in need of care and not to the family carer. This could also generate conflicts and tensions.

#### **2.2.4 Well-being and Burden of Care-giving**

It can be expected that carers who spend large amounts of time looking after persons in need of care experience a lot of strain which can in turn have a negative effect on the quality of the relationship between them and the persons in need of care. If the main carer has taken on the caring duties as a result of intense social pressure then a statistically relevant increase in the emotional strain on the carers, which is intensified by a negative relationship between them and the person in need of care, becomes evident. Fortunately, the relationship between the family carer and the older person in need of care is not always dominated by such strain but rather the role as a carer can also lead to valuable changes which have a positive effect on the relationship (Wahl & Wetzler, 1998). Many family carers, often together with the person they care for, are confined indoors because they have to be available around the clock. Consequently, they can rarely take part in social activities outside the home, don't have the opportunity of relaxing by taking part in leisure activities or talking to friends. They get more and more socially isolated.

Investigations of N = 1,911 care-givers showed that family care-givers who spend large amounts of time looking after persons in need of care, reported physical complaints such as exhaustion, pain in arms and legs, heart trouble and more severe stomach pain than in the general population. These symptoms are found to be more pronounced in carers of cognitively impaired persons than in persons who care for older people who are largely unimpaired in their cognitive performance (Gräßel, 1998b).

The investigations of Schacke and Zank on mental stress factors in N = 78 carers of demented persons showed that the main factors impairing their quality of life were role conflicts and the feeling of not being able to provide adequate care. As pointed out above, this mental stress can in turn have a negative effect on the quality of the relationship between them and the persons in need of care (Schacke & Zank, 1998).

Recent representative research data confirm these investigations and revealed that 42 % of all family carers assess to be rather heavy and 41 % of all family carers assess to be extremely physically and mentally burdened and only 7 % assessed no to be burdened (Infratest, 2003).

Meanwhile it is quite evident that in particular caring for persons suffering from dementia is associated with severe burden. Dementia is a main factor for an admission into a nursing home or a similar in-patient institution.

Due to the lack of capabilities of care at home, around 80 % of all persons suffering from dementia are moving into a nursing home and live there till death (Bickel, 2001). The probability of dementia patient's admission to nursing homes will be enhanced by certain conditions. Besides the severity of the dementia disease, incontinence as well as the occurrence of various non-cognitive symptoms, such as aggression, sleep disorders, and agitation were identified as significant factors (Kurz, 1998).

However, a recent study of Reggentin (2005) revealed that the family caregivers' perceived burden will not be entirely reduced even after transition from home to a nursing home or to a residential dementia group.

Schulze and Drewes (2004) conducted an analysis of the health situation of German caregivers based on a data set from the "Life-Expectancy Survey" provided in 1998 by the Statistisches Bundesamt (federal statistical office). According to this study caregivers report more frequently to suffer from physical disorders than non-carers. On the other hand the perceived subjective health status of carers does not differ significantly from those who haven't taken over caring duties. However, a higher prevalence of several diseases support the assumption of a reduced health status of carers. Furthermore the study revealed also that carers who are gainfully employed besides their caring duties do show a better health status compared to non-carers. This might be based on a healthy-worker effect.

### 2.2.5 Violence and Abuse

Difficult domestic care arrangements which are characterised by long lasting mental and physical stress and strain on both sides, the carer and the person in need of care, are endangered to escalate in physical or psychological violence if no professional support is received. The German government and the committee of experts responsible for a report on the older people regarding risks, quality of life and care for the aged with special focus on persons suffering from dementia agree that more research on the subject of abuse and old age must be done. Old women are more often the victims of domestic abuse than old men and *"also the allocation of domestic caring tasks according to gender and the relative frequency of female abuse in cases involving neglect and abuse in care giving should be focused on as central themes for discussion..."* (BMFSFJ, 2002, p. 34).

Representative data on the prevalence of domestic abuse in Germany are still not available (Brzank et al., 2003). This issue is very difficult to investigate. Some available research data (e.g. Hirsch & Brendebach, 1999) have to face with specific problems like selectivity, low response-rates and generalisation: About 10.8 % (n = 46) of all persons questioned by Hirsch and Brendebach (N = 425) reported experiences of violence in the home, whereas psychological maltreatment and financial damage were reported more frequently. The authors regard the response rate of 10.8 % as high in comparison with Anglo-American research findings. It became evident that an increase in the experience of violence goes hand in hand with increased need for support and care in connection with a decline of physical strength. Domestic violence was shown to occur often amongst couples or in family relationships between children and their parents and is hidden well from public view (ibid.).

The public and subject-specific discussion on abuse against older people is often narrowed down to the theme of violent family care-givers suffering from the stress and strain of caregiving. On the basis of their research results Görden et al. (2002) do not agree with this focus. On the basis of an analysis of counselling cases concerning abuse which were dealt with on a crisis- and counselling telephone service, they claim that explanations for abuse against older persons in need of care which use "strain on the carers" as the main explanatory variable cannot do justice to the heterogeneity of the cases involved. The analysis of data from N = 59 reported cases of abuse showed, that the constellation of family carers acting violently towards their older relatives constituted only 22 % of all reported cases of abuse against older people. The authors point out that even the *neglect* of persons in need of care is not always considered by family carers as abuse and therefore was not always reported by

potential informants because they did not realize that the model project also targeted neglect as a form of abuse. Görden et al. (taking the very small data base into account) found that violence against older people is almost always violence against women with partners / husbands or sons acting violently towards their partners / wives and mothers respectively.

It should however be remembered that family carers themselves are often subject to acts of domestic violence. These are often a result of excessive demands on the carers due to their self-sacrificing care and their total concentration on the person in need of care, due to putting aside their own needs, as a result of reproaches from third persons or feelings of guilty as well as subjection to verbal and physical abuse from the person in need of care (Hirsch, 2000). A range of differentiated preventive and intervening measures are necessary in order to prevent domestic abuse and neglect and to improve domestic care on a long term basis (BAGSO, 2002).

Hirsch and Meinders (2000) suggest a.o.:

- advice in advance of care-giving;
- professional's sensitisation to be aware of domestic abuse;
- information on dementia;
- support in dealing with problematic situations related to care-giving;
- easing the density of the relationship between the care-giver and the person in need of care;
- services to relieve the burden of care for family carers;
- advice and therapeutical supplies (p. 215 *ibid.*).

Within the framework of research undertaken by Krause et al. (2004) family carers were interviewed about their caring situation after death of the cared-for. Since the focus of the study lay on the aetiology of decubitus ulcer, only family carers with relatives who actually had developed decubitus ulcer were included. The study revealed that family carers are highly burdened whereas expenditures of time and psychological strain were identified as crucial dimensions of burden. As a result of high burden and the feeling of helplessness carers have difficulties to self-evaluate their nursing capabilities. Moreover, it is shown by this study that support by family members or formal carers has a considerable influence on care-giver's perception of strain whereas support by family members predominantly leads to a psychological relief rather than relief from physical strain.

## 2.2.6 Interdependency of Labour and Care

Employment and labour participation amongst the family care-givers of working age (16-64 years) is not an exception. About 68 % of all family carers must reconcile labour participation with the support and care of older persons. It can be estimated that roughly one third of all employed adults support or administer family care-giving (Reichert & Naegele, 1997,1999).

Two out of three family carers are not in paid employment. 8 % are in minor employment, 13 % are in part-time employment up to 30 hours and 16 % are in full-time employment. It is noticeable that there is a distinct difference between East and West Germany with regard to labour participation: Whereas on average 65 % of all family carers of working age in West Germany are not in paid employment, this is only true for 56 % of family carers in East Ger-

many. It is also noticeable that nearly every third family carer (31 %) in East Germany is in more or less full-time employment of at least 30 hours a week (Schneekloth, Müller, 2000).

According to the federal ministry for families, about 16 % of the female and about 8 % of the male care-givers gave up their jobs after taking over the care for their relatives. Among those caring for relatives in need of daily or permanent care even 34,4 % quit their jobs (BMFSFJ 1997a).

For a long time experts (Reichert & Naegele, 1999) have been demanding political decision makers to implement far-reaching measures in order to make working and caring more compatible with each other. The results of an international expert conference were documented as a catalogue of recommendations concerning state and non-state options for action with the aim of promoting equal opportunities for family carers. These recommendations are particularly relevant to EU member states and include:

- the expansion of legal regulations for the exemption from work comparable with the American "Family and Medical Leave Act";
- the promotion of further professionalisation in nursing;
- the promotion of equal opportunities on the labour market in order to prevent or minimize discrimination due to care obligations, especially in the case of women;
- the promotion of the willingness to care amongst men;
- the promotion of further education intended to make the return to work easier for people who have fulfilled private care obligations.

Due to the fact that the public sector is the largest employer this sector should be a forerunner and should make efforts to improve the situation regarding job-sharing and care leave. The expansion of company interventions includes increased flexibility of regulations on working time as the most important instrument needed to avoid problems pertaining to the compatibility of working and caring. The role played by superiors on low and middle leadership levels is estimated to be central, due to the fact that the search for formal and informal solutions to arising problems is influenced most by these decision-makers, who can contribute measurably to the development of a working atmosphere which does justice to care-givers. In order to promote company acceptance of working and caring, comprehensive measures which appeal to all groups and which cover their needs independent of certain "problems" should be developed. This could prevent care-givers from being identified as a "problem group" with special rights within the company (ibid. p. 330). Small and middle-sized companies could be granted tax relieves to enable them to implement measures regarding working and caring. Local social and nursing services should structure their range of services more effectively and cooperate with companies to a greater extent. This means that their services must be orientated towards the needs of working family carers.

Finding ways of making working and caring compatible is not the responsibility of a few social groups but should rather be regarded as the responsibility of society as a whole (ibid. p. 333). In this context the Ministers of Equal Opportunities and Women's Issues demanded that the head associations in German industry intensify their efforts concerning the agreements passed in 2001 on the promotion of equal opportunities for men and women in private industry and to implement measures which improve the situation of families within companies (GFMK, 2003).

Up until now working carers in Germany have not been entitled to any legally defined company measures to help make care-giving and occupational activity more compatible. Flexible working hours are one of the widespread methods implemented in order to promote the compatibility of family responsibilities and occupational activity. In 2001 a law on part-time work was introduced which makes it possible for employees to demand a reduction of their working hours. However employers can refuse this on certain internal company reasons. Up until now only scattered initiatives from usually large firms which agree on flexible hours or job sharing with employees can be observed. Leave in order to take care of relatives can be granted for short periods or for up to one year and can be granted with or without wage adjustment.

However, no legal regulations exist to preserve the compatibility of employment and care-giving. Short term release from employment duties for caring tasks have not been safeguarded, e.g. like the model for caring for sick children at home.

On the basis of their research Bäcker and Stolz-Wittig (1997) have a very pessimistic view on the compatibility of occupational activity and care-giving in Germany: It is not predictable when unions and management will be willing to give widespread attention to matters concerning the implementation of working time regulations which make family care-giving possible for employees. The federal government has made specific suggestions regarding job-sharing, flexible working hours, working time accounts, home and long distance work and leave over long time periods. In order to make company managements and works committees more aware of this problem the Federal Department for Family, Citizens, Women and Youth – BMFSFJ – issued practical guidelines for *"the compatibility of occupational activity and care-giving: company measures to support family carers"* (BMFSFJ, 2000). The CDU (Christian Democratic Party) in Düsseldorf (North Rhine-Westphalia) recently demanded the CDU federal fraction to bring an initiative for the creation of unpaid care leave for employees into discussion in parliament. This should lay down a right to re-employment after a period of care leave in the same way as this is made laid down in the context of parental leave. In addition an entitlement to the payment of pension contributions financed by income taxes such as the entitlement during parental leave shall be considered. In it's last session the Conference of the Ministers of Labour and Social Affairs decided to examine the suggestion made by the Saarland to introduce care leave comparable with the existing legal parental leave because the introduction of care leave "would be of great relief to home health care (...)" (Forum Sozialstation, 2003). Critics fear that women will once again have to shoulder the main burden of family care-giving if these plans are translated into action.

In the long run an exact evaluation of the social consequences of care giving at home regarding carer's incomes can only be carried out when more information about the size of care-giving households is available. However, it is certain that the limitation or giving up of paid employment and the cessation of the earnings involved always has negative consequences regarding the individual social security situation of the mostly female main care-givers (Dallinger, 1997). Limitation of paid employment has many facets. It does not only concern the reduction of working hours, but also encompasses the abandonment of qualifying or training measures fostering an occupational advancement. Furthermore, limitation means also that potential job changes facilitating a better payment were not taken into consideration by care-givers.

The incompatibility of care-giving and employment entails not only a further increase in social inequity amongst men and women (Barkholdt & Lasch, 2004). Moreover, it leads also to an

increase in inequity among the older persons, between households with and without children, partner as well as relatives in need of care (ibid.).

Furthermore, the concurrence of employment with caring duties seems to increase the strain of carers since it affects both carers private life and work. According to Hammer (2004) carers report – beside physical disorders – on lack of sympathy of both superiors and colleagues since they e.g. presume less flexibility with respect to overtime and reduced productivity.

The extent of labour participation of family carers correlates closely with the level of need for support and care of the older person as well as with the experience of strain: The more time is spent administering care-giving to the older person, the less labour participation takes place. It is quite obvious that the opportunities for labour participation and simultaneous administration of care-giving to an older relative are far more limited for the full-time employed than for persons in part-time employment. As a result the number of persons in minor or part-time employment rises slightly with an increase in the degree of need of care up on a daily basis (Dallinger, 1997).

The family carers' level of education is closely connected to occupation and to the question of whether or not labour participation is limited or even given up completely. Dallinger's analysis shows that main care-givers who have completed secondary modern school make up a total of 70.8 % of the group of those who limited or gave up paid employment whereas they make up only 54.5 % of the group of those in continued labour participation. On the contrary the percentage of main carers continuing labour participation (41.8 %) exceeds that of those limiting labour participation (28.8 %) in the group of family carers with a higher school education (O-levels, A-Levels) (ibid. p. 147). There is practically no difference in the group of family carers in qualified employment regarding the limitation or continuation of labour participation (Dallinger, 1997).

In general family carers looking after older people who do not suffer from dementia are significantly more often engaged in labour participation (30.9 %) than those taking care of older persons suffering from dementia (25.3 %). This can be partially explained by the fact that male care-givers are significantly more often involved in the care of older people not suffering from dementia, making up 20 % of this group of main carers, than in the care of older persons suffering from dementia where they make up only 15 % of the group of family carers (N = 1,911) (Gräßel, 1998a).

### **2.2.7 Migrant Family Carers and Domestic Workers**

The fragmented and intransparent system of service provision also favours the fact that the "legal" and "illegal" domestic care workforce is widely unknown and less investigated. Currently there are no representative or official data available on the subject of care services provided by migrants and legally or illegally employed persons. Meanwhile, there are first efforts to "name key elements for a research agenda to study the increasing importance of the transnational migration for the formation of the social caring processes in the developed part of the world. [...] It is agreed that in the future the service branch holds an increasing potential for employing people with migrant background. However, up to now, an initiative to qualify these younger migrant cohorts intensively is needed in order to compensate their educational and social disadvantages." (Kondratowitz, 2005). Secondly, Kondratowitz demands to concentrate "on the impact and development of informal work structures in care

seen as irregular work participation in private households by migrants who are mostly from east-European countries." (ibid.)

In 1994 the socioeconomic panel – SOEP – determined about 4 million households in Western Germany which regularly employed a "domestic help" and according to estimates about 50,000 foreign persons do undeclared work in the domestic care sector. Private households are the second-greatest grey employment market in Germany. It is estimated that every second female unemployed migrant is employed in the grey labour market particularly in private households (Thiessen, 2002).

In the course of the last few years there has been an influx of domestic careworkers from eastern Europe, particularly from Poland, Czechia and Slovenia, into Germany, mainly in regions near the border, who tend to be employed in private homes. These careworkers are much cheaper than their German counterparts and hold many different types of qualifications. Officially they are employed to do household tasks but in fact they almost certainly take on some caring duties and are often at the disposal of their employers 24 hours a day. The type and amount of tasks carried out by these persons cannot be quantified. The working conditions of domestic care workers in private homes are highly variable and there is no legally minimum quality standard. This emerge also new challenges for protecting care workers with regard to health and safety issues.

Up until now foreign care workers were illegally employed because they only possessed a three month visitor's visa which does not allow employment rather than a work permit. It became necessary to think about issuing green cards for these domestic care jobs. Based on a special decree concerning the ban on recruitment (ASAV, 2002) foreign domestic careworkers can be issued with a work permit for up to three years of full-time, compulsorily insured employment doing as a home help in private homes with persons in need of care in accordance with the Long-term care insurance law. The introduction of the so-called "green card" led to the disappearance of the status "illicit worker". The number of those employed care workers since the introduction of the green card is unknown. However it is thought that the numbers of those still employed illegally in domestic care are probably still quite high due to the cost of compulsory insurance for those in possession of a green card.

Recent political discussions highlighted the situation of migrant "domestic workers" who care for people in need of care in private households and there is a disagreement related to a limited access to the German labour market. In the course of the EC eastern enlargement and a new legislation it is claimed to make the access easier and to facilitate a three-years social security-based employment in domestic care (Forum Sozialstation 9, 2004).

Possible strategies for meeting future care needs include policies to stimulate informal care, using migration and other mechanisms to increase the pool of low-skilled care workers, or professionalising care work to attract a more highly educated workforce. Experts concern that the EU enlargement brings with it an imbalance between the location of labour and the availability of jobs, and hence the possibility of migration to take up openings in the care sector in more affluent Member States and the danger of undermining efforts to enhance and professionalise the sector there (European Foundation, 2003).

### **2.2.8 Rural vs. Urban Areas**

A comparison of urban and rural areas shows that especially carers living in rural areas do not have access to the services they require in order to ease the burden of care because the

service spectrum is underdeveloped due to specific structural conditions. Furthermore, there is still some prejudice about the inner family solidarity in rural areas by saying, solidarity would be higher and family caring taken for granted. However, this picture of an “ideal world on the country site” is not true, even more the opposite is the case due to higher burden in relationship to lack of services (Schultz-Nieswandt, 2000; Walter & Schwartz, 2000).

In order to analyse the situation regarding service provision it is necessary to take a closer look at small area analyses; general statements about service provision are not possible (Walter & Schwartz, 2000, Schultz-Nieswandt, 2000). The research data revealed that the provision of doctors, therapists, in-and out-patient services and hospices is best in cities and the surrounding countryside, whereas a positive correlation between decreasing community size and lower provision scores could be observed. A lack of suppliers of remedies and aids and of provision with speech therapists and chiropodists was determined. In comparison to urban areas with many self-help groups and associations there is a general lack of diversified counselling and provision of services for family carers in rural areas. Family carers and the persons in need of care complain about the lack of information services pertaining to professional care giving and experience deficits with regard to social communication and participation in society because mobile services combined with meeting places and visiting services are few and far between (Busch, 1999, 2000; Haupt, 2001).

In urban areas networking activities are more frequent to be found which expresses the tendency towards a higher complexity of urban care provision with a greater variety and higher density of supplies than in rural areas (Kofahl et al., 2004). According to research data from Northrhine-Westfalia Roth and Reichert (2002) assume that the structural differences in social and health service provision between rural and urban areas will come into alignment with each other in the long run due to processes of “suburbanisation” (ibid. p. 15, 2002).

### **2.2.9 The Role of Services for Family Carers**

Recent representative research data revealed that only a minority of family carers fall back on complementary services like counselling and other supplies of support. Only 7 % (N = 1,060) of family carers regularly talk with professionals. About 4 % regularly use counselling by telephone, about 19 % occasionally; about 6 % regularly visit coffee-groups for family carers or counselling hours. Only 2 % meet in private self-help groups and 3 % regularly meet in groups for family carers with professional counselling. Only about 16 % of all family carers regularly and about 37 % occasionally take up counselling and advice (Infratest, 2003, p. 24), which is partly due to the fact that carers often experience extreme physical and psychological strain but are unable to react accordingly at an early stage (Ühlein & Evers, 1999 / 2000).

Related to a broad provision of different services the Alzheimer Society Germany and the Federal Association of Advice Centres for Older People and Family Carers (BAGA) belong to the most important pressure groups in Germany who attend older people's and family carer's interests. Their work is mainly voluntary based.

The Alzheimer Society founded in 1989 in Germany is a federation of family carers of older people suffering from dementia, professionals and self-help groups in order to stand up for the interests of older people and their family carers. The society is the federal association of several regional associations as well as of 77 local Alzheimer Centres.

The society calls for:

- adequate consideration of older people suffering from dementia through the long-term care insurance (realized meanwhile by the “Law on Supplementary Care Benefits” (PflEG));
- support for family carers and self-help;
- the development of a nation-wide network of advisory centres for family carers;
- the diagnose of the Alzheimer disease in an early stage and
- infrastructural changes in nursing homes – e.g. special training for professionals – in order to improve the quality of life of older people suffering from dementia in residential care.

In order to achieve these aims the society has developed a great variety of activities such as:

- comprehensive information to the public;
- support, advice and counselling to family carers and older people;
- information exchanges for family carers and professionals;
- courses on the subject of dealing with persons suffering from dementia;
- an Internet chat forum;
- discussion rounds as well as self-help groups for family carers;
- publishing brochures dealing with different topics and
- fostering relevant research by (financial) awards.

The Federation of Advice Centres for Older People and Family Carers (Bundesarbeitsgemeinschaft der Beratungsstellen für ältere Menschen und ihre Angehörigen (BAGA)) is another important pressure group in Germany. The BAGA has elaborated standards for psychosocial advice of older people and their family carers as well as criteria for giving successful advice to older people (BAGA e.V., 1999).

According to data collected by the German Board of Trustees of Help in Old Age (Kuratorium Deutsche Altershilfe (KDA)) there is little general knowledge about the services on offer in the population as a whole (KDA, 2003) and recent representative data revealed (Infratest, 2003) that about 18 % of the households (N = 3,622) refer to the fact that the older person in need of care or help doesn't receive sufficient help (ibid. p. 32).

On the whole the service structure does not reflect a need led approach but rather still tends to be organized according to the categories of a service led approach which does not necessarily offer family carers the services they really need (Schaeffer, 1999).

Since the introduction of the statutory long-term care insurance a diversified and intransparent market of independent charitable and private out-patient services has emerged. This quantitative expansion and the regionally dense network of services as well as a focus on types of financing tailored to the "classic long-term care insurance patient" (Schaeffer, 1999) has not been followed by qualitative improvements in the social and health care services tailored to the special needs of certain groups. Complementary services such as shopping, visiting services, accompaniment to doctors and other local services, gardening and household maintenance are not offered although the need for these "light" services has been determined (Ühlein & Evers, 2000). In general the density of health care institutions decreases

according to a reduction in community size and centrality. Community based intervention programmes for the improvement of health care in particular in rural areas are difficult to implement as a result of the lack of cooperative structures and partners (Walter & Schwartz, 2000).

Recent research on palliative home-care services in North Rhine-Westphalia (Ewers & Schaeffer, 2003) revealed an unequal distribution of patients in community based hospices and indicate to strengthen the efforts in motivating general practitioners to prescribe on more domestic care. About 89.9 % of the patients (N = 603) cared by a palliative home-care service live in their own home and 59.3 % are living together with a spouse as family carer. More than 81 % of the family carers were female: wives, daughters or daughters in law. It has to be noticed that 32 % of these family carers were additionally in paid employment and related to the daughters the proportion amounts 61 % (!); 87 % of them additionally were responsible for their own household (ibid. p. 28). These figures demonstrate the situation of family carers related to the care of terminally ill relatives and the challenges they have to deal with. According to the German Hospice Foundation only about 6 % of the 850,000 terminally ill or dying persons in Germany are cared for by one of the 1,200 Hospice societies and the further development and contouring of hospital and community-based palliative-care services needs more public attention to relieve the family carers burden.

### *Respite Care*

In Germany there are 4,150 respite care institutions – mostly run by residential care facilities – with a total of 14,200 places / beds (BMFSFJ, 2002). Respite care is one kind of the complementary benefits of the long-term care insurance either to relieve the burden on family care-givers or following a hospital stay. Influenced by the introduction of the long-term care insurance respite care has changed dramatically over the last few years and patients' average stay decreased from 45.7 days in 1995 to 26.3 days in 2001; other surveys state the figure 22.4 days (Hartmann & Heinemann-Knoch, 2002). There is a certain danger that the patients' self-help potential is not made use of if he or she is admitted to in-patient care again straight after hospital stay. It is obviously possible to make respite care much more effective under other circumstances, for example by building networks between respite care institutions and GPs (Kolip & Güse, 2002).

### **2.2.9.1 Quality of Services**

Since the introduction of the long-term care insurance and market principles an open market of public, independent charitable and private commercial out-patient care services has evolved which then pushed the responsibility of the local authorities for the provision of social and health care services into the background. This quantitative expansion of services with varying regional density of care provision and the financial orientation towards the classical "long-term care insurance patient" did not automatically lead to qualitative and structural improvements (Schaeffer, 1999).

Since the long-term care insurance law doesn't know the overall responsibility related to the infrastructure of formal care provision the regulations reflecting the institutions overall responsibility and competences remain unclear. To ensure the societal care provision the "overall responsibility" can only be realized by institutional cooperation and coordination in order to develop quality control criteria (Klie, Schmidt, 1999, p. 17).

In July 2001 an additional legislation was passed (PQsG, 2001) aiming to guarantee certain quality levels through the long-term care insurance law (§ 80 SGB XI). Moreover, the long-term care insurance and service providers have to agree contracts, regulating quality standards. But these standards only relate to structures and processes rather than to the outcomes of care. There is hardly any quality control in the care provided by families (Rothgang, 2003a).

The only legal monitoring process on quality control in out-patient / domestic care consists on the review of the need for care by the Medical Advisory Board at regular intervals and on the other hand of self-responsible promotion of quality through the family carer. Specially selected professional community care services control the quality of care provision on behalf of the long-term care insurance. Persons in need of care who receive benefits in cash in the care categories 1 and 2 must be make use of professional care services with a mandate from the long-term care insurance at least twice a year and persons in care level 3 every three months in order to secure the quality of family care-giving and to provide and advice and support to care-giving households. These services supposed to determine whether or not the necessary family care-giving can be administered, if it is wise to involve professional out-patient care services or even necessary to suggest the transfer of the person in need of care from the home to residential care. Experience shows that these intervals, which are laid down on the basis of the medical advisory board report and on the prognosis regarding the future need for care (SGB XI, § 18), are far too long and do not guarantee continuous quality control.

The long-term care insurance can control the quality of care on the basis of it's regulations for professional service providers. These regulations lay down the content of services offered, organizational modes and the required qualifications for carers / nurses: Carers in management positions in professional out-patient nursing care services must have completed a nursing training programme recognized by the state (in adult, child or geriatric care) and must have worked full time in the nursing profession for a total of at least two years within the last five years and have at least one year of full-time experience in the out-patient setting (SGB XI, § 75). All other members in nursing care services can have different types of training (fully qualified nurses, auxiliary nurses, short training as nurses aid) and some of them are persons doing community (instead of military) service and have no specific qualifications. There is no state controlled training programme for community care. However, specialist community care training is offered by various educational institutions.

### **2.2.9.2 Research on the Take Up of Benefits or Services**

About 50 % of the households (N = 3,622) spend on monthly co-payments related to social or health services. The monthly average amount is estimated at 355 Euro. About 9 % of the households who spend money for self-financed help invest in privately employed "domestic help" and about 4 % spend their money for "meals on wheels". Complementary and voluntary services to relieve family carers are taken up one or two times a week by 11 % of all persons in need of care (N = 1,111) (Infratest, 2003, pp. 26-27).

### **2.2.9.3 Family Carer's Perceptions and Expectations on Services**

Research on Family Carer's expectations and perceptions of day care services revealed some reasons for both family carer's potential refusal as well as for acceptance of day care services. Refusal might be based on their presumption that admission could worsen the

mental well-being of their family member. An additional reason for the potential rejection of day care services by family carers is grounded in their assumption that their dependent older relative would not be able to integrate themselves into day care groups due to demanding behaviour caused by dementia. Thus, they judge such services as not being appropriate. However, family carers who actually use day care services for their older person argue rather positively (Zank & Schacke, 1998; Kofahl & Mnich, 2005).

### **2.2.10 The Grey Market of Care**

In addition to the market for professional services there is also a "grey market" for complementary services mainly based on voluntary work which is hardly to be overviewed. These services are rendered regularly by neighbourhood help, family support services and self-help groups and are organized and financed by churches, municipalities and charitable organisations or on private basis (Ühleln & Evers, 2000; Infratest, 2003).

Up to now an essential desideration in research is to be seen in the fact that it is founded on the reduced definition of "need of care" in the long-term care insurance law and therefore predictions on the future needs for care are very limited (Meyer, 2004).

### **2.2.11 Models and Interventions**

Related to the health care provision of older chronically ill people disease-management-programmes and integrated care management are currently under discussion. It is criticised a strong medical and disease orientation rather cross-sectional care-networks should build up with a participation of all professional groups. Due to the administrative separation of the health and social sector in the social security system and between medical treatment, social, nursing and rehabilitative care these incentives will remain difficult to realize but are absolutely necessary (Kofahl et al. 2003; Ewers & Schaeffer, 2003).

In the different federal states there are many model projects with various foci and aims. They all aim to promote the transparency of the social and health services by building up networks and supporting cooperation between the different services offered, especially between the in-patient and out-patient care sector. The relevant subsystems should then be able to tailor their benefits more fittingly to the needs of family carers and persons in need of care. A solid cross-section (N = 58) of innovative and good practices aimed on improving the quality of life of older people in Germany have been gathered through a synopsis of the relevant networking activities in this field (Kofahl et al., 2003). This analysis investigated approved as well as innovative elements including integrated supplies to support family carers: either information and advice, training, measures to relieve the burden of care or all together such as talking rounds or weekend breaks for family carers and the older person suffering from dementia. One example for this kind of care and support is the "Hamburg Bridge" (Hamburgische Brücke), a society for private social work founded in 1913.

Some of the model projects being investigated through this synopsis are listed in the following and should act as an example for good and innovative practices:

- The "Network for the Aged" (Netzwerk im Alter) was grounded by the organization "Albatros" in Berlin-Pankow (Berlin) in order to promote the cooperation between all institutions concerned with the provision of care for older people. A binding case management and transition system and qualification programmes for networking were developed and

tested. In addition relatives were qualified and a complaints management office was called into being. This network made the social services more transparent to family carers and improved their consumer competencies.

- The Network for Geriatric Rehabilitation (GeReNet.Wi) in Wiesbaden (Hessen) concentrates on problems which arise in the context of intersecting areas between old age care institutions and the health care system (Dialog, 5, 2003). A course which qualifies people as "voluntary senior citizens companions" is offered by the Department for Social Work in Wiesbaden with the intention of lessening the burden of care and giving support to family carers. The main focus of this service is on voluntary work and the psychosocial assistance of family carers who are in need a few hours of free time.
- The project "Fourth Phase of Life" in Stuttgart (Baden-Württemberg) and "KUNZ" which is a church neighbourhood centre set up by a parish in Bielefeld (Northrhine Westfalia), also put the idea of voluntary helpers and community centres into practice. In addition to the reduction of strain on family carers through voluntary helpers a main aspect of these projects is the development and promotion of services for older people living alone which cater to their specific needs.
- The project "HALMA" e.V. in Würzburg (Bavaria) offers support for cognitively impaired people by arranging volunteers to relieve family carers by the hours.
- The project "GeNA" – a gerontopsychiatric network of family carers in Neustrelitz (Mecklenburg-Western Pomerania) focuses on building up networks of existing supplies to support family carers and to look for needs-orientated supplies.
- Care-giving courses are also offered to the target group of migrant care-givers, for example a course in Wiesbaden offered to Turkish migrants in the Turkish and German languages, a future-orientated service which is tailored to fit the needs of the growing group of migrant carers ([www.seniorennet.de](http://www.seniorennet.de)). Another project tailored for older persons chronically ill migrants and their family carers is carried out by two charitable organisations in Berlin: Arbeiterwohlfahrt – AWO – and Caritas (for more details: Kofahl et al., 2003).

Furthermore the Federation of Advice Centres for Older People and Family Carers – BAGA – has published a manual for professionals on how to give advice and support to family carers of older people suffering from dementia. This manual incorporates best practice and innovative projects focussed on groups for family carers, practical training, support groups for older people suffering from dementia, advice and counselling in domestic care environment, volunteer services, café for family carers or the Alzheimer-dancing-café. The reader is completed by comprehensive information related to family caring, folders and the relevant legislation (BAGA 1999).

Moreover, within the framework of the project "TANDEM" in Cologne support will be given to family carers. This project aims to enhance life quality of caregivers for relatives suffering from dementia through providing respite from care for some hours (Knauf, 2002).

### **2.2.12 Case Management and Integrated Care**

In the course of the modernization of the health insurance (GMG, 2003, § 140 a-h) as well as on the basis of model contracts (§§ 63-65 and 73a, SGB V) a legal basis was introduced to test innovative methods of solution in the care provision for older people and also for family

carers. Concrete approaches for building up networks of social and health services are to be seen in integrated care planning, disease- as well as care and case management programmes.

Except the recently started model program “Pflegebudget” (“budget for caring”) there is no systematic case management and integrated care. It is only possible to build up networks and coordinate services when all involved go to great organisational lengths (cp. Kofahl et al., 2004).

The program „Pflegebudget“ is testing the use of a personal budget from the LTC-Insurance in seven German regions with 1,000 persons in need of care and a randomised control of also 1,000 dependent people in 2004 to 2008 (Arntz & Spermann, 2004). It is following the proven Dutch model where a budget for care is standard for more than 11 years now. In the German model the given budget is higher than the usual benefits in cash – it is as high as the costs for the benefits in kind, but the dependent people and their families have more freedom to decide for the use of specific supporting services or measures. Relevant people and their families who want to participate will be given advice and will be counselled by a trained case manager, mostly nurses or social workers with an education in case management. The communication with the case manager is compulsory. The project is occupying several social researchers and activists from different research institutes and has a total budget of 8 million Euros. Therefore, it is very central for the actual conceptualisation of the German care system. Results from this project are expected with eagerness, since the combination of counselling and also controlling in one person is criticised by several experts in the field. The “Pflegebudget” has an own website: [www.pflegebudget.de](http://www.pflegebudget.de). ([www.pflegebudget.de](http://www.pflegebudget.de) accessed at 15.7.05).

## 2.3 Conclusions and Future Research Needs

Research data show a current trend towards professional care-giving in residential care on the one hand and a decrease of benefits in cash with simultaneous increase of benefits in kind in family care-giving on the other hand (Roth and Reichert, 2002, p. 15; Rothgang 2003b, pp. 12-14). Although the data show in general a high satisfaction with the benefits of the long-term care insurance which have shared in the stabilisation of family care-giving (Schneekloth & Müller, 2000, p. 85; Runde et al. 1997, p. 84; Blinkert and Klie, 1999, p. 163).

Rothgang states that the trend off benefits in cash towards benefits in kind as well as residential care will intensify in the future because some secular trends were not influenced by the long-term care insurance:

- a decrease in the family care-giving potential;
- increasing trends in female employment rates;
- an increase in single-households;
- and a middle-term trend in the opposite direction: fewer widows and an increasing care-giving potential with the spouses (Rothgang 2003b, p. 24; Rothgang 1997, pp. 131-144).

Although there is a sufficient provision of “classical” benefits in kind highly visible gaps de-hisce in the network of low-thresholded care supplies and volunteer services e.g. visiting services (Forum Sozialstation 2003). Based on recent experiences with projects in the model

programme Future Structures in Help for the Aged – Altenhilfestrukturen der Zukunft – (BMFSFJ, 2003) the current discussions and efforts concentrate on the following:

- The mobilisation of new care- and self-help-potentials through the further development of training concepts for volunteer workers;
- offers for talks to exchange experiences as well as qualification which are the key elements for quality assurance in family care-giving;
- the improvement of building up networks, controlling and coordination of social and health services;
- new forms of “community housing” beyond the in-patient-out-patient dichotomy (Roth & Reichert, 2002) particularly for older persons suffering from dementia in order to relieve the family carers;
- the improvement and differentiation of services towards more complementary supplies, and
- the development and delivery of integrated care and management concepts in the kind of *health-centres* or multidisciplinary *service networks* with a comprehensive service provision (ibid. p. 21).

There is a broad consensus in the necessity of cooperation, coordination and networking to constitute synergies between all actors in gerontological fields of action but the “core-problem” is to be seen in the predominant “particular interests” and the purchaser’s competition among each other. Apart from a lot of model projects in the last years networking of services is still a “blind spot” in the legal service provision (Kofahl, 2003; Schneekloth, 2002).

In Germany gerontological research has been very well institutionalised for more than 40 years, for example the well known gerontological research institutes e.g. at the Universities of Heidelberg, Dortmund, Erlangen-Nürnberg or Kassel. The German Centre of Gerontology (Deutsches Zentrum für Altersfragen (DZA)) in Berlin began operating in 1974 and has been influenced and arranged strongly socio-political decision making with a lot of publications, enquiries, expertises and studies (for example: “Gerontology and Social Policy” 1979; “Health and Social Care for the Aged” 1990 or the major report “Aging in the Federal Republic of Germany” for the UNO meeting in Vienna 1982). The DZA is the only institution in Germany which offers the combination of applied research and documentation. The office of the Expert Commission for the Report on the Aged set up at the DZA by the federal government is directly responsible for policy advice. The report takes stock of the life situations of older people in Germany, documents the needs and measures in social policy for the aged and in society and develops policy perspectives for the 21<sup>st</sup> century.

Ongoing or more future research is needed in:

- Migrant care services and migrant family care-giving. This is a neglected area as well in gerontological as in nursing science research. Gerling (2003a) points out that “*only a few attempts have been made in Germany to take a look at the experience of other countries*” (ibid. p. 216). In the course of the EC-project “Services for Elders from Ethnic Minorities – SEEM – conducted by the University of Dortmund the research data revealed a lack of cooperation and networking, a lack of consultation policies, a strong competition between self help organisations and charitable associations, a hesitantly behaviour of the black voluntary sector, a lack of information on the situation of older migrants,

poorly visible needs and demand (poor lobby), a lack of political influence, a lack of information and advice about community care services in native languages and a lack of commitment on the relevant persons in charge (Gerling, 2003b, pp. 20-21; Gerling & Miller, 2002). According to these findings the authors formulated several socio-political recommendations on the planning and the development of social services for ethnic minorities<sup>1</sup>. Services are not specialized on the specific migrant needs related to cultural, religious and language barriers, which make the migrants' take up of services more difficult (Wingenfeld, 2003) and the latter would confirm the research data found in SEEM.

- Evaluation research has to be continued towards innovative structures of case and care management in order to optimize the service provision and to build up more cooperative, coordinative and effective networks in service provision aiming on more transparency and more support for both family carers and older people in need of care (dip, 2003a).
- Evaluation research has to be continued towards model projects to develop new care concepts and service structures and to introduce "personal budgets". The aim of the personal budget is to transfer more client-sovereignty to family carers and the older person in need of care in order to buy their own "care-package" from the care-market. In the course of the law of rehabilitation and participation (SGB IX) several model projects already tested the "personal budget" for more client's autonomy in decision making (Wansing et al., 2003). The socio-political starting point based on new orientations in the help for the handicapped and recommends a needs-led approach with monetary transfers. This form of financing requires obligatory quality criteria which have to be developed but also depends on well coordinated care- and case-Management structures.
- More gender research is needed on the situation of family carers because the increase in the number of smaller and more unstable family types and increased employment rates for women could undermine family networks of solidarity and make the provision of health and care within families more difficult to sustain. Economic objectives in terms of employment rates reconciling the needs of work with social and family goals could be especially problematic and is a central challenge for national and EU policy makers (European Foundation, 2003).
- A nearly totally neglected and only now (e.g. Kondratowitz, 2005, s. 2.2.7) arising area is the role of domestic care-workers and their employment situation. The access is difficult because of an increasing number of mostly illegal and precarious employed migrant workers. It has to be paid more attention in a new role of private households as private employers in general and particularly in the area of domestic care-giving. On the one hand the professionalising of domestic care work could be a future area to qualify (also migrant) women and to develop new models of employment. This could increase the value of domestic employment in general through social contributions and training. The economic distinction between the public and the private household could be abolished and also the difficult situation of domestic care giving would become known (Thiessen, 2002). On the other hand professional care-work could contribute to a more differenti-

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<sup>1</sup> Related to the consequences and the future development of social and health services this issue is still debated divergently: Supposing on the one hand a stable migrant family carers' potential with older people being cared for in their own home, no changes in the demand of services will temporarily be expected. On the other hand an increasing erosion of migrant family care-giving potentials will be expected with increasing demand towards services.

ated and more needs-led service provision within private households to relief family carers and to support older people without stable family networks (Schmidt, 1999).

- Related to the bullet point above, there is also hardly any research or project activity focussing employers and / or companies to give their employees the opportunity to combine their work with family care duties without getting into loyalty conflicts or to have a decrease in their productivity.
- More research is needed on the issue of older peoples' abuse at home and also in residential care facilities (Hirsch, 2000).
- Research is needed in the development of diagnostic measures such as dementia telemedicine centres and telephone assessment to improve the medical treatment of older people through a specialist doctor and to ensure the early diagnosis of dementia (BMFSFJ, 2002).
- According to the support of family carers by electronic information- and communication systems, a few years ago there was no research in the German speaking countries. Meanwhile there is a huge amount of IT-services but a quality control of these services remain underdeveloped. Applied research is absolutely necessary. Today some activities are starting up to promote the out-patient care sector including the care-givers (e.g. the Fraunhofer-Institute: Telemom; Telehomecare).
- On a community-based level the further development of new forms of "sheltered housing" necessary to allow older people to live at home as long as possible or housing communities for older people suffering from dementia to relief the family carers (ibid.).

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### 3 The EUROFAMCARE Common Assessment Tool (CAT): Item and scale development and description<sup>2</sup>

*Kevin McKee, Cristian Balducci, Barbro Krevers; Beata Wojszel, Eva Mnich, Costis Prouskas*

#### 3.1 Introduction

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

Items and instruments were developed by the partners or selected from the research literature with reference to a model of carer service use and quality of life as a guiding framework. Figure 1 presents this model. Derived from the work of Aneshensel and colleagues (Aneshensel et al., 1995), the model conceptualises the relationship between constructs that are hypothesised to impact on carer and elder service use and carer quality of life. Following further development, the constructs were operationalised in the CAT via a series of variable categories: *Elder's demographic and background characteristics; Elder's disability and need; Carer's demographic and background characteristics; Carer's caregiving situation; Carer quality of life (QoL); Financial circumstances; Service use; Characteristics and quality of services*. In addition, some variables in the CAT addressed issues related to the administration of the questionnaire. The CAT also included a project consent form. Finally, each EUROFAMCARE partner was allowed to include a small number of country-specific items in their own version of the CAT. The description of these items can be found in the partners' respective NASURES.

The items and instruments in each of the above variable categories will be described in detail below. Where items / instruments were drawn from the research literature, the source will be referenced. Where no reference is provided, the item / instrument was developed by the partnership for the purpose of this study, or drawn from previous unpublished work of partnership members.

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<sup>2</sup> National questions focusing on the German Long-Term Care Insurance are described in chapter 8.

## 3.2 CAT Items and Instruments

### 3.2.1 CAT administration

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

#### 3.2.1.1 Mode of recruitment

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

### 3.2.2 Elder's demographic and background characteristics

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

#### 3.2.2.1 Elder's residence and cohabitation status

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

### 3.2.3 Elder's disability and need

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

### 3.2.3.1 Need for support

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

### 3.2.3.2 Mental health problems

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

### 3.2.3.3 Behavioural problems

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

### 3.2.3.4 Dependency

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

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

### 3.2.4 Carer's demographic and background characteristics

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

#### 3.2.4.1 Carer employment status

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

### 3.2.5 Carer's caregiving situation

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

### 3.2.5.1 Role inflexibility

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

### 3.2.5.2 Decision to care

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

### 3.2.5.3 Positive and negative aspects of care

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

### 3.2.5.4 Future care role

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

### 3.2.5.5 Caregiving and employment

Respondents were asked if ‘caring for Elder has caused any restrictions to your working life or career’. For *currently employed carers*, this was quantified as a reduction of working hours (response options yes = 1; no = 0). Respondents selecting ‘yes’ were then asked ‘how many

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

### 3.2.6 Carer quality of life

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

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

### 3.2.7 Financial circumstances

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

#### 3.2.7.1 Caregiving costs

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

#### 3.2.7.2 Caregiving allowances

Four items (country specific) asked whether the carer or elder received financial support or allowances because of the care situation. For each item, the response options were 'Elder yes = 1, no = 0; Carer yes = 1, 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).

### 3.2.8 Service Use

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

### 3.2.9 Characteristics and quality of services

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

A series of items were developed to assess carers' perceptions of the importance of different service characteristics. Twelve items were used to assess this domain. Each item was pre-

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

### 3.3 Item transformation

A number of variables pertaining to the different CAT categories were transformed in order to assist data analysis. Variable transformation was driven by a careful examination of the distribution of the original variables and guided by both the model used as a framework for the study (Figure 1) and the relevant literature on caregiving and service use. Transformations mainly consisted of recoding variables’ response categories. In a number of circumstances this recoding was followed by a combination of two or more recoded variables to create new theoretically relevant third variables (e.g., summary measures). A summary of the transformed items is presented in Table 2.

#### 3.3.1 Elder’s demographic and background characteristics

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

#### 3.3.2 Elder’s disability and need

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

A measure of elder’s dependency was derived taking into account both cognitive and functional disability. To this end a disability index was first derived, which took into account ADL, IADL, and the additional mobility item (see section 3.2.3.6). These items were first dichotomised as to separate elders with the highest degree of disability (1 = not able or not continent, where appropriate) from the less disabled others (0 = able with or without help or continent, where appropriate) and then summed to produce the disability index, which had a theoretical range of 0 to 17. The dependency variable was then constructed by combining a dichotomous version of the cognitive status variable above – where elders without cognitive disorder were differentiated from those with cognitive disorder – and a dichotomous version of the overall disability index – where the median (50th percentile) of the distribution was

used to distinguish elders with no / slight disability from elders with more severe functional disability. Thus, the elder's dependency variable was made up by the following categories (groups) of elders: 'cognitively able and no / slight disability' (0); 'cognitively able and more severe disability' (1); 'cognitively impaired and no / slight disability' (2) and 'cognitively impaired and more severe disability' (3). A three-category ordinal measure of elder's dependency was also made available for more complicated – rather than merely descriptive – analyses, in which the 'cognitively able and more severe disability' category was merged with the 'cognitively impaired and no / slight disability' category of the original dependency variable.

### 3.3.3 Carer's demographic and background characteristics

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

### 3.3.4 Carer's caregiving situation

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

From variables reporting on respondent's caregiving in a typical week, a measure indicating the number of nights of caregiving was derived. This was done by creating a new dichotomous variable for each day of the week, indicating whether caregiving activities were carried out during the night and early morning (from 10 p.m. to 9 a.m., see 3.2.5 above) (1) or not (0). By summing together all these seven variables representing each day of the week, an index reporting on the number of nights of caregiving in a typical week was produced, with values ranging from 0 to 7.

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

### 3.3.5 Financial Circumstances

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

### 3.3.6 Service use

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

## 3.4 Scale development

In this section, the psychometric procedure followed in order to construct scales from individual CAT items will be described. Descriptive statistics for Elder-related scales are presented in Table 3, while descriptive statistics for Carer-related scales are presented in Table 4.

### 3.4.1 Elder disability and need

The three items of the BISID (Keady and Nolan, 1996; see 3.2.3.3) were used to develop a measure of behavioural problems. Participants' responses to these three items had a satisfactory internal consistency ( $\alpha = .78$ ). Thus, responses to the three items were summed to produce a behavioural problems scale with a theoretical range of 0 to 9 (highest frequency of behavioural problems). The strong positive skew obtained on the scale implies that it is not optimally suited to discriminate individual differences at lower levels of behavioural problems in this sample.

The six items of the Duke OARS assessment of IADLS (see section 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 3.2.3.4) were then considered. The two Barthel items with four response categories had their two middle categories collapsed, prior to determining the internal consistency of the items, which was high ( $\alpha = .92$ ). The Index makes use of a weighting system for scale scoring, with each item response score multiplied by 5 prior to summing, producing a theoretical range 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 3.2.3.1). Items were recoded into dichotomous variables (partial need for help (1) vs. no need for help (0)). The newly created items had satisfactory internal consistency ( $\alpha = .69$ ), and were summed to produce a scale of overall need for assistance with a theoretical range of 0 to 8 (highest need for assistance). The scale mean and median were high ( $M = 6.02$ ,  $SD = 1.79$ ; Median = 7.00) indicating a substantial need for help.

### 3.4.2 Carer-related scales

#### 3.4.2.1 Well-being Index

The five items of the World Health Organisation-5 Well-being Index (WHO, 1998) demonstrated high internal consistency ( $\alpha = .87$ ) and were summed to produce the Well-being Index with a theoretical range of 0 to 25 (highest well-being). The mean and median ( $M = 13.89$ ,  $SD = 5.99$ ; Median = 15.00) were close to the scale mid-point.

#### 3.4.2.2 Caregiving Indexes

Items assessing the Elder's need for support (see Section 3.2.3.1) were recoded into dichotomous items for use in four scales assessing the number of Elder's needs covered by the carer, by other informal supporters, and by formal supporters, and needs for which more help was required.

##### 3.4.2.2.1 Elder's needs covered by carer

The items assessing elder's need for support were here recoded into 'need covered by carer' (1) vs. 'need not covered by carer' (0) and checked for internal consistency ( $\alpha = .70$ ) and were then summed to create a scale of elder's needs covered by carer, with a theoretical range of 0 to 8 (highest number of needs covered by interviewed carer).

##### 3.4.2.2.2 Elder's needs covered by informal supporters

The items assessing elder's need for support were here recoded so as to indicate needs for which other informal carers provided help (1 = need covered by other informal carers vs. 0 = not covered by other informal carers). The items' internal consistency was good ( $\alpha = .84$ ) and they summed to produce a scale of elder's needs covered by informal support other than carer with a theoretical range of 0 to 8 (highest number of needs covered by other informal carer).

##### 3.4.2.2.3 Elder's needs covered by formal services

The items assessing elder's need for support were here recoded so as to indicate needs for which help was received by services or other dedicated organizations (1 = need covered by services or support organizations vs. 0 = not covered by services or support organizations). The items' internal consistency was good ( $\alpha = .82$ ), and when summed produced a scale of elder's needs covered by formal support with a theoretical range of 0 to 8 (highest number of needs covered by services or support organizations). The scale mean and median ( $M = .85$ ,  $SD = 1.60$ ; Median = 0.00) clearly indicated that elder's needs covered by services or support organizations were on average very few.

#### 3.4.2.2.4 *Elder's needs for which more help is required*

The items assessing elder's need for support were here recoded so as to indicate needs for which the carer would like to have more support (1 = yes, 0 = no / not applicable). Internal consistency for these items was very good ( $\alpha = .86$ ), 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).

#### 3.4.2.3 **COPE Index**

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

A principal component analysis (PCA) with varimax rotation was run on the COPE items, first within countries to determine variability in the resultant solution, and then on the complete six-countries dataset once the variation across country-specific solutions was determined to be relatively minor. The analysis indicated the presence of three underlying components. Table 5 presents the item loadings and percent variance explained of the three components following varimax rotation. The first component (23.63 % of variance explained) consisted of items 2-7 and 14 and tapped a dimension of caregiving burden. In accordance with McKee et al. (2003), the component was named Negative Impact. The second component (13.96 % of variance explained) consisted of items 1, 9, 11, 13 and tapped aspects of value related to the caregiving role. Accordingly, this component was named Positive Value. A third component (13.61 % of variance explained) consisted of the remaining four items: 8, 10, 12 and 15, and tapped the perceived adequacy of social and professional support available. Again in accordance with McKee et al. (2003), this component was named Quality of Support.

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

After this preliminary exploratory work, the COPE Index subscales were developed. The Negative Impact items were analysed for their internal consistency, which was satisfactory ( $\alpha = .83$ ), 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).

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

#### **3.5.1 Background**

As part of the EUROFAMCARE project, a follow-up phase of data collection occurred one year after the initial survey (see Chapter 10). For this second wave of data collection, a follow-up questionnaire (CAT-FUQ) was developed that drew substantially on the CAT instrument used in the first wave, in order that comparison between the two waves of data would be most optimally effected. This section therefore describes the development of the instrument and its content.

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

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

In addition to the inclusion of variables in the CAT-FUQ that addressed issues related to the administration of the questionnaire, some new items were also included that the project group felt were justified on the basis of issues emerging from the first wave of data. For new items, development proceeded in the same way as for the original CAT items (see 3.1). Following the development of the CAT-FUQ, the draft questionnaire was tested in a pilot study carried out in each partner country. The final instrument described below therefore represents a second version, which incorporates minor changes to the original that followed evaluation of the pilot study results.

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

The items and instruments in each of the above CAT-FUQ variable categories will be described below. Where items / instruments were drawn from CAT and remain unchanged, the

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

### 3.5.3 CAT-FUQ Items and Instruments

#### 3.5.3.1 CAT-FUQ administration

A series of items were required to clarify the source of the data. The date of issue of the questionnaire was indicated (dd / mm / yyyy), and the questionnaire number, which was required in order to case match with the CAT questionnaire completed by the same participant. Country code was also included, as well as the name of the interviewer and the number of the interviewer (see section 3.2.1). The mode of administration was then indicated by the interviewer, with response options being 'postal' (1), 'phone' (2), 'postal supplemented with phone' (3), 'face to face' (4), other' (5). In case the latter mode of administration was used, the interviewer was required to specify (open response).

#### 3.5.3.2 Items to determine current caregiving status

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

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

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

After these two questions answered only by participants no longer providing more than 4 hours of care, all participants answered Question 4 (and subsequent questions). This question was the single item measure of carer health status drawn from the Short Form-36 (SF-36; Brazier et al., 1992). Following this question, a single item assessed overall carer quality of life for the preceding two weeks, also drawn from the SF-36, and information on carers' psychological well being was gathered using the World Health Organisation-5 Well-being Index (WHO, 1998) (see 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 3.5.3.3.6) before returning the questionnaire to the researcher. Carers providing more than 4 hours of care per week were asked to continue to the main questionnaire.

### 3.5.3.3 CAT-FUQ Main Questionnaire

#### 3.5.3.3.1 *Elder’s residence*

An item determined Elder’s usual place of residence (see 3.2.2.1).

#### 3.5.3.3.2 *Elder’s disability and need*

##### 3.5.3.3.2.1 *Mental health problems*

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

##### 3.5.3.3.2.2 *Behavioural problems*

The three items from the CAT assessing the frequency of specific behavioural problems (see 3.2.3.3) were again used here (Behavioural and Instrumental Stressors in Dementia, BISID; Keady & Nolan, 1996).

##### 3.5.3.3.2.3 *Dependency*

As in the CAT, dependency was assessed through the 10-item Barthel scale (Mahoney & Barthel, 1965), a 6-item IADL scale derived from the Duke OARS assessment (Fillenbaum & Smyer, 1981), plus an additional item on mobility (see 3.2.3.4).

#### 3.5.3.3.3 *Carer’s demographic and background characteristics*

##### 3.5.3.3.3.1 *Carer employment status and impact of caregiving on employment*

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

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

this had made to their net income per month (open response in national currency units, e.g. Euro, Pound Sterling, etc.).

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

Finally, two items drawn from the CAT were asked of *all carers* regarding restrictions to working life or career (see 3.2.5.5): 'can / cannot develop professional career or studies'; 'can / could work only occasionally' (all response options yes = 1; no = 0).

#### 3.5.3.3.3.2 *Change in circumstances*

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

#### 3.5.3.3.4 *Carer's caregiving situation*

As in the CAT, The number of hours support per week provided to Elder was established, as was the total number of hours of support / care per week provided to all people apart from Elder, both determined as open response items in units of hours per week. The proximity of the respondent to Elder was assessed using the same item as in the CAT (see 3.2.5).

##### 3.5.3.3.4.1 *Role inflexibility*

One item drawn from the Social Restriction Scale (McKee et al., 2001) assessed this construct as in the CAT (see 3.2.5.1): The respondent was asked 'If you needed a break from your caring role is there someone who would look after Elder for you?' The response options were 'Yes, I could find someone quite easily' (1), 'Yes, I could find someone but with some difficulty' (2), and 'No there is no one' (3).

##### 3.5.3.3.4.2 *Positive and negative aspects of care*

As in the CAT, The COPE Index (McKee et al., 2003) was used to assess the respondent's perception of their caring role (see 3.2.5.3).

##### 3.5.3.3.4.3 *Future care role*

The CAT item assessing carers' willingness to continue caring (adapted from Gilhooly, 1986) was utilised in the CAT-FUQ (see 3.2.5.4).

#### 3.5.3.3.5 *Caregiving allowances*

Four items (country specific) asked whether the carer or elder received financial support or allowances because of the care situation, with response options for each item being yes (1) vs. no (0). An additional item allowed the respondent to indicate whether they or their elder received any other form of financial support (specified; response options as above). The total amount of benefits received per month was then required (open response format). This group of items was a slightly modified version of those included in the CAT (see 3.2.7.2).

### 3.5.3.3.6 *Service Use*

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

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

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

### 3.5.3.3.7 *Additional comments*

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

## 3.6 References

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**Table 2: 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
	Widowed, divorced / separated and single	1
	Married / cohabiting	0
	Partner	0
	Child	1
	Son / daughter in law	2
	Others	3
	None	0
	At least one	1
	Low	1
	Intermediate	2
	High	3
	Retired	0
	All other non-working (e.g., housewife / househusband)	1
	Working	2
	Cohabitant	1
	Non-cohabitant	0
Number of nights of caregiving in typical week		0-7
Units of caregiving during week-end		0-10
Additional costs index		0-5
Number of services used by elder		0-15
Number of services used by carer		0-15

**Table 3: Elder-related scales**

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Behavioural problems	5,894	29 (.50)	2.00 (2.56)	1.00	1.12 (.03)	.14 (.06)	0.00	9.00	.78
IADL	5,869	54 (.90)	4.27 (1.74)	5.00	-.63 (.03)	-.64 (.06)	0.00	6.00	.78
Barthel Index	5,684	239 (4.0)	69.70 (29.75)	80.00	-.99 (.03)	-.17 (.07)	0.00	100.00	.92
Disability index	5,617	306 (5.2)	5.43 (5.04)	4.00	.88 (.03)	-.30 (.07)	0	17.00	.93
Overall need for assistance	5,811	112 (1.9)	6.01 (1.79)	7.00	-.89 (.03)	.07 (.06)	0	8.00	.69

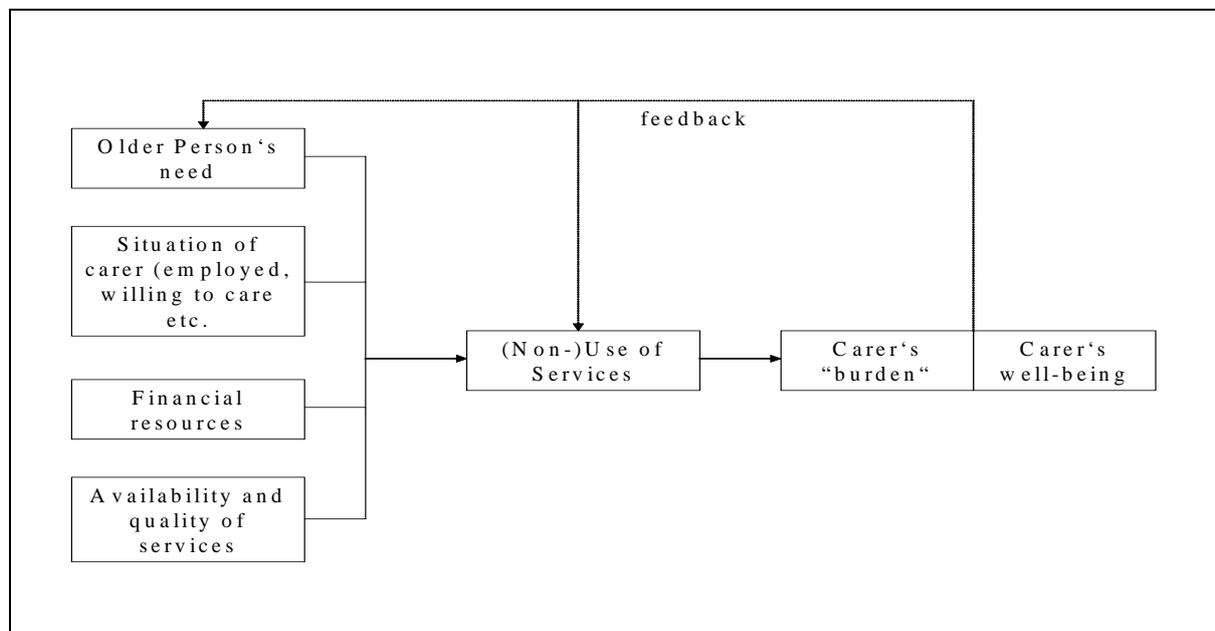
**Table 4: Carer-related scales**

Scale name	N	N missing (%)	Mean (SD)	Median	Skew. (SE)	Kurtosis (SE)	Min.	Max.	Alpha
Negative impact of caregiving	5,847	76 (1.3)	11.89 (4.35)	11.0	1.07 (.03)	.78 (.06)	7.00	28.00	.83
Positive value of caregiving	5,783	140 (2.4)	13.45 (2.2)	14.0	-.74 (.03)	.01 (.06)	4.00	16.00	.65
Quality of support in caregiving	5,810	113 (1.90)	10.78 (3.01)	11.0	-.11 (.03)	-.69 (.06)	4.00	16.00	.66
Well-being index	5,880	43 (.70)	13.89 (5.99)	15.0	-.31 (.03)	-.65 (.06)	0	25.00	.87
Elder's needs covered by carer	5,830	93 (1.6)	5.31 (2.00)	6.00	-.54 (.03)	-.55 (.06)	0	8	.70
Elder's needs covered by informal support other than carer	5,829	94 (1.6)	1.82 (2.26)	1.00	1.12 (.03)	.14 (.06)	0	8	.82
Elder's needs covered by formal support	5,827	96 (1.6)	.85 (1.6)	0.00	2.06 (.03)	3.6 (0.6)	0	8	.86
Carer perceived need for more support	5,634	289 (4.9)	2.13 (2.46)	1.00	.98 (.03)	-.25 (.07)	0	8	.86

**Table 5: The Cope Index: Items and factor loading**

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

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



Adapted from Aneshensel et al. (1995)

## **4 Sampling, recruitment and representativeness of the German sample**

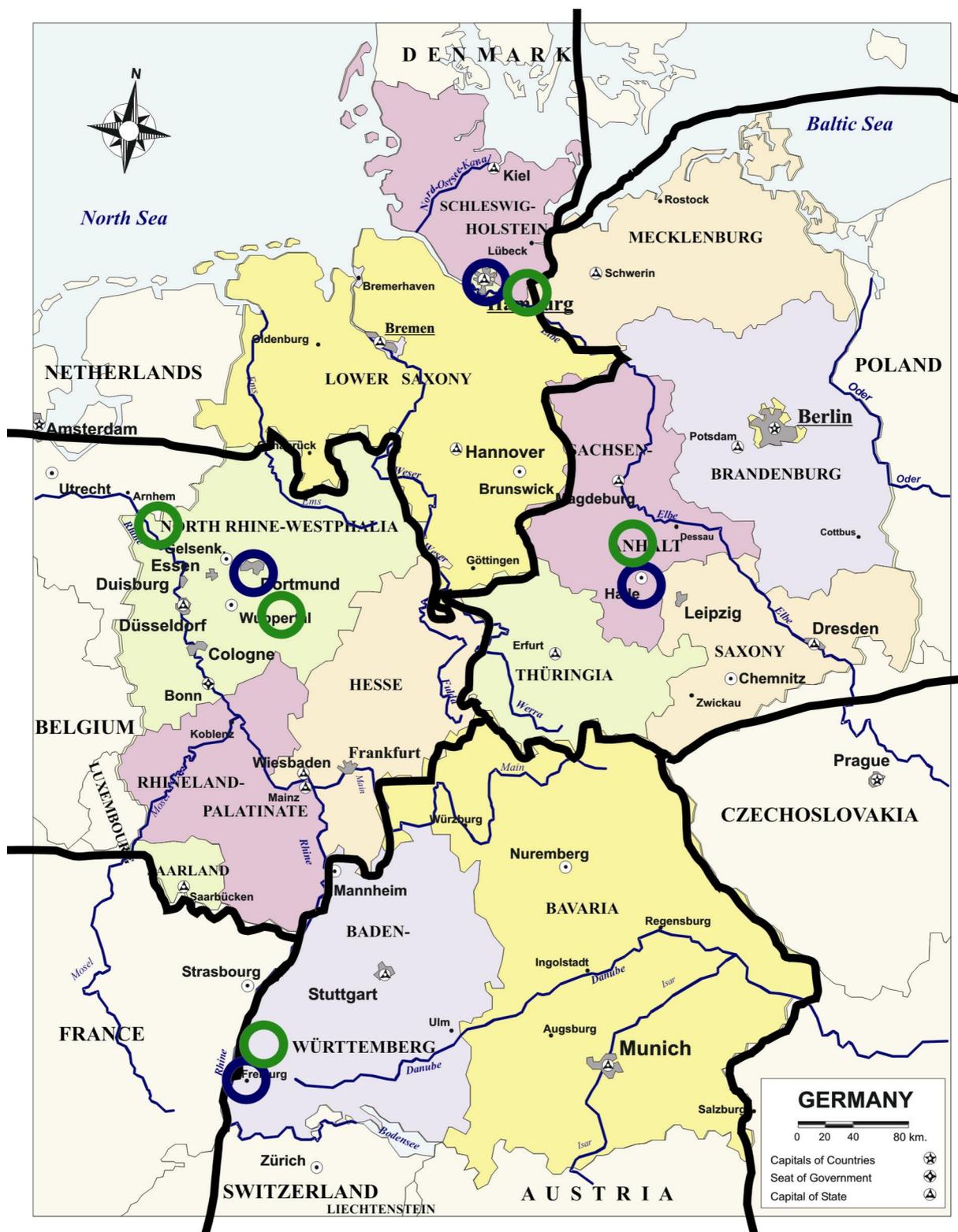
*Daniel Lüdecke, Hanneli Döhner, Eva Mnich*

The aim of this chapter is to show how the data was collected and which sampling strategies were used in Germany. At first the preparation of the data collection phase is being described. Since there were six countries which carried out the data collection with the aim of achieving a common European database which allows cross national analyses, a common strategy plan for collecting the data, defining the target group and recruiting interview partners was developed (see Deliverable 1: STEP for NASURE). This procedure is described in the first part of this chapter with respect to the original planning. However, in the course of preparing the sample strategy and the data collection phase, in Germany the research realized several problems which made changes in the sampling strategy and for recruiting interview partners inevitable. These problems are described in sections 4.3.1 and 4.3.2.

### **4.1 Sampling strategy for family carers survey**

The sample size for each of the six core countries should be 1,000 carers. The reached sample size of the German sample is  $n = 1,003$  family carers of older people in need of care. The design for the national data collection in Germany contained a sampling procedure in four defined regions: North, south, west and east Germany (see figure 2). The decision for this sampling procedure was based on cultural and religious aspects and the fact that the service offer in the four German regions are very different. In each region certain metropolitan, urban and adjoined rural areas have been chosen to define the area of recruiting family carers.

Figure 2: Sample regions in the German survey



0 = urban regions  
 0 = rural regions

Since the data of each of the six countries where this study was carried out should be merged into one European database and therefore be comparable, a standard evaluation

protocol (STEP) for the national surveys (NASUR) was developed. 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”).

These aspects are described in the following sections.

#### 4.1.1 Target group

The target group of this project were *main family carers* und their *dependent older cared-for*. To ensure a reasonable level of representativeness on the national and comparability on a 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*, thus the real distribution of care situations in each country is not necessarily reflected.

The *main family caregiver* in our study is “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 to be a carer according to the definition itself (supporting an older person for at least 4 hours per week);
- organises the care provided by others, and this organisational tasks engage him / her for more than 4 hours per week;
- provides care to an older 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 will also be accepted in the sample, provided that they meet the inclusion criteria as specified by the definition of primary caregiver given above.

This definition **excludes** any person who:

- supports only financially the older relative;
- just “visits” (even if for more than 4 hours per week) an older relative living in residential care settings.

In case a carer provides support to more than one older person, data should refer to the most relevant caregiving situation; in case more than one carer provide support to the same person, data should be collected from the relative providing most care.

### 4.1.2 Sample distribution in the different regions

To prepare the sampling procedure, the population of each sampling region was evaluated and the amount of older people (aged 65 and higher) determined. This relation between older people in need of care compared to the whole population should be adopted for each region and could result into different sample sizes in each region. This sampling strategy was meant to take into account an as broad as possible spectrum of regional and site differences, but following this strategy, for Germany, would have resulted in very unbalanced samples for each region. The aim of measuring regional and site differences might not have been achieved. In addition, there would have been too few cases for meaningful and significant data analysis in some regions. Thus, the decision in Germany was to take four equal sized samples. According to the revised sampling strategy, in each region 250 family carers of older people should have been interviewed. Furthermore, the distribution of questioned persons in relation to metropolitan, urban and rural areas should follow a certain, defined strategy, to take the influence of infrastructural criteria into account.

### 4.1.3 Planned sample distribution according to metropolitan, urban and rural differences

For the sampling not only regional differences, but also differences in metropolitan, urban and rural structures were considered. In Germany 50 % of the population lives in cities with less than 100,000 inhabitants. About one third lives in cities with more than 100,000 inhabitants. The only available data from the Federal Statistical Office Germany according to the distribution of people aged 65 or older between metropolitan, urban and rural areas show, that it does not differ completely from the distribution of older people in the whole population. This resulted in the sample weighting, described in table 6.

**Table 6: Distribution of Interviews according to rural, urban and metropolitan areas**

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

## 4.2 Training for local co-ordinators and interviewers<sup>3</sup>

The data collection was planned to be carried out by interviewers experienced with data collection in research with older people. These interviewers have been recruited among students and candidates graduated in sociology, psychology, nursing and health, as well as social workers, geriatric nurses or other professionals involved in the field of social and health work. Since careful planning for this procedure is necessary, the training of locale co-ordinators and interviewers became an own work package in the EUROFAMCARE project. Responsible for the recruitment of interview partners within each region were the respective local coordination centres. That means, based on recruitment strategies defined by the research team in Hamburg the development of recruitment channels were given into the responsibilities of each coordination partner. The parallel data collection in different regions required guidelines for training of both the local co-ordinators and the interviewers.

### 4.2.1 Training and tasks for the locale co-ordinators<sup>4</sup>

In each of the four regions a co-operation with a department of gerontology / nursing sciences of Universities of Applied Sciences was established. Locale co-ordinators in each region were employed to

- contact local institutions and organisations in order to announce the study and eventually to obtain lists of subjects to be interviewed;
- document the data collection (letters to be sent to subjects, monthly progress reports including note of refusals, and any other cause for missing interviews).

Furthermore, the tasks of these locale co-ordinators were to coordinate and control the sampling and data collection in their region. They were trained and monitored by the Hamburg research team.

One local co-ordinator for each region where the data collection will be carried out has been contracted. The local co-ordinators were recruited among candidates with similar characteristics mentioned above for interviewers, but they had to show a higher ability to co-ordinate groups, interact with local authorities and capacity to solve the practical problems often connected with a data collection<sup>5</sup>. The locale co-ordinators had to do the public relation work and

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<sup>3</sup> We greatly acknowledge Ingrid Kandt, supported by Bettina Leuchtman, for developing and organising the training of the local co-ordinators and interviewers in four regions.

<sup>4</sup> We greatly acknowledge following local co-ordinators for their support: *Region South*: Philipp Stemmer; supervised by Prof. Dr. Thomas Klie, Director of the work area Social Gerontology and Care at the University of Applied Sciences Freiburg; *Region East*: Stephanie Hanns and Christiane Luderer, supervised by Prof. Dr. Johann Behrens, Director of the Department for Health and Nursing Sciences at the Martin-Luther-University in Halle/Saale; *Region West*: Gabriele Jancke from the Kaiserswerther Diakonie supervised by Prof. Dr. Sabine Kühnert, University of Applied Sciences Rheinland-Westphalen-Lippe; *Region North*: Bettina Leuchtman supervised by Dr. Hanneli Döhner, University of Hamburg.

<sup>5</sup> Therefore the senior scientists of the Universities of Applied Science were contacted to choose the local coordinators for the project. They knew those persons from earlier work and could assess their abilities to fulfill the tasks in high quality.

recruit family carers, address management of interview partners, convey the addresses of potential interview partners to the interviewers etc.

Local co-ordinators have been charged with the following tasks:

- contacting local institutions and organisations in order to obtain lists of subjects to be interviewed;
- recruitment and monitoring (Hamburg) of interviewers;
- coordinating pilot phase;
- preparing the documentation for the data collection (letters to be sent to subjects, monthly progress reports taking note of refusals, and any other cause for missing interviews).

Information to be provided to interviewers included:

- background of project;
- copy of the questionnaire and of the official document that have been delivered to interviewees;
- user's guide for interviewer including specifications about most "sensible" questions (to be provided as Deliverable of WP2);
- handling of ethical and safety issues.

#### **4.2.2 Advanced training for the interviewers**

Since the interviewers mostly were recruited from students, some of them had less experience with complex assessment tools and also only few knowledge about family care. Therefore, and for the reason to make the interviewers more familiar with the EUROFAMCARE project, the interviewers in Germany had an advanced training on how to carry out the interviews. This training was a one-day-education and was planned and conducted by the Hamburg research team. The training session in each region was organized by the local co-ordinators.

The training began with an introduction to the project followed by sampling and recruitment aspects (different regions, locality types, possible recruitment channels etc.). After that, the definition of the target group was given and how to better define this group by using "filter questions". Based on these question, the interviewer could easily decide whether a person fits to the definition of the target group or not. Examples of filter questions:

- How old is your older cared-for? (must be 65+)
- How long do you give care to your older relative per week? (must be at least 4h / w)
- Are you still giving care to the older person? (must be yes)
- Are you the primary carer? (must be yes)
- Is the older person still alive? (must be yes)

The preparation for the interview event was divided into two parts. A minor part consisting of how to introduce oneself and how to introduce into the topic of the EUROFAMCARE study.

The major part was a detailed examination of the questionnaire followed by two example interviews which were performed in a role play.

The advanced training session ended with a postprocessing of the interviews and what to do afterwards, when the interview was done.

The interviewers have been charged with following tasks:

- contacts with local co-ordinators for planning of interviews;
- modalities of (postal and phone) contact of the interviewees;
- use of filter questions to identify carers;
- doing the telephone contact and arrange the meeting and interview with the family carers, mainly in their home environment;
- documentation of all (un-)successful contacts, including recruitment procedure etc.;
- information to be provided to the interviewees, including the possible need for informed consent forms and the follow-up study;
- modalities of collection of completed interviews;
- suggestions regarding safety and proper behaviour before, during and after the interview.

### **4.3 Recruitment of family carers**

While national representativeness of the collected data should be achieved by the application of the criteria described in section 4.1, cross-national comparability required that all partners share the same recruitment methodology. The assumption was, only an as broad as possible spectrum of recruitment strategies will ensure that all the multifaceted types of care situations can be found in our sample. To this purpose, partners have agreed to employ a common saturation method, aimed at reaching the universe of family carers living in the chosen sample communities through the parallel or consecutive application of any suitable recruitment strategy.

#### **4.3.1 Recruitment strategies**

Since Germany has no lists of family carers nor national lists of dependent older people living at home, the defined ways to contact potential interview partners were mainly:

- Contacts via self help groups or carer support groups.
- Advertisements in newspapers and other mass media.
- Flyer, which have been spread at places where the target group was supposed to be found (pharmacy, general practitioner, ambulatory services, carer support groups etc.).
- Personal contacts by the interviewer.
- Contacts through volunteer associations, private organisations etc.
- Word-of-mouth recommendations.

- Contacts via health care insurances as well as the medical advisory board (Medizinischer Dienst der Krankenkassen, MDK).

The recruitment of interview partners in Germany was much more difficult than anticipated. One reason for these difficulties was the insufficient support from service providers. Due to the introduction of the health modernisation law (Gesundheitsmodernisierungsgesetz, GMG) many service providers indicated a lot of additional workload. Thus, they didn't have much time to support our project by helping to find interview partners. Other recruitment ways were not very successful, either. Even with a broad usage of the above mentioned methods and highest engagement of the coordination centres after four months only a quarter of all planned interviews could be conducted (see Table 7). In the Northern region the most interviews could be done, which can be ascribed to the long lasting grown contacts of the project leader of the Hamburg research team as well as to the higher recruitment capacities. To complete the data collection, in Germany the authorization of a specialised sub contractor was necessary.

**Table 7: Total amount of interviews at the end of the own data collection period**

Region	North	East	South	West	Total
Rural	35	13	18	0	66
Urban	23	8	5	15	51
Metropolitan	97	42	8	5	152
<b>Total</b>	<b>155</b>	<b>63</b>	<b>31</b>	<b>20</b>	<b>269</b>

#### 4.3.2 Authorizing a sub contractor

Since the planned ways of recruiting family carers did not succeed to get the aimed sample size within the agreed time table of the sampling procedure, it was agreed by the consortium and the EC that a specialised institution should be authorized with collecting the remaining three quarter of the planned interviews. The allegation was to recruit interview partners in the same areas, which have been defined for data collection in the STEP for NASUR and using the same recruitment channels. But after some weeks it became obvious that the specialised survey institution also had many problems to access family carers for the study. Using the given criteria for recruitment the only way to reach the necessary number of interviews in time was to expand the sampling area to the whole Germany. Using this new strategy, finally the aim of a sample size of 1,003 family carers could be reached. This aspect is reflected in the type of recruitment channels for family carers. Expanding the sampling area to whole Germany allowed the survey institution to deploy more interviewers who themselves again had many family carers as personal contacts. A positive effect from this sampling procedure was the good mixture of older persons with low and high dependencies in the German sample. The group recruited by the local coordinators was biased due to too many cared-for with higher degrees of dependency. In the end, the cooperation with the sub contractor was a good and positive experience for the Hamburg team.

The following tables (8 to 11) give an overview about the final distribution of the sample according to the locality site and the recruitment channels for the German sample. These tables don't include classifications by region (north, south east and west), since this does no longer make sense with the expanded sampling area.

**Table 8: Distribution of sample by Locality Type in %**

Locality Site	Percentage of total
Metropolitan	32.8
Urban	45.2
Rural	22.0
Total	100 (n=1,003)

**Table 9: Mode of recruitment for the final sample in %**

Mode of recruitment	Percentage of total
Personal contacts, neighbours, friends, relatives of interviewer	38.1
Door to door	19.2
Health or social care professional (e.g. doctor or soc worker)	15.9
Advertisement	11.8
Religious organisations	6.0
Voluntary organisations	5.1
Other	2.0
Lists (of older residents, or electoral roll, etc.)	1.3
Missing	0.7
Total	100 (n=1003)

**Table 10: Mode of recruitment by Locality Type in column %**

Mode of recruitment	Percentage of Total within Locality Type		
	Metropolitan	Urban	Rural
Personal contacts, neighbours, friends, relatives of interviewer	37.9	42.0	31.7
Door to door	12.8	21.2	25.3
Health or social care professional (eg doctor or soc worker)	15.6	15.0	18.6
Advertisement	16.5	9.4	10.0
Religious organisations	5.2	6.5	6.3
Voluntary organisations	9.5	3.3	2.3
Other	1.2	0.9	5.4
Lists (of older residents, or electoral roll, etc.)	1.2	1.8	0.5
Total	100 (n=327)	100 (n=448)	100 (n=221)

**Table 11: Mode of recruitment by Locality Type in row %**

Mode of recruitment	Percentage of Total within Mode of Recruitment			
	Metropolitan	Urban	Rural	Total
Personal contacts, neighbours, friends, relatives of interviewer	32.5	49.2	18.3	100 (n=382)
Door to door	21.8	49.2	29.0	100 (n=193)
Health or social care professional (e.g. doctor or social worker)	32.1	42.1	25.8	100 (n=159)
Advertisement	45.8	35.6	18.6	100 (n=118)
Religious organisations	28.3	48.3	23.3	100 (n=60)
Voluntary organisations	60.8	29.4	9.8	100 (n=51)
Other	20.0	20.0	60.0	100 (n=20)
Lists (of older residents, or electoral roll, etc.)	30.8	61.5	7.7	100 (n=13)

#### 4.4 Representativeness of family caregivers survey concerning family carer and the cared-for<sup>6</sup>

To give a better picture of the sample and the quality of the collected data, first results of certain frequencies will be compared with another study which claims to be representative for older people in Germany, the "Möglichkeiten und Grenzen selbständiger Lebensführung III"<sup>7</sup> (MuG III) (Schneekloth/Wahl 2005). As said before, the EUROFAMCARE sample is not representative for certain frequencies of family care situations in a strong statistical sense, since the sampling strategy chosen did not fulfil the criteria which allows us to talk about representativeness. However, the method of saturation chosen for the EUROFAMCARE sampling allows the assumption, that the different types of possible family care situations are well reflected in the German sample. The comparison between chosen variables like sex, age, care level and hours of care in the EUROFAMCARE sample with MUG III shall give an impression on how good sub samples of our German sample can be used to get significant results.

The research project MuG III gives an overview of the situation of people living in their own household, who are in need of care. This study was carried out in 2002 and reclaims representativeness for the population of older people in need of help and care in Germany, due to the methodological approach and sample size. As in the EUROFAMCARE study, the MuG III distinguishes between two types of dependency which are very relevant for the German situation and are related to the system of the Long Term Care Insurance.

<sup>6</sup> We greatly acknowledge Ulrich Schneekloth from TNS Infratest Sozialforschung for providing data from their representative survey for comparison with our sample to check it for representativeness.

<sup>7</sup> Possibilities and limits of an autonomous lifestyle in private households of persons in need of care or nursing.

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

Considering the distinction of “need of help” / “need of care”, the total amount of people who are in „need of help“ in the population preponderate the amount of people who are in “need of care”. This relation is reversed in the EUROFAMCARE sample (table 12).

**Table 12: Comparison between MuG III and EUROFAMCARE by “Need of help” / “Need of care” and by gender of the cared-for person in %**

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

**Table 13: Comparison between Mug III and EUROFAMCARE by gender and care level of the cared-for person in %**

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

A part of the deviations from table 12 and 13 might be explained by recruitment effects of the EUROFAMCARE study. Considering the sub groups of “own” interviews done by the recruited interviewers and those interviews made by the survey institution, there are huge variations in the distribution of people in need of help and people in need of care (table 14).

**Table 14: Distribution of older people in need of help and in need of care in the EUROFAMCARE sample by own interviews and interviews made by sub contractor in row %**

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

Although the amount of people who are in “need of care” in the EUROFAMCARE study is higher than the average of the whole population, the relation between male and female persons within each group correspond to the actual distribution with the whole population (table 15 and 16).



**Table 18: Comparison between MuG III and EUROFAMCARE by gender of the cared-for person and grouped age according to care level in %**

Need of help / care by age of cared-for person (grouped)		Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Level 1	65-69	19.6	7.7	19.6	2.2	10.9	6.8
	70-74	15.5	11.5	17.6	8.6	12.6	11.1
	75-79	19.6	15.6	29.4	18.0	16.7	21.1
	80-84	20.9	24.6	19.6	28.1	23.6	25.8
	85-89	12.8	21.7	5.9	20.9	19.3	16.8
	90+	11.5	18.9	7.8	22.3	16.9	18.4
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Level 2	65-69	17.6	7.0	19.2	8.8	10.6	12.2
	70-74	20.4	10.7	15.4	8.2	14.0	10.5
	75-79	19.4	14.5	17.9	12.6	16.1	14.3
	80-84	20.4	21.0	19.2	25.8	20.8	23.6
	85-89	12.0	22.0	17.9	21.4	18.6	20.3
	90+	10.2	24.8	10.3	23.3	19.9	19.0
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Level 3	65-69	16.0	3.8	28.3	13.4	7.8	18.2
	70-74	20.0	9.6	21.7	5.2	13.0	10.5
	75-79	16.0	9.6	15.2	18.6	11.7	17.5
	80-84	8.0	34.6	17.4	25.8	26.0	23.1
	85-89	8.0	17.3	8.7	15.5	14.3	13.3
	90+	32.0	25.0	8.7	21.6	27.3	17.5
	Total	100.0	100.0	100.0	100.0	100.0	100.0

Since the main family care givers are the target group of the EUROFAMCARE study, the following tables show data comparison according to family carer aspects. At first, results related to the gender criteria between primary carer and cared-for person is focused on. Looking at male persons who are in the role of the primary family carer, the EUROFAMCARE sample has noticeable variations compared to the representative Mug III study (table 19 and 20). Especially in the group of older people in “need of care”, this discrepancy is very pronounced.

**Table 19: Comparison between MuG III and EUROFAMCARE by gender of main family carer and gender of cared-for person in %**

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

**Table 20: Comparison between MuG III and EUROFAMCARE by gender of primary family carer and gender of cared-for person in %**

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

Looking at the age of the primary carers, the EUROFAMCARE sample has on the average younger family carers than the MuG III study (table 21 and 22).

**Table 21: Comparison between MuG III and EUROFAMCARE by age of main family carer and gender of cared-for person in %**

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

**Table 22: Comparison between MuG III and EUROFAMCARE by age of main family carer and gender of cared-for person in %**

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

Concerning the average hours of care per week given to a cared-for person the care-giver in the EUROFAMCARE study provide much more care and help. Especially for the group of older people who are in need of care the amount of given care hours per week is much higher than in the MuG III study (table 23).

**Table 23: Average hours of care per week given to cared-for person according to “Need of help / care” in %**

Average hours of care given to elder per week	Need of help / care				Total	
	MuG III		EUROFAMCARE		MuG III	EFC
	Need of help	Need of care	Need of help	Need of care	Total	Total
- 4	24.1	2.5	3.9	2.9	16.5	3.3
5-9	20.1	5.9	30.6	15.7	15.1	21.9
10-13	12.1	10.3	16.1	8.6	11.5	11.8
14-19	10.5	8.8	13.5	10.2	9.9	11.6
20-29	9.0	18.5	16.6	18.0	12.4	17.4
30-39	4.4	12.6	5.3	7.8	7.3	6.7
40-59	2.6	14.7	7.7	9.3	6.9	8.7
60+	2.9	15.8	6.3	27.5	7.4	18.6
Missing	14.3	11.0	-	-	13.1	-

Considering the employment status of the family carers the group of fulltime employed persons within the EUROFAMCARE sample is much higher than in the MuG III study while the amount of unemployed family carers is noticeable lower. Differences between men and women are emerging stronger in the MuG III study than in the EUROFAMCARE project (table 24).

**Table 24: Employment of main family carer by gender of cared-for person according to “Need of help / care” in %**

Need of help / care	Employment of family carer	Gender of cared-for person				Total	
		MuG III		EUROFAMCARE		MuG III	EFC
		Male	Female	Male	Female	Total	Total
Need of help	Fulltime (30 hours and more)	8.1	23.6	29.4	33.5	18.8	32.1
	Part-time (15 to 29 hours)	9.8	10.3	11.0	15.1	10.2	13.8
	Minor employment (less than 15 h.)	3.4	2.0	2.9	4.0	2.5	3.6
	Unemployed	78.0	62.2	56.6	47.5	67.1	50.5
	Missing	0.8	1.9	-	-	1.5	
	Total	100.0	100.0	100.0	100.0	100.0	100.0
Need of care	Fulltime (30 hours and more)	3.9	15.4	14.6	22.7	12.0	20.2
	Part-time (15 to 29 hours)	5.7	10.7	3.9	8.5	9.2	7.1
	Minor employment (less than 15 h.)	1.1	5.8	3.9	4.7	4.4	4.5
	Unemployed	89.0	67.7	77.5	64.1	74.1	68.2
	Missing	0.4	0.5	-	-	0.4	-
	Total	100.0	100.0	100.0	100.0	100.0	100.0

## 4.5 Quality of the representativeness

Looking at the comparison tables of the previous sections, the EUROFAMCARE data seems to be quite reliable according to the reflection of different, typical care situations. Many distributions of family carer and cared-for criteria come very close to the representative Infratest-Study.

## 4.6 References

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## 5 Characteristics of the sample

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The main aim of this chapter is to present the profiles of both groups involved in the caring situation: the main family carers as well as the older relatives they care for. Variables such as age, sex, civil status, family or financial situation are seen as important factors influencing the caring process. Our research confirms this “social wisdom” in many aspects. In this chapter, we present a high number of factors which are of major importance in the description of a variety of complex caring situations. Because of the large number of the above mentioned variables, our data is presented in a simple and descriptive way. This helps the reader to answer the really basic question: Who are the main family carers and who are the old persons they care for?

### 5.1 Characteristics of the cared-for people

#### 5.1.1 Socio-demographic characteristics of the cared-for people

The cared-for persons in our sample are 65 years or older. The mean age is 79.7 years (median = 80). The mean age of the male older persons is slightly lower (76.5), the mean age of the female cared-for persons slightly higher (81.1) than the total mean.

Considering the two age groups (below and above 80 years) of the older persons, we find an almost balanced distribution (table 25), while there are noticeable differences within the different gender groups of the cared-for persons. Within the group of male cared-for, only about one third is aged 80 and higher while almost 60 percent of the female older persons are older than 80 years.

About two thirds of the elder persons in the German sample are female (see table 25).

**Table 25: Mean Age of Older Person by Gender (in years), Older Person’s Gender and Age Groups of Older Person (in %)**

Total Mean Score	Male	Female
79.67	76.53	81.11
Age of Older Person grouped	Total Percentage	
65-79	48.6	
80+	51.4	
Total	100	
Older Person’s Gender	Percentage	
Male	31.5	
Female	68.5	
Total	100	
Age of Older Person grouped	Male	Female
65-79	65.8	40.7
80+	34.2	59.3
Total	100	100

Considering the marital status, most of the older persons are widowed (63.5 %), while the second largest group is married or cohabiting (28.5 %). Only five percent are divorced or live separated, and three percent are singles (table 26).

**Table 26: Older Person's marital status (in %)**

<b>Older Person's marital status</b>	<b>Percentage</b>
Widowed	63.5
Married / cohabiting	28.5
Divorced / separated	5.0
Single	3.0
Total	100

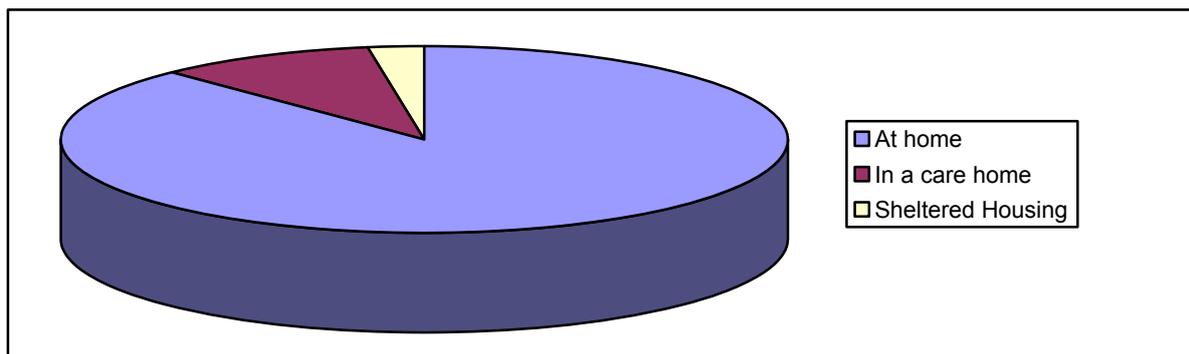
Nearly all of the older persons are Germans or of German ethnic origin (see table 27).

**Table 27: Older Person's nationality and ethnic origin (in %)**

<b>Older Person's nationality</b>	<b>Percentage</b>
German	98.5
Turkish	0.8
Russian	0.2
Other	0.5
Total	100
<b>Older Person's ethnic origin</b>	<b>Percentage</b>
German	97.0
Turkish	0.6
Russian	0.4
Polish	0.3
Other	1.7
Total	100

### 5.1.2 Place of living and household composition

Most of the older people live at home (87.7 %). This means that they either still live in their own house (alone, with partner or other persons) or they live at their children's house. "At home" only refers to one's own, private domesticity and has to be distinguished from offers like care homes or sheltered housings (figure 3).

**Figure 3: Place of living of cared-for older person**

One third of the elder people from the German sample live in metropolitan areas. The majority, about half of them, live in urban-type localities (see table 28).

**Table 28: Place of living and locality type of the cared-for older person (in %)**

Place of living of the cared-for older person	Percentage
at home	87.7
in care home	9.8
in sheltered housing	2.5
Total	100
Locality type	Percentage
metropolitan	32.8
urban	45.2
rural	22.0
Total	100

Nearly half of the cared-for persons live alone. Of those who do not live alone, almost half live together with their partners and about one third lives together with their children. Only few cared-for persons live with their grandchildren (5.7 %) or with paid carers (1.6 %).

Of those cared-for older persons, who do neither live with the main carer nor in an institution (e.g. care home), about three quarter live alone. One fifth lives together with another person, only a few older persons live together with more than one person in their household (see table 29).

**Table 29: Living situation and Household composition of Elder (in %)**

<b>Elder lives alone or with others</b>	<b>Percentage</b>
alone	44.5
with others	55.5
Total	100
<b>Household composition*</b>	<b>Percentage</b>
with partner	48.5
with children	35.9
with grandchildren	5.7
with paid carers	1.6
<b>Number of people in elder's household, elder included</b>	<b>Percentage</b>
1	76.6
2	20.7
3	1.7
4 and more	1.0
Total	100

\*Multiple answers possible – percentages are not summing up to 100 %.

### 5.1.3 Older Persons' health situation and need of support

The main reasons why elder persons need care or support are mobility problems (27.9 %) and physical illness or disabilities (24.8 %). Memory problems or cognitive impairments ranks third with 14.9 %, followed by age-related declines (12.1 %). Mobility problems and physical disabilities are predominantly the decisive factors for the elder person claiming support or care, while memory problems or cognitive disorders seem to be less crucial. However, more than half of the elder cared-for persons are stated to have (also) memory problems, which means that, in many cases, the family carer has to deal with mobility problems as well as with memory problems (see table 30).

**Table 30: The reason of support / care (in %)**

<b>Reason</b>	<b>Percentage</b>
mobility problems	27.9
physical illness / disabilities	24.8
memory / cognitive problems / impairments	14.9
age-related decline, old age	12.1
non self-caring	10.0
sensory problems	3.8
social reasons, loneliness, need for company	2.2
safety / feeling of insecurity	1.7
psychological / psychiatric illness / problems	1.5
other reason	1.1
Total	100

55.8 % of the cared-for persons in the German sample suffer from memory problems. This group can be divided into three subgroups:

- Undiagnosed memory problems (20.5 %)

- Dementia diagnosed by a doctor (60.5 %)
- Other diagnosis or explanation than dementia by a doctor (19 %)

Thus, for one fifth of the older people the family carers give no explicit diagnosis for their cognitive impairments, but nevertheless these problems are experienced as memory problems by the family carers. 41.8 % of the elder persons show behavioural problems. The two largest groups are elder persons with neither memory nor behavioural problems (40.2 %) and elder persons with memory as well as behavioural problems (37.4 %) (table 31).

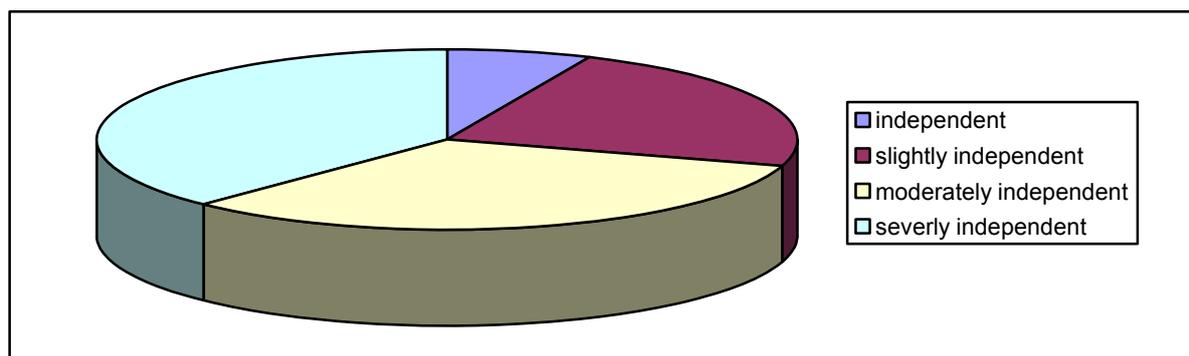
**Table 31: The problems of the cared-for older persons (in %)**

Memory or Behavioural Problems*		Percentage
memory problems	<b>Total</b>	<b>55.8</b>
	Undiagnosed memory problems	20.5
	Dementia	60.5
	Other diagnosis / explanation	19.0
behavioural problems		41.8
Memory and / or behavioural problems		Percentage
no memory and no behavioural problems		40.2
no memory problems, but behavioural problems		4.3
memory problems, but no behavioural problems		18.1
memory and behavioural problems		37.4
Total		100

\*Multiple answers possible – percentages are not summing up to 100 %.

Only 6.7 % of the cared-for older persons are stated to be “independent”, which means they can manage almost all typical daily activities on their own. They usually only need little help with more “complex activities” (like cooking, shopping or housework). Most of the cared-for in the German sample are moderately or severely dependent, which means that they can hardly manage any activities of daily living and cannot cope with more complex activities. The possible answers and the related description of the level of dependency that carers could choose were:

- independent: able to carry out most activities of daily living, but may need some help occasionally;
- slightly dependent: able to carry out most activities of daily living, but requires help with some instrumental activities (e.g., shopping, cooking, housework, etc.);
- moderately dependent: able to carry out some basic activities of daily living (for example, bathing, feeding, dressing) but unable to carry out most instrumental activities of daily living (e.g. shopping, cooking, housework) without help;
- severely dependent: unable to carry out most activities of daily living without help (e.g. feeding themselves or going to the toilet) (see figure 4).

**Figure 4: The level of dependency of the cared-for older persons**

Since the validity of the dependency level is based on the estimation of the interviewed carer, it is no “objective measure”. But comparing the correlation between the estimated dependency level of the older persons and the Barthel-Index, we find prove for very valid scores of dependency levels (see table 32).

**Table 32: The level of dependency of the cared-for older persons (in %)**

Dependency level	Percentage	Mean Barthel-Index
independent	6.7	94.47
slightly dependent	22.9	85.88
moderately dependent	32.5	72.68
severely dependent	37.9	31.43
Total	100	61.1

According to the mean Barthel-Index, older people living at home seem to be slightly more physically disabled (mean BI of 64.24; median = 70) than those living in sheltered housings (mean score 75.2; median = 80). Cared-for persons living in a care home have, as expected, the lowest Barthel-Index mean score (35.31).

The cared-for persons predominantly do not need help from others in terms of financial support, which means that they usually have enough money to cover their demands and needs. Most help needed refers to the domains *domestic needs* (60.2 %) and *financial management* (57.1 %) and other *organisational management* (52.8 %). In the domains of *emotional / psychological / social, mobility* and *health needs*, the number of elder persons who have to rely completely on others is very similar.

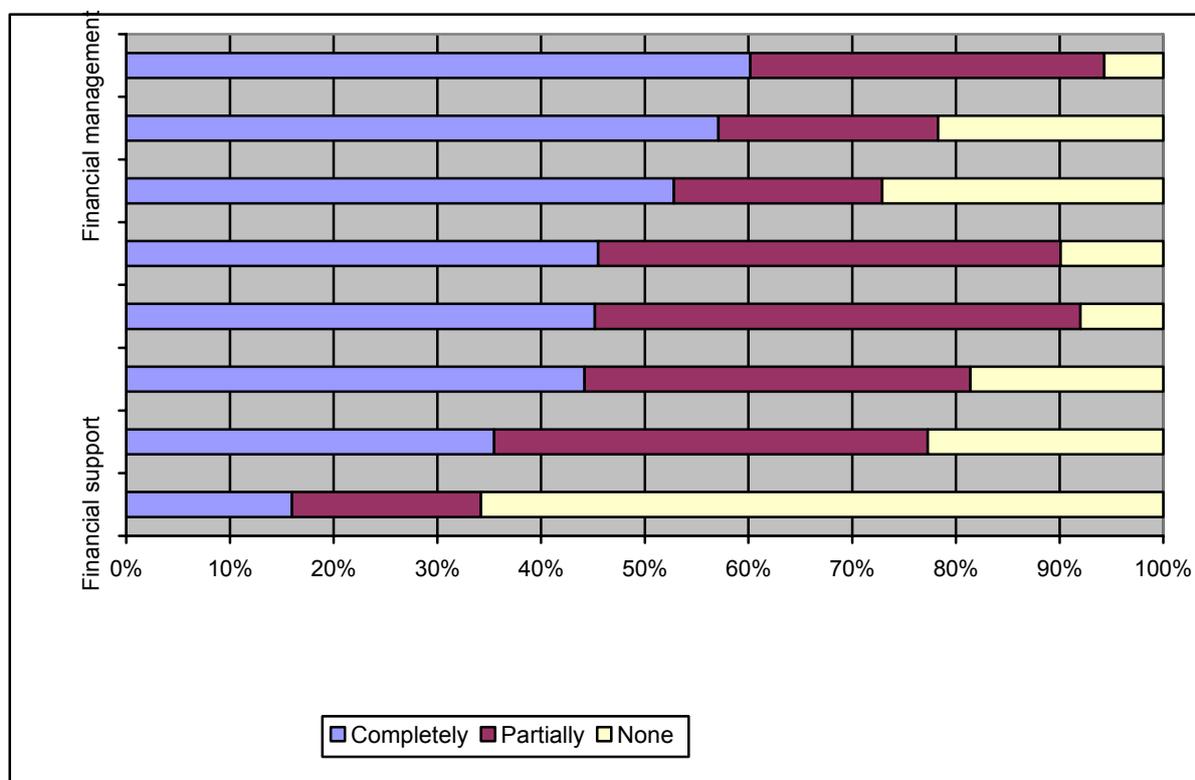
Looking at the three domains *emotional/psychological/social, mobility* and *health needs* again, which show almost no differences in their frequencies in the category “completely rely on others”, we can see some differences regarding the fact whether no help is needed at all. Most cared-for have the least needs of support from others according to *health needs*, while only 9.9% abdicate help for *emotional/psychological/social needs* and even less (8.0) have to rely on others for mobility needs (table 33/figure 5).

**Table 33: Cared-for people who have to rely partially or completely on others in meeting their needs (in %)\***

Needs	Percentage Completely	Percentage Partially	No help needed
domestic needs	60.2	34.1	5.7
financial management	57.1	21.2	21.7
organising and managing care and support	52.8	20.1	27.1
emotional / psychological / social needs	45.5	44.6	9.9
mobility needs	45.2	46.8	8.0
health needs	44.2	37.2	18.6
physical / personal needs	35.5	41.8	22.7
financial support	16.0	18.2	65.8

\*Multiple answers possible – column percentages are not summing up to 100 %.

**Figure 5: Cared-for people who have to rely partially or completely on others in meeting their needs (in %)\***



## 5.2 Characteristics of the family carers

### 5.2.1 Socio-demographic characteristics of the family carers

The mean age of the main carer in the German sample is 53.8 years. These values do not differ significantly when differentiated according to gender. The vast majority of carers in our German sample is under 65 years old, while only one fifth is aged 65 or above. Slightly more male carers are older than 64 years (26.1 %) compared to female carers (20.7 %). This dif-

ference does not seem to be significant and obviously cannot be explained by the role of “caring daughters”, since more than three quarters of the main carers in the German sample are female anyway. Therefore, this rather points to gender aspects of care. The mean age of male main carers is 53.4 years, while it is 53.9 years for female carers (see table 34).

**Table 34: Mean Age of Carer by Gender (in years), Carers’ Gender and Age Groups (in %)**

Total Mean Score	Male	Female
53.75	53.4	53.85
Age of Carer	Percentage	
Until 64	78.0	
65+	22.0	
Total	100	
Elder’s Gender	Percentage	
Male	23.9	
Female	76.1	
Total	100	
Age of Carer	Male	Female
Until 64	73.9	79.3
65+	26.1	20.7
Total	100	100

### 5.2.2 Carer’s religious dominations

Only 5.3 % of the main carers in our sample state that they are “very religious”. 37 % say they are not religious at all. The two predominant religious denominations are Protestants (60.0 %) and Roman Catholic (34.9 %). Other religious denominations hardly appear in the German sample.

### 5.2.3 Employment situation of the family carers

About one fifth of the carers stated to have a low level of education, another fifth stated a high level of education, the remaining 59.8 % have an intermediate level of education. Less than half of the family carers were employed at the time they were interviewed. Of those who were employed, more than half worked in the private sector and about one quarter in the public sector. One fifth were either self employed or worked in other, non-specified sectors (see table 35).

**Table 35: Employment situation and sector of work of the family carers (in %)**

Employment situation	Percentage
non-working	57.7
employed	42.3
<b>Total</b>	<b>100</b>
Sector of work	Percentage
private sector employee	51.8
public sector employee	26.5
self employed	12.1
other	9.7
Total	100

When employed, most family carers usually experience negative income effects when they reduce working hours due to the care situation. The financial support from the cash benefits of the German Long Term Care Insurance is mostly no adequate substitution for the family carers' wages on the one hand, on the other hand, not all family carers can keep the cash benefits completely for their own needs. Other helps have to be paid (by cash benefits) to ensure quality standards of care. Thus, only 9.6% of the family carers state a positive income effect by the reduction of working hours.

One fifth of the employed carers had to reduce working hours due to the care situation, about 10% can only work occasionally and another 8% had such working restrictions due to caring that they couldn't develop their career or studies (table 36).

**Table 36: Work restrictions due to caring (all carers) (in %)\***

Level of Restriction	Valid percentage	Total percentage
reduce working hours	20.6	8.7
give up working	11.8	6.6
can work only occasionally	9.6	9.5
cannot work at all	9.5	5.3
cannot develop career or studies	8.0	7.9

\* Valid percentages excluding missings and N / A-answers. Total percentages refer to the whole sample.

#### 5.2.4 Marital status of the family carer

More than 70 percent of the carers are married or cohabiting. Twelve percent are divorced or separated. About an equal number of carers are single in the German sample. Five percent are widowed (see table 37). One fifth of the carers have no children. One third of the carers in our sample have two children, one fourth have one child.

**Table 37: Marital status of the carers (in %)**

Marital status	Percentage
married / cohabiting	71.2
divorced / separated	12.0
Single	11.7
Widowed	5.2
Total	100

### 5.2.5 Carer's family relationship to the cared-for older persons

More than half of the carers are either daughter or son of the dependent older persons. Nine percent are the son- or daughter-in-law. Almost one fifth of the carers are the partners of the elder person, another fifth is otherwise related to the elder person (see table 38).

**Table 38: Carer's family relationship to the cared-for older persons (in %)**

Family relationship	Percentage
child	53.4
others	19.3
partner	18.4
son / daughter in law	9.0
Total	100

Most of the cared-for persons live either in the same household or the same building (but different households) with the family carer. These are nearly half of the cases and can be summarised as "close distance". Another third of the family carers live within walking distance or 10 minutes by public / motorised transport. This group can be labelled as "medium distance". The last 17.8 % of the family carers live at least 30 minutes away from their cared-for older persons (see table 39).

**Table 39: Distance between the carer's and the cared-for person's places of living (in %)**

Distance	Percentage
in the same household	36.7
in different households but in the same building	13.9
Within walking distance	17.7
Within 10 minutes drive / bus or train	14.0
Within 30 minutes drive / bus or train	12.6
Within 1 hour drive / bus or train	3.7
over 1 hour drive / bus or train	1.5
Total	100

### 5.2.6 Reasons for caring and willingness to care

The main reasons for caring are emotional bonds between the family carer and the older person. About one third of family carers, the second largest group, felt obliged to care for their dependent relative, which means that their decision to care was influenced by a per-

sonal sense of obligation or a sense of duty. Economic aspects play almost no important role for the decision to care (table 40).

**Table 40: Principle reason for caring (in %)**

Reason	Percentage
emotional bonds	45.1
a personal sense of obligation	17.9
a sense of duty	16.6
there was no alternative	6.1
caring makes me feel good	3.6
elder would not wish any one else to care for them	2.9
I came to caring by chance	1.9
the cost of professional care too high	1.7
economic benefits for both	0.6
religious beliefs	0.5
other	3.0
Total	100

Most of the family carers (40.9 %) in the German sample are willing to continue to provide care, even if they have to increase their efforts. 15.8 % would at least increase their effort for a limited time. About one third is only willing to continue to care if the situation will not get worse. 1.2 % is not willing to continue care (table 41).

**Table 41: Willingness to continue to provide care (in %)**

Answer	Percentage
yes, and I would even increase	40.9
yes, and I would increase for a limited time	15.8
yes, if the situation remains the same	35.7
yes, but only with more support	6.3
no, no matter what extra support I receive	1.2
Total	100

43.4 % of the family carers answered that they do not at all consider a placement of the elder person in a care home. More than half of the carers would consider a placement into care home if the care situation gets worse. 2.9 % would put their cared-for older persons into a care home even if the situation stays the same or will not get worse (table 42).

**Table 42: Consideration of the placement of the cared-for in a care home (in %)**

Answer	Percentage
no	43.4
yes, but only if elder's condition gets worse	53.7
yes, even if elder's condition remains the same	2.9
Total	100

### 5.2.7 Burden, coping, health status and quality of life

The COPE Index is a screening instrument that tries to detect the family carers' coping strategies regarding the perceived burden and social or informal support, and how they feel in their role as a carer. Table 43 shows the 15 questions presented to the carers, with 7 of the questions focussing on the positive values, 4 focussing on the negative impacts of caring and another 4 questions which are related to quality of support aspects.

The most negative impact of caring to family carers is the fact that they feel trapped in their role as a carer. Probably linked to this issue is the result, that many carers find caring too demanding, which has a negative effect on their well-being.

Family carers feel they cope well as carer, but still caring is not seen as an absolutely worthwhile job nor feel the family carers enough appreciated by others for the work they do.

Merging the categories "Always" and "Often" together to one category which describes positive statements, we can say that most family carers feel well supported by their families. About one third feel never well-supported by friends and/or neighbours, and even 40.7% state that they don't feel well-supported by support services.

**Table 43: COPE Index – How the family carers perceive their caring situation**

Question	Always	Often	Sometimes	Never
<b>Negative impact</b>				
Do you find caring too demanding?	4.1	14.3	59.7	21.9
Does caring cause difficulties in your relationship with friends?	5.6	8.5	27.5	58.4
Does caring have a negative effect on your physical health?	6.1	9.7	38.2	45.9
Does caring cause difficulties in your relationship with your family?	1.8	5.5	23.9	68.8
Does caring cause financial difficulties?	2.0	4.3	14.7	79.0
Do you feel trapped in your role as a carer?	8.4	12.3	42.2	37.2
Does caring have a negative effect on your emotional well-being?	5.5	12.3	44.9	37.4
<b>Positive value</b>				
Do you feel you cope well as carer?	23.4	65.3	11.0	0.4
Do you find caring worthwhile?	34.5	34.8	22.6	8.1
Do you have a good relationship with the person you care for?	63.3	30.7	5.4	0.6
Do you feel that anyone appreciates you as a carer?	29.3	36.3	25.4	8.9
<b>Quality of support</b>				
Do you feel well supported by your friends and / or neighbours?	12.5	26.6	25.2	35.6
Do you feel well supported by your family?	33.2	31.6	20.7	14.6
Do you feel well supported by health and social services?	14.7	24.9	19.8	40.7
Overall, do you feel well supported in your role of caring?	13.4	44.1	28.6	14.0

The health status of family carers is, according to their self-evaluation, somewhat worse.<sup>8</sup> About half of the family carers stated a moderate health status, one fifth specified their health status a bit worse and one fifth slightly better. The majority of family carers state their quality of life as predominantly positive. On average, the family carers tend to give an answer between the items “good” and “neither good nor poor” with a slight tendency to the item “good” (table 44).<sup>9</sup>

**Table 44: Health status and Quality of life of the carers (in %)**

Health status	Percentage	Mean Age	Average number of hours of care
excellent	4.2	44.5	24.1
very good	18.3	48.2	28.4
good	52.9	53.3	37.4
fair	21.5	59.8	51.8
poor	3.0	63.1	83.2
Total	100	53.7	39.7
Quality of life	Percentage	Mean Age	Average number of hours of care
very good	6.4	49.1	25.1
good	49.2	51.5	31.1
neither good nor poor	37.9	56.9	47.3
poor	5.5	57.6	71.2
very poor	1.0	53.8	55.2
Total	100	53.76	39.3

It is noticeable that the older the carer is, the worse is the self-estimation of the health status and the quality of life. The only exception is the category “very poor quality of life”, where the mean age is lower than in the previous categories, thus “breaking” the tendency of increasing mean age values.

We find the same conspicuousness in the average numbers of hours of care given to older persons: The more care is given to elder, the worse the health status is stated. And, again we find the same anomaly mentioned before within the categories of quality of life. Looking at the median of “Average numbers of hours of care” within “poor quality of life” (median = 36; standard deviation = 65.7) compared to the category “very poor quality of life” (median = 22.5; standard deviation = 62.5) this conspicuousness seems to be no bias due to low case numbers.

The results from the previous table are closely related to the WHO-5-Well-being-Index in dichotomized form, which divides the 5-item-scale into two, showing the part of family carers who state they have a worse or better quality of life (table 45).

<sup>8</sup> Mean value of 3.01.

<sup>9</sup> Mean value of 2.46 with “2 = good” and “3 = neither good nor poor”.

**Table 45: WHO-5 Well-being Index (dichotomized)**

WHO-5	Percentage
Worse quality of life	44.3
Better quality of life	55.7
Total	100

### 5.3 Final Remarks

The aim of this chapter was to give an idea of how the profile of family carers and the cared-for older persons in the EUROFAMCARE sample is like.

The cared-for persons are on average 80 years old and about two thirds of them are female. While almost two thirds of the male cared-for are aged below 80 years, nearly 60% of the female dependent persons are 80 years or older. Most of the cared-for persons (63%) are widowed and even more (88%) live at home, which means that they either still live in their own house or they live at their children's house.

The three most frequent mentioned reasons for caring were mobility problems (28%), physical illness/disabilities (25%) and memory/cognitive problems/impairments (15%). 55.8% of the cared-for persons in the German sample suffer from memory problems. This group can be divided into three subgroups: Undiagnosed memory problems (20.5%), Dementia diagnosed by a doctor (60.5%) and other diagnosis or explanation than "Dementia" by a doctor (19%).

The mean age of the family carers in our sample is 53 years. This is true for the female as well as the male carers. While one fourth of the male carers is 65 years or older, only on fifth of the female carers is aged 65 and above. The higher proportion of younger female carers could be explained by the fact, that these persons might be the caring daughters or daughters-in-law.

42.3% of the carers were employed. One fifth of them had to reduce working hours due to the care situation, about 10% can only work occasionally and another 8% had such working restrictions due to caring that they couldn't develop their career or studies.

60% of our sample are care-giving children, about 20% are caring for their partner and another 20% are "other" relatives or friends of the older person. Almost half of all older cared-for persons live in the same household or at least in the same building as the family carers do.

The carers in our sample have a very close relationship to their cared-for older person, which can be seen in the fact that nearly the half of all carers stated „emotional bonds“ as a principal reason for caring and even more than half of them are willing to continue to provide care, at least for a limited time, independent from increasing burden or amount of care.

Considering the coping resources, most family carers feel well supported by their families. About one third feel never well-supported by friends and/or neighbours, and even 40.7% state that they don't feel well-supported by support services. The majority of family carers state their quality of life as predominantly positive. On average, the family carers tend to give an answer between the items "good" and "neither good nor poor" with a slight tendency to the item "good". It is noticeable that the older the carer is, the worse is the self-estimation of the health status and the quality of life.

## 6 Typology of Care Situations

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Each interview conducted with a carer represents a specific relationship between the carer and the cared-for that is moreover embedded in relevant informal and formal social relationships. In order to create comparable groups of cases that represent different possible constellations, a list of relevant characteristics is required. It is advisable to be reticent regarding the number of characteristics, their degree of differentiation or the dimension of time. The interview presents the care-giving situation at the specific time of the interview, i.e. the genesis of the care-giving situation is not additionally explored. The catalogue used consists of characteristics that were assumed, when designing the survey instruments, to be able to gather relevant information for the description of a care-giving situation. The collected data allow to develop a typology of care-giving situations; these are explorative, simplified descriptions and serve to identify clusters of similar situations while the differences between the clusters should be as great as possible.

Against this background, selected questions will be analysed, such as the demand for support of the cared-for, informal and formal support available to the carer, the group specific impact of the caring role on the carer and her/his willingness to continue care. Thus, a condensed picture of the determinants of family care evolves. These clusters will be used in further analysis later.

### 6.1 Methods

Based on all the databases from the six core countries, a cluster analysis was carried out to identify different care situations (see chapter 6 TEUSURE). Following **carer related** variables were considered (see also chapter 3 TEUSURE): Carers' demographics as indicated by their gender, educational level, working status and generation with respect to the older people; characteristics of the carers' place of residence in terms of settlement area; variables related to the care-giving situation, namely duration of care-giving, availability of help if ill and availability of help in case of necessity. To explore carers' well-being, we included the perceived burden associated with care-giving as indicated by the Cope Index's negative impact subscale (McKee et al., 2003, see also chapter 3 TEUSURE), and measures of carers' reported state of health and quality of life (World Health Organization, 1998).

For variables **related to the older persons**, we took into consideration their age and gender, cohabitation status with carer and whether they were in need of financial support. Functional disabilities were measured in terms of the cognitive status and IADL abilities of the older persons.

A previously performed **dimension analysis** (factor) can show the extent of correlations between the selected characteristics. In two cases we found higher correlations between two variables. This applied to the reported state of health and the subjectively perceived quality of life of the caregiver. A higher correlation also occurred between caregivers getting help if they feel ill and if they need a break from care-giving. Therefore we excluded these two variables from the analysis (table 46).

**Table 46: Variables for the cluster analysis**

<b>ELDER</b>	
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
<b>CARER</b>	
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
<b>Not included</b>	
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

First we selected a cluster fusion procedure (Ward procedure) that is to give information about the possible number of clusters. A solution with 6 clusters is considered the limit of possible simplification. In order to verify the selectivity between the clusters, a **discriminating analysis** is performed. It selects 15 variables for a separation of the six subgroups (cluster) and then tries to reproduce the individual group membership only on the basis of the 15 original characteristics. The degree of success can be interpreted as a quality factor of the cluster solution. The present cluster solution resulted in a rate of 81 % correctly classified cases. After that we used a **non-hierarchical cluster approach** (quick cluster in SPSS) in order to use the possibility of "re-sorting" the first results. The newly arranged cluster now

delivers 92 % correctly classified cases as shown by the discriminating analysis based on the new classification. The corresponding value in each individual cluster now reaches at least 85 %.<sup>10</sup>

## 6.2 Main results

### 6.2.1 Characteristics of the European care situations

On the European level we identified following clusters:

Cluster 1 and 2: The carers have high objective and subjective burden. The two clusters differ in so far as the carers in the first cluster are not working. Both clusters are about the same size.

Cluster 3 and 4: “Spouses” care for each other, and they also have subjective and objective higher strain. They differ only in the fact that one cluster consists of caring women (cluster 3) and the other one of caring men (cluster 4). The latter is the smallest cluster in our sample.

Cluster 5 and 6: The carers found in these two clusters mentioned that they can find support if they need it. They differ in the fact that one cluster (cluster 5) has high objective but no subjective strain, and the other (cluster 6) has both subjectively and objectively relatively little strain. It is the biggest cluster in our sample.

### 6.2.2 Characteristics of the German care situations

In Germany, the patterns of care situations showed some typical deviations from those prevailing in the six participating countries. Carers live to a lesser extent close to the cared-for (same building). In three of the clusters – mostly when care-givers are working – the average duration of care is shorter than in the other countries (table 47).

It is also Germany-specific that, on the one hand, carers’ sense of well-being is in general higher though, on the other hand, cognitive impairments of the cared-for are above the average of all countries.

Functional impairments above the European average were only found in the group of cared-for (wives) women. In this subgroup, however, caring (husbands) men have more opportunities than any other group to get support if they feel ill, compared to the other European countries.

The current situation in Germany can be summarised as follows: In most groups, the carer and the cared-for do not live under the same roof, and the cared-for person has more often cognitive impairments. Group specific the duration of care is shorter, especially in the case of working female carers; men, on the other hand, have more opportunities to get help if they need it.

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<sup>10</sup> For a full explanation concerning the used methods see chapter 6: TEASURE.

**Table 47: Care situations in Germany; differences between German and European care situations (+ / - percentage points)**

Care situation	Cohabitation status: % same house	Care giving duration: % > 2 years	Quality of life: % better	Help if ill: % only with difficulties or no	Cognitive status: % higher impairment	IADL abilities: % higher impairment
(1) Subjective and objective high burden	41 -11	64 -7	32 +9	75 +6	84 +10	95 +5
(2) Subjective and objective high burden, working	23 -12	48 -15	43 +10	65 +8	81 +10	85 +3
(3) Wives (women) with subjective and objective high burden	86 -6	70 -2	36 + / -0	75 +2	69 +10	79 + / -0
(4) Husbands (men) with subjective and objective high burden	86 -6	72 -1	56 +3	55 -18	58 +13	80 +11
(5) Subjective low and objective high burden	18 -12	50 -13	86 +9	31 +4	66 +18	100 + / -0
(6) Subjective and objective low burden	7 -14	35 -18	82 +9	41 +12	27 +10	0 + / -0
Total	36 -11	54 -10	57 +7	56 +5	64 +13	71 +5

### 6.2.3 Needs and support in different care situations

Support demands can be divided into support related to domestic tasks and mobility, and personal support related to emotional / psychological care and health / hygiene related care.

Concerning domestic tasks and mobility, support needs are more than 85 % in all care situations, i.e. all of them have more or less the same needs. Differences exist in cluster 6, where the cared-for are less dependent and health related needs much less important, though the demand for emotional / psychological support continues to be high.

With regard to particular areas of needs and demand for support, we asked to which extent the cared-for older people could get support from

- informal carers like relatives, friends, neighbours etc. and / or
- formal services like professional nursing services etc.

Table 48 presents an overview of all care situations and shows the rates of additional support received from this group of helpers. The rates can be as high as 40 %, but in most cases about 25-30 % of all care situations. Informal support prevails in the domestic sphere, mobility support and emotional help; formal support is more relevant for the two health related types of care.

In general, care giving (wives) women receive rather less informal support and also less emotional support. The latter, which is important for all care situations, is in general given by informal rather than by formal carers. This is true also for domestic support, which is claimed especially by working carers (cluster 2, 5 and 6).

Formal support is predominantly concerned with health related care, where they reach at least 20 % but most often 30 % of the care situations. The only exception is cluster 6, where the level of disabilities is comparatively low and, therefore, health related care less relevant.

**Table 48: Care situations, spheres of needs and received support**

Spheres of care needs and help received from...	Care situations needing help according to spheres of needs (%):					
	(1)	(2)	(3)	(4)	(5)	(6)
	Subjective and objective high burden	Subjective and objective high burden, working	Wives (women) with subjective a. objective high burden	Husbands (men) with subjective a. objective high burden	Subjective low and objective high burden	Subjective and objective low burden
Domestic	97.1	95.3	95.4	100.0	94.7	85.6
Help from:						
▪ informal carer	24.9	35.1	18.3	23.6	30.0	37.6
▪ formal carer	17.3	19.3	6.1	19.1	23.5	3.3
Mobility and transport	94.8	94.2	92.4	90.9	94.2	85.1
Help from:						
▪ informal carer	29.9	29.1	23.7	21.8	32.2	39.2
▪ formal carer	22.4	16.3	19.1	14.5	25.1	3.3
Emotional, social, psychological	98.3	91.9	87.8	92.7	88.8	80.1
Help from:						
▪ informal carer	36.2	37.2	23.7	25.5	37.1	40.3
▪ formal carer	16.7	12.8	10.7	9.1	17.1	2.2
Health Care	94.3	88.4	84.0	87.3	93.5	43.1
Help from:						
▪ informal carer	19.5	23.8	7.6	20.0	26.5	16.0
▪ formal carer	32.8	26.7	27.5	25.5	34.7	9.4
Personal Care	89.7	85.5	88.5	87.3	81.9	36.1
Help from:						
▪ informal carer	25.9	25.0	13.7	18.2	18.7	13.9
▪ formal carer	35.6	27.9	27.5	21.8	36.3	4.4

If additional help is claimed in a specific area, a gap in the existing support offers can be assumed (table 49). Half of the responders mentioned that they want more emotional support, therefore, this type of support must be emphasised. This is mentioned especially by women in inter-generational care relations with a subjectively felt high burden, but also by caring (husbands) men, who wish more emotional support for the cared-for (43 %).

In all other areas of support, employed women with a subjectively high burden (cluster 2) are found to receive the lowest supply of additional support. The highest degree of additional support is provided in care situations, where carers reported a subjectively low burden but where the cared-for have high functional impairments (cluster 5). The level of inadequate provision is about 45 % in the first group and about 25 % in the second group.

**Table 49: Care situations and fields requiring more support**

Spheres of care needs and help received from...	Care situations needing help according to spheres of needs (%):					
	(1)	(2)	(3)	(4)	(5)	(6)
	Subjective and objective high burden	Subjective and objective high burden, working	wives (women) with subjective a. objective high burden	Husbands (men) with subjective a. objective high burden	Subjective low and objective high burden	Subjective and objective low burden
Domestic	34.3	41.5	29.6	32.7	25.3	32.0
Mobility and transport	38.8	46.6	36.4	30.0	23.1	34.2
Emotional, social, psychological	44.7	53.2	37.9	43.1	34.7	36.4
Health care	25.0	42.8	26.4	31.3	25.8	20.3
Personal care	31.4	45.6	29.3	26.5	22.1	27.0
Domestic	34.3	41.5	29.6	32.7	25.3	32.0

In general, a structural division of work emerges, with formal support given for health related care and informal support in most other fields. Caring (wives) women (cluster 3) in general receive the lowest degree of support. In the different care situations with their different degrees of burden, the need for more help (in addition to that already received) can be as high as 50 % in a specific sphere.

#### 6.2.4 Burden of care-givers

The perceived burden of carers is recorded using two concepts. One is an index that establishes the negative impact of the care situation on the carer using a scale ranging from 7 to 28. But care giving can also have positive aspects (scale from 4 to 16), e.g. satisfaction provided by the role of a carer. These two scales allow to describe the constellation of „negative impact“ and „positive value“ for each care situation.

The negative impact is already a classifying criterion of the clusters. Thus, the basic pattern of the clusters shows rather higher felt burdens in clusters 1 to 4 and rather lower felt burdens in clusters 5 and 6. Positive values, in general rather pronounced, are also higher in these less burdened groups. But care giving husbands also feel particularly confirmed in their caregiving role (cluster 4). Thus, the indicators of burden and of relief correspond with each other, but it must be taken into account that in cluster 6, the impairments of the older persons are lower and that in cluster 5, impairments are most often only functional rather than cognitive, which would be a higher burden for the carers.

When trying to determine the compensatory effects of the positive value, it is recommended to consider the corresponding relationships among the care types, in order to neutralise other marginal conditions. Higher positive values have almost no compensatory effect on the felt burden of working women in intergenerational care situations (cluster 2: Pearson'  $r = -.13$ ). Otherwise, these effects can be detected and they are very distinct in intra-generational care situations. Married couples, who state that they feel well appreciated in their caregiving role, accordingly feel fewer burden (table 50).

**Table 50: Cluster specific index scores (means) of “negative impact” and “positive value” and the correlation between “negative impact” and “positive value”**

	(1)	(2)	(3)	(4)	(5)	(6)
	Subjective and objective high burden	Subjective and objective high burden, working	wives (women) with subjective a. objective high burden	Husbands (men) with subjective a. objective high burden	Subjective low and objective high burden	Subjective and objective low burden
Negative impact	13,80	14,58	13,22	11,91	8,83	8,92
Positive value	11,94	11,48	12,38	13,22	13,35	13,18
Pearson's corr (neg x pos)	-.28	-.13	-.42	-.56	-.30	-.39

### 6.2.5 Future care

Which are the prospects of family carers' future care work? We collected answers to this question under two possible development scenarios (see table 51 with selected answer options): a) the carer is willing to provide care to the elder in the next year and b) the carer is prepared to consider elder's placement in a care home.

It is important to explore the willingness to expand care if necessary because in many cases this may be necessary in the future. It is a specific German feature that an expansion of care and the related additional burden would most often be accepted only temporarily, i.e. for a limited time. Irrespective of the cared-for relative's condition, most family carers would be willing to consider a placement in a nursing home; care giving (married) couples show the least willingness with less than 50 %. For all the other groups, this alternative ranges highest in the cross-Europe comparison of this study – with the exception of Sweden, where it ranges even much higher.

**Table 51: Future care: % of answers**

Care situation	a) In the next year, are you willing to continue to provide care to ELDER?*	Total	Germany
	b) Would you be prepared to consider ELDERS placement in a care home?***		
Subjective and objective high burden	a) Yes, and I would even increase	37	35
	a) Yes, I would increase for a limited time	14	17
	b) Yes, despite from elder's condition	56	90
Subjective and objective high burden, working	a) Yes, and I would even increase	26	37
	a) Yes, I would increase for a limited time	22	13
	b) Yes, despite from elder's condition	67	95
wives (women) with subjective a. objective high burden	a) Yes, and I would even increase	43	49
	a) Yes, I would increase for a limited time	12	10
	b) Yes, despite from elder's condition	48	79
Husbands (men) with subjective a. objective high burden	a) Yes, and I would even increase	46	69
	a) Yes, I would increase for a limited time	13	4
	b) Yes, despite from elder's condition	44	79
Subjective low and objective high burden	a) Yes, and I would even increase	51	58
	a) Yes, I would increase for a limited time	13	13
	b) Yes, despite from elder's condition	56	95
Subjective and objective low burden	a) Yes, and I would even increase	45	63
	a) Yes, I would increase for a limited time	18	9
	b) Yes, despite from elder's condition	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 from elder's condition" in this table

### 6.3 Discussion

We used a number of information for the description of a care situation to identify different types of arrangements. This has been done on the level of our six core countries. In Germany we found some specific patterns of care situations:

- In all German care situations the caregivers live to a lower extent close to the cared-for (same building) and the cared-for in the Germany sample have more cognitive impairments.
- If the caregiver is working the duration of care is in most of the cases lower than two years.

Between 20 % and 40 % of the caregiver receive informal or formal support if they need it. Whereas the formal support is more concentrated to the health spheres. The largest need for additional support emerged in the emotional sphere. As a group the working women with higher subjective burden have the biggest gap in getting support. Their perceived burden can

also not be compensated if they cope well with their role as a caregiver. But such positive effects are to register for caregiving couples. Reinforcement in terms of more acceptance would consequently reduce the perceived burden in this group. On the other hand would this effect for working women with inter-generational care relations at least not to be due.

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## 7 Service Usage

*Eva Mnich*

### 7.1 Aims of the chapter

For carers in Germany, a broad range of supporting services exists. Although these services most often address primarily the cared-for, it is seen in general as a relief from the burden of the care situation. In this chapter, we will show which services were used by the carers and also by the cared-for. We report their experiences of using services as well as the greatest help and the major access barriers they encountered. We also present results concerning the cost of services. A further focus is on the question why necessary services were not used or why the carer or cared-for stopped using some services. At least effects of service use on the well-being determinants of the carers will be presented.

### 7.2 Methodology used to analyse the data

To investigate the utilisation of services, each of the six research teams prepared a national list of services in addition to the common questionnaire of the baseline study (for a detailed description see chapter 4: *The EUROFAMCARE questionnaire: contents & psychometrics*) to cover the country specific situation. For Germany, we prepared two lists: One with health and social services that are likely to be used by the cared-for (this list covered 44 services), and another one with services that are likely to be used by the carer (this list covered 15 services).

For each service we asked the interviewees if they had used it in the 6 months preceding the interview, if the used services met their own needs or those of the cared-for, if they or the older relative paid for the service and how often they or the cared-for used the service. We also asked if they stopped using a service and the reasons for this and if they never used a service though they or the cared-for need it and the reasons for this as well. We also added questions concerning the greatest helps or the greatest difficulties in accessing services.

### 7.3 Main findings

Most of the cared-for were in need of help or support in domestic affairs and mobility, and also in need of emotional, social and psychological help. The largest amount of necessary support was given by the family carer him/herself, and in every third case they also received help from other informal carers. Family carers and other informal carers were involved twice as frequently as professional services. Especially the emotional, social and psychological needs can serve as an example for this: 90% of the older people had these needs, and in most of the cases the family carer provided this support with help from their informal network. Formal services were less involved in that kind of help, although the need of additional support was relatively high. Another high demand of additional help is found for “financial support”, although the group of older persons that were in need of this support consists, with 34.4%, of only one third of all cared-for.

In contrast to this, the domains of professional services used by elder are predominantly health and personal care. Here, support by family carers and/or other informal helpers was a

little less, and the need for more support was mentioned by approx. 30% of the carers (see table 52).

**Table 52: Spheres of needs of care recipient and informal / formal network**

Spheres of needs of care recipients	OP needing help with these spheres of needs (%)	Need help with these spheres of need and receive it from:				Would like more support with these tasks (%)
		Nobody	Carer	Other informal carers	Formal services	
Health Care	81.4	0.9	80.3	23.4	33.8	28.8
Personal Care	77.3	1.3	83.1	25.4	35.5	31.7
Mobility and transport	92.0	1.1	88.3	33.0	19.6	35.7
Emotional, social, psychological	90.1	0.9	94.0	39.6	13.6	43.1
Domestic	94.3	0.6	86.7	31.4	15.6	32.3
Financial management	78.3	1.4	85.5	22.9	3.8	9.8
Financial support	34.4	8.6	79.0	20.7	-	44.7
Organisational management	73.0	2.3	88.1	21.0	11.6	31.5

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

In Germany, there exist special services offered to the carer and also special services offered to the cared-for.

#### Services for carer

Overall, most of the German carers (77.8%) in our sample did not use any special service for carers in the 6 months preceding the interview (see table 53). If carers utilised services, these were mostly advisory services like medical counselling for carers or counselling on social laws (8.9% and 6.1% of the carers respectively). With regard to these counselling services, the highest satisfaction exists with the local social worker who visits the carer at home (91.7%). But it must be noticed that only 1.2% of the carers used this kind of support. Only a small number of the carers used support in terms of support groups (3.7%) or self help groups (2.8%). Also, training courses for non-professional carers, which are provided by many organisations (e.g. the Alzheimer's Association) in Germany, were not often used by the carers (2.1%). But if they were used, nine out of ten carers were satisfied with this service.

#### Services for older people

Looking at the services used by the cared-for (see table 54) we find a reversed picture. Most of them (91.6%) used at least one service in the 6 months preceding the interviews, and the general practitioner is mentioned by 82.2% of the responders. Specialist doctors and mobile chiropodists were used by about 30%. Every fourth cared-for used nursing services at home,

and the rate of satisfaction is almost 90% compared with nearly 100% related to the other services mentioned before.

All other services played a role for only every fifth older person or even less. Concerning the satisfaction with the services, we find that among the services more often mentioned, counselling on social law reaches a relatively low percentage of 81.5% compared to percentages between 92% and 99% for other Services like the GP or meals on wheels. Only among the less utilised services, we find some with similarly low satisfaction rates that deviate from the normally high level of satisfaction. These are day hospitals (73.3%), respite care (nursing) (75.7%) and logopedia at hospitals or special centres (81.8%).



**Table 54: Services used by cared-for (percentages, frequencies, meets needs, payment, costs) (Sorted by "USE")**

Code	Description of service used by carer	Use		Frequency				Mostly meets needs % of users	Contribution of users to payment of service costs (% of users)			Amount paid in the last 6 month (Euros / total sample)			
		% on total sample	Count	Daily	At least once a week	At least once a month	Less frequently		Completely paid	Partially paid	Not paid				
													Contribution of users to payment of service costs (% of users)		
													Completely paid	Partially paid	Not paid
101	GP	82.2	824	0.4	18.5	56.7	24.5	96.3	5.8	-	94.2	9,355			
103	Specialist doctor	33.0	331	-	12.0	9.5	19.4	97.2	4.5	-	95.5	3,169			
124	Mobile Chiroprapist	29.9	300	0.3	1.0	56.2	42.4	99.3	96	-	4.0	23,627			
104	Nursing at home (home care)	26.5	266	67.1	23.1	5.2	4.8	86.8	49.0	-	51.0	454,720			
127	Care equipment	20.9	210	51.8	3.6	21.7	22.9	98	38.3	-	61.7	26,832			
123	Mobile hairdresser	20.1	202	1.0	3.2	52.6	41.1	99.5	97.0	-	3.0	28,879			
102	Specialist for neurology	16.9	170	-	6.0	11.1	10.8	91.6	7.1	-	92.9	1,239			
135	Physiotherapy at hospital or special centre	15.7	157	1.4	83.8	7.7	7.0	92.3	46.5	-	53.5	12,647			
113	General Hospital	14.2	142	2.2	3.3	4.5	91.0	89.4	40.4	-	59.6	42,873			
139	Domestic help with cooking and cleaning	11.3	113	7.1	82.2	10.7	-	95.5	92.0	-	8.0	69,393			
107	Medical counselling	11.1	111	1.2	7.0	38.4	53.5	95.5	3.6	-	96.4	1,240			
125	Meals on wheels	11.1	111	62.4	33.9	1.8	1.8	98.2	97.3	-	2.7	97,283			
112	Counselling and advice by pastor	10.2	102	1.1	27.7	46.6	24.4	96.0	3.0	-	97.0	620			
136	(Permanent) admission into nursing home	8.5	85	82.1	-	11.5	6.4	93.6	86.9	-	13.1	434,099			
108	Counselling on social law	8.3	83	-	6.0	19.4	74.6	81.5	4.9	-	95.1	1,680			
130	Transport services	8.2	82	-	26.4	31.3	41.2	98.8	72.0	-	28.0	12,016			
128	Telerecue / tele-alarm	5.6	56	-	-	-	-	98.2	78.2	-	21.8	9,726			

Code	Description of service used by carer	Use		Frequency				Mostly meets needs % of users	Contribution of users to payment of service costs (% of users)			Amount paid in the last 6 month (Euros / total sample)
		% on total sample	Count	Daily	At least once a week	At least once a month	Less frequently		Completely paid	Partially paid	Not paid	
	No service used	84										
	At least one service used	919										
	100.0	1,003										
120	Mobile ambulatory rehabilitation at home	5.3	53	-	86.0	12.0	2.0	88.7	73.1	-	26.9	14,493
122	Laundry service	5.0	50	4.3	56.6	30.8	8.7	93.9	76.0	-	24.0	12,253
115	Day care centre (night at home)	4.2	42	14.6	68.3	7.3	9.8	95.2	83.3	-	16.7	103,275
126	Senior citizen lunch programmes	3.9	39	48.6	45.9	5.4	-	97.4	82.1	-	17.9	16,161
132	Private care / nurse	3.9	39	36.1	47.2	11.2	5.6	86.8	84.6	-	15.4	76,478
129	Home modifications / adaptations	3.8	38	4.8	-	4.8	90.5	97.2	67.6	-	32.4	28,785
116	Respite care (nursing)	3.7	37	6.3	-	6.3	87.5	75.7	91.9	-	8.1	106,586
106	Counselling by a community social worker at home	3.2	32	12.5	15.7	28.2	43.8	96.8	29.0	-	71.0	4,835
121	Temporary rehabilitation centre / clinic	3.2	32	3.8	11.5	3.8	80.8	86.7	48.4	-	51.6	4,611
134	Occupational therapy at hospital or special centre	3.2	32	3.2	64.5	19.4	12.9	93.5	46.9	-	53.1	1,671
140	Gardener	3.0	30	-	24.1	62.0	13.8	96.7	96.7	-	3.3	10,559
141	Domestic help with shopping	3.0	30	3.4	68.9	20.6	6.9	100.0	76.7	-	23.3	10,878
109	Counselling on guardianship laws (self-determination) living will or legal guardian	2.6	26	-	10.0	20.0	70.0	92.3	24.0	-	76.0	777
133	Logopedia at hospital or special centre	2.3	23	-	81.8	18.2	-	81.8	34.8	-	65.2	2,819
137	Care attendant at home	2.2	22	14.3	71.4	9.6	4.8	86.4	36.4	-	63.6	6,158
138	Sheltered accommodation	2.2	22	84.2	-	15.8	-	95.2	95.5	-	4.5	72,534
110	Psychosocial counselling	2.1	21	-	42.1	26.4	31.6	85.0	28.6	-	71.4	1,648

Code	Description of service used by carer	Use		Frequency				Mostly meets needs % of users	Contribution of users to payment of service costs (% of users)			Amount paid in the last 6 month (Euros / total sample)
		% on total sample	Count	Daily	At least once a week	At least once a month	Less frequently		Completely paid	Partially paid	Not paid	
	No service used	84										
	At least one service used	919										
		100.0	1,003									
144	Voluntary visiting services at hospital or at home	1.6	16	-	57.2	28.5	14.3	87.5	31.3	-	68.8	324
111	Service and counselling hotlines	1.5	15	-	42.9	14.3	42.9	93.3	20.0	-	80.0	2
114	Day hospital	1.5	15	8.3	25.0	8.3	58.3	73.3	53.3	-	46.7	3371
131	Private home care in co-habitation	1.0	10	50.0	-	40.0	10.0	100.0	50.0	-	50.0	12,070
105	Socio-psychiatric home visiting service by social worker or psychiatrist	0.9	9			50.0	50.0	100.0	-	-	100.0	0
119	Nursing / Home care in order to prevent hospital	0.6	6	40.0	-	-	60.0	66.7	16.7	-	83.3	0
118	Night care at home	0.5	5	75.0	-	-	25.0	100	60.0	-	40.0	14,079
142	Holidays for couples with special care needs	0.5	5	-	-	-	100.0	100.0	80.0	-	20.0	6,590
143	Hospice	0.4	4	50.0	50.0	-	-	100.0	50.0	-	50.0	16,900
117	Night care in an institution (day at home)	0.1	1	100.0	-	-	-	100.0	0	-	100.0	0
	TOTALS											

**Services and care situations**

The use of services may be combined with different care situations. To describe these different situations we developed six different care situations using a cluster analysis approach. The first two groups describe care situations in which carers perceive high objective and subjective burden, and they differ in so far as in the first group the carers are not working. Then we have two situations in which “spouses” care for each other, and they also have subjective and objective high strain. These two groups differ only in the fact that one group consists of caring women and the other group of caring men. Additionally, we found two groups that both mentioned that they can find support if they need it. They differ in the fact that one group has objective strain but no subjective one and the other has relatively low strain both subjectively and objectively (for more information see chapter 6).

We can distinguish the different care situations by the level of dependency of the cared-for and the burden of the carer. According to this the number of services used by the cared-for declines clearly in the sixth clusters. Also, in care situations where higher functional disabilities were mentioned but the burden for the carer was below average (because help is available if the carer needs time off from care), comparatively lower service use is found (cluster 5, mean 3.7) than in other situations with higher functional disabilities.

**Table 55: Total number of services used by the older person and by the carer in contrast to caring situation cluster**

		Care situation (cluster)					
		1	2	3	4	5	6
Total number of services used by elder	F-Test 15.9 P = .000	4.3	4.4	4.8	5.0	3.7	2.5
Total number of services used by carer	F-Test 9.2 P = .000	0.3	0.4	0.6	0.8	0.3	0.1

The highest request of services is found when husbands are the main carers (cluster 4). They mostly request services like specialists for neurology and medical counselling, but also domestic help and care equipment. This wide range of utilised services tends to result in the highest degree of utilisation (mean 5.0) compared to any other care situation. If the carers are wives, they generally use the same services above average. But due to the fact that they claim less services such as domestic care and care equipment, the average total number of services is lower (mean 4.8). It is remarkable that in both of these groups (cluster 3 and 4), specialists of neurology were named in every third case while this service has been mentioned by only 18% of other groups on average (table 55).

The pattern of utilisation in the second care situation (high burden and working) does not show any striking characteristics like in the first group (high burden and not working). The second group utilises services like mobile hairdressers, mobile chiropodist, nursing at home and care equipment more often than the first group. In both groups, averages of more than 4 services were claimed (table 56).

**Table 56: Utilisation of services according to care situations (cared-for)**

Code	Description	Care situations						
		1	2	3	4	5	6	all
1	GP	87.2	92.3	89.6	92.3	89.7	89.8	89.9
3	Specialist doctor	26.8	29.7	44.8	40.4	36.5	40.8	35.5
24	Mobile Chiropodist	43.9	32.9	24.0	23.1	35.9	17.7	30.9
4	Nursing at home (home care)	37.8	31.0	33.6	34.6	22.4	10.2	27.5
27	Care equipment	32.3	26.5	27.2	34.6	14.7	6.1	22.3
23	Mobile hairdresser	25.6	29.0	18.4	23.1	21.2	12.2	21.7
2	Specialist for neurology	15.2	16.1	32.8	32.7	16.0	7.5	18.0
35	Physiotherapy at hospital or special centre	15.9	16.8	23.2	23.1	10.3	15.6	16.5
13	General Hospital	14.6	20.6	13.6	17.3	16.0	10.2	15.3
39	Domestic help with cooking and cleaning	8.5	14.2	10.4	23.1	9.6	13.6	12.0
7	Medical counselling	8.5	9.7	16.8	23.1	9.0	10.9	11.5
25	Meals on wheels	9.1	21.3	4.8	15.4	17.3	5.4	12.1
12	Counselling and advice by pastor	16.5	12.3	8.8	15.4	10.9	4.8	11.1
36	(Permanent) admission into nursing home	10.4	12.3	4.8	7.7	19.2	0.7	9.6
8	Counselling on social law	10.4	11.0	12.8	13.5	5.1	7.5	9.5
30	Transport services	9.8	7.1	13.6	5.8	10.3	7.5	9.3
28	Telerescue / tele-alarm	7.3	7.7	4.0	1.9	5.1	4.8	5.6
20	Mobile ambulatory rehabilitation at home	4.9	3.9	14.4	9.6	2.6	0.7	5.3
22	Laundry service	6.1	7.1	1.6	9.6	5.8	5.4	5.6
Cases		164	155	125	52	156	147	799

(%; only service user and services that are mentioned at least by more than 50 cases)

Services that support carers were especially in demand in those constellations (cluster 4) where care was given and received by persons of the same generation, that means also that the mean age of persons in this cluster is higher. In the fifth group, the objective burdens (impairments of the cared-for) are likely to be higher, while the subjective burdens of the carer are likely to be lower. Still, the carers used, on average, the same number of services as those from the first two groups in which both the objective and the subjective burdens of caring are above average.

The table of the utilisation of special services for carers (mentioned by at least 30 carers) in the different care situations reveals that medical counselling was predominantly used in all groups. Another focal point is the counselling on social laws; caring husbands (cluster 4) asked for this kind of service comparatively more often. Caring wives (cluster 3), on the other hand, constitute the clientele for self help groups, as half of the nominations origin from this type of care situation (table 57).

**Table 57: Utilisation of services differentiated by care situation (carer)**

Code	Description	Care situations						
		1	2	3	4	5	6	all
206	Medical counselling for carer	43.8	40.5	40.5	55.6	55.6	63.6	46.7
207	Counselling on social laws	34.4	27.0	31.0	61.1	22.2	27.3	32.2
205	Special services for counselling on care, social laws etc.)	21.9	27.0	23.8	22.2	18.5	36.4	24.0
201	Support group for family carers	25.0	16.2	21.4	33.3	18.5	18.2	21.6
212	Internet (Information about the disease, caring etc.)	9.4	21.6	11.9	-	25.9	9.1	14.4
202	Self help group	6.3	8.1	28.6	-	3.7	9.1	11.4
Cases		32	37	42	18	27	11	167

(%; only service user and services that are mentioned at least by more than 25 cases)

### 7.3.2 Do these services reach the person in need of support?

Considering only the indicators of care situations that deal with functional or behavioural problems of the older person (table 58), the demand for services corresponds with the disabilities of the older person. A person, who requires the services of a general practitioner, has more functional impairments. For all other necessary services we found that the frequency of service utilisation increased with the older person's increased dependency on help – with the exception of specialist doctors and physiotherapy at hospital. This general correlation is fewer true for some services that are less care related, such as domestic help, tel-erescue or transportation services.

**Table 58: The use of services by the older people and their carers and physical and psychological efficiency of the cared-for**

Code	Description	Worse functional IADL-ability	Worse efficiency of the cognitive sphere
<b>Services for elder</b>			
1	GP	↑***	↔
3	Specialist doctor	↔	↓*
24	Mobile Chiropractist	↑***	↑*
4	Nursing at home (home care)	↑***	↑**
27	Care equipment	↑***	↔
23	Mobile hairdresser	↑***	↔
2	Specialist for neurology	↑***	↑**
35	Physiotherapy at hospital or special centre	↔	↑**
13	General Hospital	↑*	↔
39	Domestic help with cooking and cleaning	↔	↔
7	Medical counselling	↔	↔
25	Meals on wheels	↑**	↑**
12	Counselling and advice by pastor	↑**	↔
36	(Permanent) admission into nursing home	↑***	↑*
8	Counselling on social law	↔	↔
30	Transport services	↔	↔
28	Telerecue / tele-alarm	↔	↔
20	Mobile ambulatory rehabilitation at home	↑**	↔
22	Laundry service	↔	↑**
<b>Services for carers</b>			
206	Medical counselling for carer	↔	↑*
207	Counselling on social laws	↑**	↑*
205	Special services for counselling on care, social laws etc.)	↑**	↑*
201	Support group for family carers	↑*	↑*
212	Internet (Information about the disease, caring etc.)	↑*	↑**
202	Self help group	↔	↔

Services that have a direct reference to medicine are generally more often used in case of functional impairments. In case of cognitive problems, utilisation preferences hardly differ, but the focus of use is less pronounced. Rather independent of the voiced need of the cared-for is the utilisation of medical counselling and the use of support in the area of housekeeping.

The degree of utilisation of almost all services for carers (exception: self-help groups) is directly related to the degree of impairment of the cared-for, i.e. the higher the degree of impairment the more services are used. In general, the utilisation of services usually corresponds with a higher need for support. This is especially true for services that address the needs of the carer.

When using the specific needs of carers as a basis, the question arises to which extent the corresponding services are claimed. Medically orientated offers generally meet an increased demand of the cared-for for personal and medical help and support.

In cases of limited mobility, however, it can be noticed that transport services were not used more often and that such services were apparently not utilised in a manner that meets the needs of the elder. A similar discrepancy also exists with regard to housekeeping orientated services and with "meals on wheels", as their demand is not dependent on the degree of need. Especially the "household help" is not correlated with any of the areas of need.

Almost all services were used more often if the organisation of care was a major problem. An increased demand is reflected by an increased utilisation of different services. However, in the field of support for the social/emotional stability of the cared-for, only little concentration on certain services can be found. For this comparatively important area – because it is in such high demand – no specific services could establish themselves yet.

The situation of services for carers is as follows: Counselling services were generally used more often in care situations with an increased demand for care and an increased demand for financial and organisational help. The Internet is to be included here as well. Self-help groups for carers do not show a correlation with specific needs of the cared-for, which was to be expected (table 59).

**Table 59: Comparison of the frequency of used services fulfilling particular areas of the older person's needs among older persons with and without need in the area of a given sphere of needs**

Sphere of needs	Elder services / Carer Services	Code	Description	
Health needs	Elder services:	1	GP	↑***
		24	Mobile Chiropodist	↑***
		4	Nursing at home (home care)	↑***
		27	Care equipment	↑***
		23	Mobile hairdresser	↑***
		2	Specialist for neurology	↑***
		13	General Hospital	↑**
		7	Medical counselling	↑**
		12	Counselling and advice by pastor	↑**
		36	(Permanent) admission into nursing home	↑***
		30	Transport services	↑*
		28	Telerecue / tele-alarm	↑*
		20	Mobile ambulatory rehabilitation at home	↑**
	22	Laundry service	↑**	
		Carer Services:	6	Medical counselling for carer
7			Counselling on social laws	↑***
12			Internet (Information about the disease, caring etc.)	↑*

Sphere of needs	Elder services / Carer Services	Code	Description	
Physical / Personal needs	Elder services:	1	GP	↑**
		24	Mobile Chiropodist	↑***
		4	Nursing at home (home care)	↑***
		27	Care equipment	↑***
		23	Mobile hairdresser	↑***
		2	Specialist for neurology	↑***
		35	Physiotherapy at hospital or special centre	↑*
		25	Meals on wheels	↑**
		12	Counselling and advice by pastor	↑***
		36	(Permanent) admission into nursing home	↑*
		28	Telerescue / tele-alarm	↑*
	20	Mobile ambulatory rehabilitation at home	↑*	
	Carer Services:	7	Counselling on social laws	↑***
		5	Special services for counselling on care, social laws etc.)	↑*
1		Support group for family carers	↑*	
2		Self help group	↑**	
Mobility	Elder Services:	24	Mobile Chiropodist	↑*
		4	Nursing at home (home care)	↑***
		27	Care equipment	↑***
		35	Physiotherapy at hospital or special centre	↑*
		12	Counselling and advice by pastor	↑*
Emotional / Psychological / social Needs	Elder Services:	4	Nursing at home (home care)	↑*
		27	Care equipment	↑***
		23	Mobile hairdresser	↑**
		36	(Permanent) admission into nursing home	↑*
	Carer Services:	7	Counselling on social laws	↑*
		2	Self help group	↓*
Domestic needs	Elder Services:	1	GP	↑***
		24	Mobile Chiropodist	↑**
		4	Nursing at home (home care)	↑*
		27	Care equipment	↑***
		36	(Permanent) admission into nursing home	↓**

Sphere of needs	Elder services / Carer Services	Code	Description	
Financial management	Elder Services	1	GP	↑**
		24	Mobile Chiropodist	↑***
		4	Nursing at home (home care)	↑***
		27	Care equipment	↑***
		23	Mobile hairdresser	↑***
		2	Specialist for neurology	↑**
		12	Counselling and advice by pastor	↑***
		36	(Permanent) admission into nursing home	↑***
		8	Counselling on social law	↑*
		28	Telerescue / tele-alarm	↑**
	22	Laundry service	↑*	
	Carer Services:	6	Medical counselling for carer	↑*
		7	Counselling on social laws	↑***
		1	Support group for family carers	↑*
12		Internet (Information about the disease, caring etc.)	↑**	
Financial support	Elder Services:	4	Nursing at home (home care)	↑***
		27	Care equipment	↑**
		12	Counselling and advice by pastor	↑***
		36	(Permanent) admission into nursing home	↑***
Organising and managing care	Elder Services:	1	GP	↑***
		24	Mobile Chiropodist	↑***
		4	Nursing at home (home care)	↑***
		27	Care equipment	↑***
		23	Mobile hairdresser	↑***
		2	Specialist for neurology	↑**
		35	Physiotherapy at hospital or special centre	↑**
		13	General Hospital	↑*
		7	Medical counselling	↑***
		25	Meals on wheels	↑**
		12	Counselling and advice by pastor	↑**
		36	(Permanent) admission into nursing home	↑***
		8	Counselling on social law	↑*
		30	Transport services	↑**
		28	Telerescue / tele-alarm	↑**
		20	Mobile ambulatory rehabilitation at home	↑***
	22	Laundry service	↑*	
	Carer Services:	6	Medical counselling for carer	↑*
		7	Counselling on social laws	↑***
		5	Special services for counselling on care, social laws etc.)	↑*
1		Support group for family carers	↑*	
12		Internet (Information about the disease, caring etc.)	↑**	

### 7.3.3 Family carers' experiences of service utilisation

#### 7.3.3.1 Cost of services

Most of the carers who used services in the last six months did not pay for these services. A small group of 9.2% paid less than 20 Euros per month and another small group (10.2%) paid more than 20 Euros per month. The overall expenses borne by the German carer to cover the costs of services they have used during the last six months preceding the interview account to 18,226 Euros (see table 60). The highest part of that accounted for services like supervision of the older person a few hours a day (69.9%), support groups for family carers (11.1%) and self-help groups (7.9%). The services most used were counselling related to the care situations, for which the carer only rarely had to pay.

**Table 60: Costs of services used by carers during the last 6 months (Euro)**

	Frequency	%	valid %
no costs by users	158	15.8	80.6
from 1 to 120 (up to 20 per month)	18	1.8	9.2
more than 121	20	2.0	10.2
Total	196	19.5	100.0
Does not use services or missing	807	80.5	
Total	1003	100.0	
Mean value 479.63 (SD ± 1,028.73)			

As to the cared-for, slightly more than one third did not pay for the services they used in the six months preceding the interviews, and another group paid only low sums (11.3%), namely less than 20 Euros a month. On the other hand, we found 20.1% of cared-for who paid up to 500 Euros per month and 15.7% who paid more than 500 Euros per month. The overall expenses borne by the cared-for during the six months preceding the interviews add up to 1,757,255 Euros (see table 61).

The highest rates are the costs for home care (25.9%, approx. 450,000 Euros) and for the (permanent admission into a) nursing home (24.7%, 435,000 Euros). In each case, approx. 100,000 Euros were paid for meals on wheels, day care centres and respite care (nursing). About 50,000 Euros per service were paid for domestic help, private care/nurse and sheltered accommodations. Overall, the expenses for these kinds of services account for about 80% of the total expenditure.

**Table 61: Costs of services used by the cared-for during the last 6 months**

	Frequency	%	valid %
no costs by users	316	31.5	34.6
from 1 to 120 (up to Euro 20 per month)	103	10.3	11.3
from 121 to 300 (up to Euro 50 per month)	77	7.7	8.4
from 301 to 600 (up to Euro 100 per month)	90	9.0	9.9
from 601 to 3,000 (up to Euro 500 per month)	183	18.2	20.1
from 3,001 to highest (more than Euro 500 per month)	143	14.3	15.7
Total	912	90.9	100.0
Does not use services or missing	91	9.1	
Total	1,003	100.0	
Mean value 2,948.42 (SD ± 10,272.23)			

### 7.3.3.2 Experiences in accessing services

We also asked the carers about the most important sources of help for accessing services. This question was phrased openly and was then post-coded on the basis of the most frequent typology of answers.

The carers think that medical and nursing professionals provided the greatest help in accessing services (table 62). This is the case when the first answer listed is taken into account and also when all three most relevant categories are considered (43.4% and 56.1%). This could be due to the fact that the carers and the older persons have contact predominantly with these institutions. The informal network of the carer seems to be also a relevant help when he needs to access services. 11.8% mentioned family, friends and neighbours in the first answer, and 23.4% mentioned them when all three relevant categories are considered. Health and social insurances play a minor part (5.1% and 11.4%). All other possible categories of services that could provide help are mentioned by less than 10% of the interviewed carers. But it is worth adding that different sources of information like social services, mass media or religious organisations can reach between 5 and 10% of the carers.

**Table 62: Greatest help in accessing services / support**

	First listed		On the whole	
	%	Count	%	Count
1 medical / nursing professionals	43.4	396	56.1	512
4 family, friends and neighbours	11.8	108	23.4	214
16 no one, nothing	6.7	61	6.9	63
12 carer's personal experience and knowledge	6.4	58	7.9	72
17 other	6.0	55	10.0	91
8 health and social insurance	5.1	47	11.4	104
15 don't know, never tried to access services	5.0	46	5.0	46
2 social services	4.4	40	7.2	66
6 NGOs, voluntary organisations, support groups	2.7	25	4.1	37
9 counselling agencies, centre of information	2.6	24	3.4	31
10 information / advertisement in mass media, leaflets	2.5	23	6.2	57
5 religious organisations	2.0	18	5.6	51
3 local authorities	0.7	6	2.0	18
11 financial resources / savings	0.2	2	0.2	2
13 good transports	0.2	2	0.2	2
7 trade unions, workers organisations	0.1	1	0.1	1
14 availability of services nearby	0.1	1	0.1	1
TOTALS				

Furthermore, we asked the carers about the most important barriers or difficulties in accessing services. Again, they could give three answers that we post-coded on the basis of the most frequent types of answers.

It is interesting to see that according to a large group of carers (40.1%) no barriers or difficulties in accessing services existed (table 63). Bureaucratic or complicated procedures seemed to be a problem for 14.2% and 18.6% respectively of the carers, and lack of information (4.6% and 6.9% respectively) was obviously a barrier in accessing services. Apparently, problems of information about available services were only relevant in some exceptional cases. Lack of acceptance from the cared-for (less than 5%), poor quality of services (2.1%) or other barriers like distance or a general undersupply of services are playing a minor role.

The category "other" is very large with 31.2%. This is because German responders often mentioned typical German institutions that cannot be assigned to other categories. These are, for example, the medical service of the health insurances and the health insurance providers themselves.

**Table 63: Difficulties in accessing services / support**

	First listed		On the whole	
	%	Count	%	Count
14 no one, nothing	40.1	304	40.1	304
16 other	25.3	192	31.2	237
7 bureaucratic / complicated procedures	14.2	108	18.6	141
6 lack of information concerning existence / access to service	4.6	35	6.9	52
1 financial / economic reasons, high costs	4.1	31	8.2	62
15 don't know, never tried to access services	3.6	27	3.7	28
11 not accepted by the elderly	3.2	24	4.6	35
12 poor quality of services	1.7	13	2.1	16
10 restricted acceptance criteria	1.3	10	1.8	14
4 few available services (with no other specification)	0.4	3	1.1	8
8 fixed / inflexible time schedules from the service side	0.4	3	0.7	5
9 distance	0.4	3	1.6	12
5 long waiting lists	0.3	2	0.5	4
13 architectural barriers	0.3	2	0.4	3
2 few available home services	0.1	1	0.1	1
3 few available 24-hours a day services	0.1	1	0.1	1
TOTALS				

### 7.3.3.3 Reasons for stopping utilising needed services

12% of our responders had stopped using a service (tables 64 and 65). The relevant categories are very diverse, and we only found some accumulation in health services (nursing at home and physiotherapy at hospital) and also for meals on wheels. For the latter and for nursing at home, the carers named as reasons for stopping the use that these services were too expensive or that the quality was low. For all other services that were no longer used, the financial aspect was mentioned most often.

**Table 64: Are there any services that you or ELDER need that you have stopped using?**

Answer	Absolute value	%
0 no	883	88.1
1 yes	119	11.9
Total	1,002	100.0

**Table 65: Services stopped using and reasons (absolute value, multiple answers possible)**

Code	Description of Service	%	Count	Expensive	Distant	Low quality	Not available	Not entitled to use
104	Nursing at home (home care)	16.0	29	14	1	9		2
135	Physiotherapy at hospital or special centre	11.0	20	5		1	5	5
125	Meals on wheels	7.2	13	7		7		
134	Occupational therapy at hospital or special centre	5.0	9	2		1	1	5
115	Day care centre (night at home)	4.4	8	1	1	2		
132	Private care / nurse	4.4	8	6		1	2	
133	Logopedia at hospital or special centre	4.4	8	1			2	1
139	Domestic help with cooking and cleaning	3.3	6	3		1	1	1
120	Mobile ambulatory rehabilitation at home	2.8	5	1		1	2	1
124	Mobile Chiropodist	2.8	5	5				
121	Temporary rehabilitation centre / clinic	2.2	4	3				2
123	Mobile hairdresser	2.2	4	3				
130	Transport services	2.2	4	2	1		1	
136	(Permanent) admission into nursing home	2.2	4	4		1		
142	Holiday for couples with special care needs	2.2	4	2				2
144	Voluntary visiting services at hospital or at home	2.2	4		1		1	
202	Self help group	2.2	4	1	1			
102	Specialist for neurology	1.7	3		1	1		
114	Day hospital	1.7	3	1				1
116	Respite care (nursing)	1.7	3	2				
122	Laundry service	1.7	3	3		2		
141	Domestic help with shopping	1.7	3	1		1		
101	GP	1.1	2	1				
107	Medical counselling	1.1	2			1	1	1
111	Service and counselling hotlines	1.1	2	1		1		
118	Night care at home	1.1	2	1				
119	Nursing / Home care in order to prevent hospital	1.1	2	1				1
126	Senior citizen lunch programmes	1.1	2	1		1		
127	Care equipment	1.1	2				1	
137	Care attendant at home	1.1	2					
206	Medical counselling for carer	1.1	2	1				
208	Counselling on guardianship laws (self-determination) living will or legal guardian	1.1	2					1

Code	Description of Service	%	Count	Expensive	Distant	Low quality	Not available	Not entitled to use
103	Specialist Doctor	0.6	1	1				
108	Counselling on social law	0.6	1			1		
109	Counselling on guardianship laws (self determination) living will or legal guardian	0.6	1		1			
110	Psychosocial counselling	0.6	1					1
131	Private home care in cohabitation	0.6	1	1				
201	Support group for family carers	0.6	1				1	
209	Psychosocial counselling	0.6	1	1				
	N =	100.0	119					

Every fourth carer mentioned that he/she or the cared-for had never used any service even though they needed it (table 66 and 67). Asked for the reasons, most carers pointed out the high costs. As second most important reason they stated that information about the services did not exist. The list of services needed is quite long and the focal points are on both care-related services and domestic help services. For some services, the responders mentioned a lack of information more often than other reasons. This relates to services like holidays for couples, voluntary visiting services at hospital or at home, mobile chiropodist, care attendant and psychosocial counselling. The common characteristic of these services (except for the mobile chiropodist) is that they have been little used, even by those who accessed services.

**Table 66: Are there any services that you or ELDER need but have not used so far?**

Answer	Absolute value	%
0 no	735	73.4
1 yes	266	26.6
Total	1,001	100.0

**Table 67: Services that are not used and reasons (% , multiple answers possible)**

Code	Description of Service	%	Count	Expensive	Distant	Low quality	Not available	Not entitled to use
139	Domestic help with cooking and cleaning	6.5	32	21		2	3	3
104	Nursing at home (home care)	5.7	28	12	1	4	5	4
116	Respite care (nursing)	5.1	25	6	1	4	3	2
125	Meals on wheels	3.8	19	9	1	5	1	2
135	Physiotherapy at hospital or special centre	3.8	19	6	1			5
132	Private care / nurse	3.6	18	15				2
115	Day care centre (night at home)	3.4	17	5	2	2	2	
141	Domestic help with shopping	3.4	17	7	2	1	5	2

Code	Description of Service	%	Count	Expensive	Distant	Low quality	Not available	Not entitled to use
142	Holiday for couples with special care needs	3.4	17	4	3		9	
128	Telerescue / tele-alarm	3.2	16	5			3	2
130	Transport services	3.2	16	6			5	5
144	Voluntary visiting services at hospital or at home	3.2	16	2	2		7	3
124	Mobile Chiropodist	3.0	15	4			6	2
120	Mobile ambulatory rehabilitation at home	2.6	13	5	2		3	4
121	Temporary rehabilitation centre / clinic	2.2	11	2		1	3	2
136	(Permanent) admission into nursing home	2.2	11	4			2	3
127	Care equipment	2.0	10	3			3	1
129	Home modifications / adaptations	2.0	10	4			3	1
134	Occupational therapy at hospital or special centre	2.0	10	5	2			3
137	Care attendant at home	2.0	10				4	2
110	Psychosocial counselling	1.8	9		2		4	
209	Psychosocial counselling	1.8	9				5	2
123	Mobile hairdresser	1.6	8	1		1	2	1
133	Logopedia at hospital or special centre	1.6	8			1	1	2
122	Laundry service	1.4	7	3			4	
126	Senior citizen lunch programmes	1.4	7	1		1	1	3
138	Sheltered accommodation	1.4	7	1	1	1	2	
201	Support group for family carers	1.4	7		1		4	
108	Counselling on social law	1.2	6			1	4	
112	Counselling and advice by pastor	1.2	6					
118	Night care at home	1.2	6	1			2	2
203	Training courses for non-professional carers	1.2	6		2		1	
206	Medical counselling for carer	1.1	2	1				
106	Counselling by a community social worker at home	1.0	5				4	
107	Medical counselling	1.0	5			3	2	
109	Counselling on guardianship laws (self determination) living will or legal guardian	1.0	5				3	
114	Day hospital	1.0	5	1		1		
131	Private home care in cohabitation	0.8	4	4				
140	Gardener	0.8	4	3			1	1
207	Counselling on social laws	0.8	4		1		2	1
208	Counselling on guardianship laws (self-determination) living will or legal guardian	0.8	4		1		3	
102	Specialist for neurology	0.6	3	1				1

Code	Description of Service	%	Count	Expensive	Distant	Low quality	Not available	Not entitled to use
103	Specialist Doctor	0.6	3	1				1
202	Self help group	0.6	3				1	
210	Counselling by a social worker at home	0.6	3	1			2	
105	Socio-psychiatric home visiting by social worker or psychiatrist	0.4	2				1	
111	Service and counselling hotlines	0.4	2				2	
119	Nursing / Home care in order to prevent hospital	0.4	2				1	1
101	GP	0.2	1					
113	General Hospital	0.2	1					
117	Night care in an institution (day at home)	0.2	1					1
	TOTALS	100.0	266					

#### 7.3.3.4 Reasons for not accessing formal services

As an answer to the general question about not using services and support, most of the carers mentioned the high cost as a restraint (table 68). But a more diffuse and normative attitude against using services is also very significant and might have a strong impact on whether a carer or cared-for person decided to use a service or not. In Germany, we have a general discussion about the comparatively slow development of a so called “service society”, which means that reservation against service use is generally quite high. The German mentality puts up a higher barrier to using services than exists in other countries. This general tendency might be most apparent when it comes to using services whose degree of intimacy is higher and whose personal character is more pronounced.

**Table 68: Reasons for not accessing services**

	First listed		On the whole	
	%	Count	%	count
8 not needed	61.2	211	67.0	231
1 financial reasons, high costs	13.9	48	22.3	77
10 social / attitudinal reasons by elderly or carer	13.9	48	25.8	89
13 other	4.6	16	10.1	35
6 lack of knowl-edge / information	2.9	10	5.2	18
7 no right to use	1.4	5	2.0	7
9 not available	0.6	2	1.7	6
12 complicated bureaucratic procedures	0.6	2	1.4	5
2 difficult access, mobility problems, barriers	0.3	1	0.3	1
4 lack of trust to service workers or service providers	0.3	1	2.0	7
5 long waiting lists	0.3	1	0.3	1
3 poor quality of services	0	0	2.6	9
11 distance	0	0	0.6	2

### 7.3.4 Where can such services (measures) be found?

The regional distribution reveals almost no emphasis of service utilisation. Services for carers, however, decline from the north to the south and metropolitan areas offer more services for the cared-for (table 69).

**Table 69: Service use by regions**

		Region			
		North	South	East	West
Total number of services used by elder	<b>F-Test 2.213</b> <b>P = .085</b>	4.32	3.84	4.26	4.11
Total number of services used by carer	<b>F-Test 7.440</b> <b>P = .000</b>	0.55	0.29	0.39	0.39

**Table 70: Service use by settlement area**

		Settlement area		
		Metropoli-tan	Urban	Rural
Total number of services used by elder	<b>F-Test 10.068</b> <b>P = .000</b>	4.66	3.71	4.10
Total number of services used by carer	<b>F-Test .449</b> <b>P = .638</b>	0.43	0.37	0.39

For individual services, expected distribution patterns regarding urban and rural regions exist (table 70). Specialist doctors and self-help groups are concentrated in densely populated areas. In rural areas, however, priests are more important than counsellors and the demand for mobile hairdressers is higher as well.

The low degree of service utilization in medium-sized German cities is remarkable. This refers to neurologists (whose domain are large cities), nursing at home and services for care equipment. The low degree of utilization reflects the availability of such services in medium-sized cities, where the demand exceeds the availability.

In Southern Germany, specialists (specialist doctors, neurologists) are consulted less, but priests are consulted more often in these regions, where religion plays a greater part, as it does in the west of Germany as well. In Eastern Germany, meals on wheels is used more often than in other areas. In Northern Germany, mobile ambulatory rehabilitation is claimed more often and special services for carers are used more often than in other regions (table 71).

**Table 71: Service use by settlement areas and regions**

Code	Service	Settlement area			
		Metropolitan	Urban	Rural	
<b>Elder</b>					
3	Specialist doctor	39	31	28	
4	Nursing at home (home care)	33	21	29	
27	Care equipment	25	17	23	
23	Mobile hairdresser	19	18	26	
2	Specialist for neurology	26	11	15	
12	Pastor	8	9	15	
<b>Carer</b>					
2	Self help group	6	2	0	
Code	Service	Region			
		North	South	East	West
<b>Elder</b>					
3	Specialist doctor	36	24	34	36
2	Specialist for neurology	23	10	16	13
25	Meals on wheels	8	11	20	7
12	Pastor	7	18	8	12
20	Mobile ambulatory rehabilitation at home	10	3	1	4
22	Laundry service	3	5	9	5
<b>Carer</b>					
6	Medical counselling for carer	12	7	8	5
7	Counselling on social laws	8	5	7	5
2	Self help group	6	0	2	2

### 7.3.5 Effects of service use on the well-being determinants of the carers

To analyse the question of effects, we used a regression analysis on different variables that could describe the negative impact of the care situation. In a second step, we add the use of services for the older persons, and only the determinants of the first step will remain in the regression model.

In the regression model, the determinant for the situation of older people and carer contributes in about the same way to the negative impact as in the original model. The influences of service use of interest here is the additionally voiced need "services that are needed but not

used so far." Under these circumstances the burden of the older person tends to increase. The same is true if the number of services used by the older people increases (table 72).

The relieving effect of a specific service can now be displayed if it is added individually to the regression model in the next step. Low relieving effects (measured with "beta-in") can arise by using specialist doctors, mobile chiropodists and (permanent admission to a) nursing home. Adverse effects can occur if nursing at home or mobile ambulatory rehabilitation at home is required. Regarding services for carers no such effects can be noticed in the regression model.

**Table 72: Regression for negative impact on relevant variables of the care situation and significant services for elder**

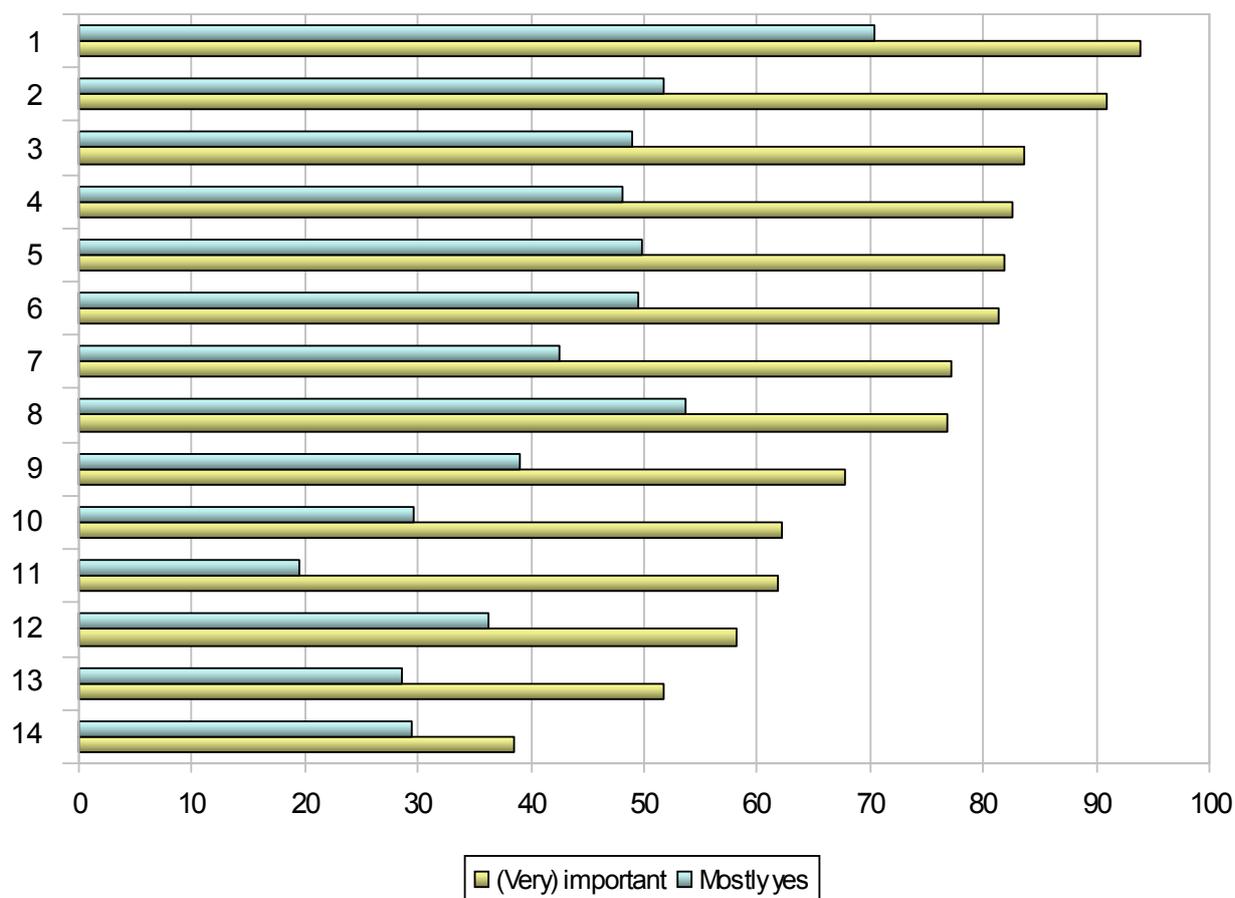
<b>MODEL 1:</b>		<b>all variables</b>	<b>reduced model</b>
	R sqr.	.319	.319
	R sqr. adjusted	.285	.313
		beta	beta
<b>Elder Demographics</b>			
E17AGE_R	elder's age recoded (0-65-79; 1-80+)	n.s.	
E23ALONE	elder lives alone	n.s.	
<b>Carer Demographics</b>			
G4LOCAR	Locality type dichotomized (0-not urban; 1-urban)	n.s.	
WORK_R	working condition dichotomized (0-non working; 1-working)	n.s.	
C21_RR	cohabitation recoded (0-different houses; 1-same house)	n.s.	
<b>Elder care needs</b>			
BARTHTOT	elder total score BARTHEL INDEX	-.17 **	-.14 ***
IADL_TOT	elder IADL total score	n.s.	
BEHAV_PR	elder behavioural problem	.24 ***	.21 ***
E35MEM1	has elder any memory problems (1-yes; 0-no)	n.s.	
E27A_R	health need recoded (0-no need; 1-need)	n.s.	
E28A_R	physical / personal need recoded (0-no need; 1-need)	n.s.	
E29A_R	mobility need recoded (0-no need; 1-need)	n.s.	
E31A_R	domestic help need recoded (0-no need; 1-need)	n.s.	
E33A_RR	financial support need recoded (0-no need; 1-need)	n.s.	
TOT_NEED	Total number of needs for which elder needs help	.21 *	.14 ***
<b>Situation of the carer</b>			
C11NUMEL	number of elderly people cared for by the caregiver	n.s.	
C12HOUR	average number of hours of care for the elder in a week	n.s.	
C13NUMO	number of other non elderly people cared for by the caregiver	n.s.	
C77FAC8	I found myself caring by chance without making a decision (1-yes; 0-no)	.08 *	.10 ***
C68_R	„If you were ill is there anybody stepping in to help with elder?“ recoded (1-yes; 0-no)	.18 **	.22 ***
C69_R	„If you needed a break there would be any- body looking after elder?“ recoded (1-yes; 0-no)	n.s.	

<b>Service use by carer / elder</b>			
S120NOUS	“Are there any services that you / Elder need but you have not used so far?” (1=yes; 0=no)	.13 **	.13 ***
S151CHAB	help provided is not too expensive- currently met (1=yes; 0=no)	n.s.	
NEEDS_S	number of needs covered by services or other organizations	n.s.	
TOT_SE	total number of services used by elder	.11 **	.10 ***
TOT_SC	total number of services used by carer	-.08 *	n.s.
<b>MODEL 2 – reduced model as above and:</b>		<b>stepwise beta in</b>	
se3ar	Specialist doctor		-.07 *
se24ar	Mobile chiropractist		-.08 **
se4ar	Nursing at home (-)		.09 **
se36ar	(Permanent) admission into nursing home		-.08 **
se20ar	Mobile ambulatory rehabilitation at home		.02 *

### 7.3.6 Kind of support and service characteristics

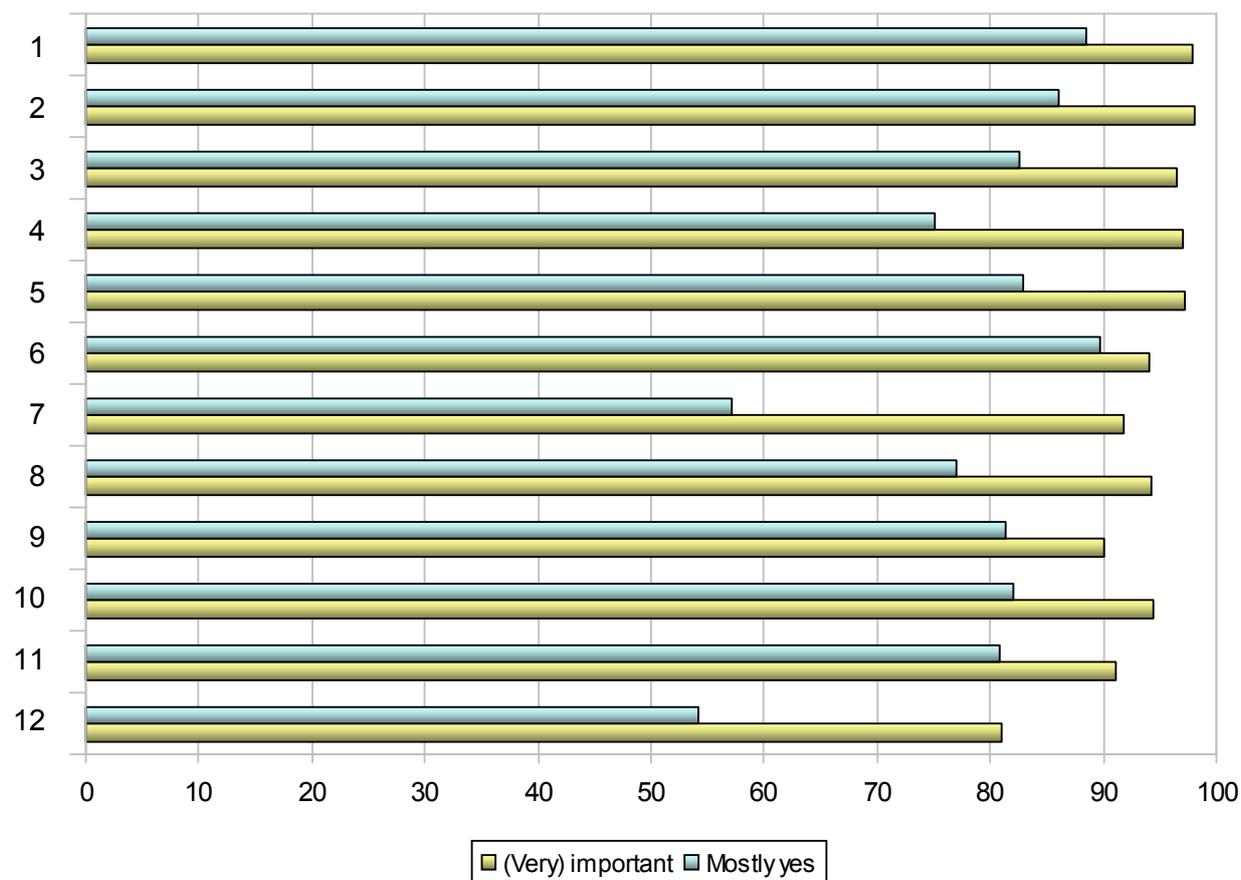
The following two overviews will contrast the preferences for specific service characteristics to the saturation rates. The latter means that a service is offered and that the specific performance is satisfying. This procedure allows to establishing an overview of the areas with the greatest needs.

The carers particularly appreciate information on caring activities and opportunities of temporary relief, which could be respite from care but also offers for common activities with the cared-for relative (always >75%). The greatest discrepancies to available offers exist in the field of temporary relief: Only every second carer has sufficient access to these offers. But deficits are also revealed by the questions related to information on available offers, which would make care planning easier in a broader sense. Similar gaps are reported for care and nursing training and for care related financial supports (figure 6).

**Figure 6: Kind of support**

1. "Information about the disease ELDER has."
2. "Information and advice about the type of help and support that is available and how to access it."
3. "Opportunities for ELDER to undertake activities they enjoy."
4. "Opportunities to have a holiday or take a break from caring."
5. "Opportunities to spend more time with my family."
6. "Opportunities to enjoy activities outside of caring."
7. "Help with planning for the future care."
8. "The opportunity to talk over my problems as a carer."
9. "The possibility to combine care giving with paid employment."
10. "Training to help me develop the skills I need to care."
11. "More money to help provide things I need to give good care."
12. "Help to make ELDER's environment more suitable for caring."
13. "Help to deal with family disagreements."
14. "Opportunities to attend a carer support group."

The assessment of service offers in terms of important criteria is more positive in general. Ten out of twelve criteria were assessed as quite satisfying by 75% or more. Only for cost related criteria, these high marks cannot be reached (about 55% of satisfaction), and, likewise, only 55% of the interviewees can count on being attended by the same person of the professional staff, although at least 80% consider this to be an important criterion.

**Figure 7: Service characteristics**

1. "Care workers treat ELDER with dignity and respect."
2. "The help provided improves the quality of life of ELDER."
3. "Care workers have the skills and training they require."
4. "Help is available at the time you need it most."
5. "Help arrives at the time it is promised."
6. "Care workers treat you with dignity and respect."
7. "The help provided is not too expensive."
8. "Help focuses on your needs as well as those of ELDER."
9. "The help provided improves your quality of life."
10. "Your views and opinions are listened to."
11. "The help provided fits in your routines."
12. "Help is provided by the same care worker each time."

## 7.4 Discussion

In nine out of ten cases, services for the cared-for relative are utilised. In the medical field, this corresponds to a large degree with the needs resulting from the older person's limitations. In the field of housekeeping services, this relationship between increased need and increased utilisation does not exist.

Services for family carers are utilised by slightly more than 20%. Caring husbands develop the greatest degree of utilisation, caring wives concentrate on self-help groups.

In the field of emotional/psychological or social support, there is a marked service gap. Since only few offers can be claimed, more than 40% of the interviewees wish to have additional support in this field. The existing service offers apparently focus on organisational problems that carers might encounter.

In general, information on service offers can be accessed through members of the medical system. In about 10% of cases, the informal network provided information. There are many barriers to service utilisation, but in many cases, they are cost related (in rare cases information deficits, long ways or quality problems). In addition, there is a German-specific reservation with respect to “strangers” meddling in one’s household.

When analysing the relief potential of services, services involving short home visits seem to bring the greatest relief to family carers. Nursing at home or mobile ambulatory rehabilitation at home are, on the other hand, examples for services that do not seem to have relief effects on the cared-for. Nevertheless, family carers expect the greatest support/relief by being able to escape the everyday routine of caring by pursuing special activities, either alone or together with the cared-for.

## 8 Evaluation of the German supplementary questions related to the long-term care insurance<sup>11</sup>

*Kay Seidl, Hanneli Döhner*

### 8.1 Introduction

The social security system of Germany is based on six main pillars:

- Old-age pension insurance
- Unemployment insurance
- Health care insurance
- Accident insurance
- Long-term care insurance
- Social assistance (taxes)

The main pillar of the social insurance in Germany relevant for the care for older persons and family carers is the long-term care insurance (LTCI). Therefore this chapter starts with a short description of the main aspects of the LTCI (section 8.2), that is necessary to properly interpret the analyses that have been carried out. Section 8.3 presents the analysis of the ten supplementary questions in the German tool concerning the LTCI. It starts with the frequency distribution, followed by a comparison of some aspects concerning the types of benefits and grades of dependency in the subsample of those cared-for who get benefits of the LTCI. Each issue is preceded by introductory explanations on the related subject. In section 8.4 we describe how family carers' health and quality of life are affected by being tied down by the care for older relatives with various degrees of dependency. Moreover, we describe family carers' requests for certain kinds of support and investigate which of these requests can be met by the LTCI (section 8.5). Section 8.6 presents a discussion with potential starting points to improve the situation of family carers in Germany.

### 8.2 Long-term care insurance (LTCI)

The long-term care insurance has been inaugurated in 1994. Payment of benefits for domestic care started in January 1995, while benefits for institutional care have only been paid since July 1996. The aims described hereafter have been taken from the First Report on the development of the LTCI (Deutscher Bundestag 1995, 8f, translation).

- Social protection against the risks of needing long-term care
- Relief of physical, psychological and financial burden resulting from the state of needing long-term care

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<sup>11</sup> We gratefully acknowledge the translation of this chapter from German to English done by Josette Haferkorn, Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf.

- Guarantee of basic maintenance, which covers in most cases care related expenses „...and thus ensures that in the vast majority of cases, persons have no longer to rely on social assistance because of their state of needing long-term care.“ (ibid. page 8)
- The LTCI should take into account demographic developments. These are characterised by a higher life expectancy and an increasing proportion of older people.
- The guiding principles are: „Prevention and rehabilitation before care, outpatient care before inpatient care, part time inpatient care before full time inpatient care “.
- Social protection of non-professional carers (e.g. relatives) in appreciation of their commitment and compensation of losses due to reduced or dropped gainful employment.
- Promotion of the infrastructure of care, e.g. by licensing ambulatory and inpatient care institutions independent of needs.

The German LTCI may be described by some guiding principles. The insurance is a partial coverage insurance system with limited benefits. The amount is based on the level of dependency assessed by a special institution called Medical Service of the Health Care Insurances (Medizinischer Dienst der Krankenkassen – MDK). There are three grades of dependency defined:

- Grade I: requires help at least once a day for at least two activities plus household help several times a week (90 – 180 minutes per day)
- Grade II: requires help at least three times a day for at least three activities plus household help several times a week (180 – 300 minutes per day)
- Grade III: requires round the clock help every day plus household help several times a week (more than 300 minutes per day)

As home care is preferred to institutional care the benefits are for the cared-for themselves as well as there are some special measures to support the families in their caring role. The benefits cover the following areas: home care / stand-in care / part-time care / short-term care / technical aids / nursing care courses for relatives and volunteer carers / social security insurance for informal care and permanent institutional care. Benefits may be payed in kind, in cash or in a combination of both. More detailed information is given connected with the description of the results of the study in the following part of this chapter.

### **8.3 Utilisation of the benefits of LTCI in the EUROFAMCARE survey**

The target group consisted of family carers and their older relatives in need of care or nursing. Inclusion criteria were a minimum age of 65 years of the person in need of care and a minimum of 4 hours a week dedicated to care giving by the main carer.

Persons in need of care or nursing in terms of the study were older relatives, who were dependent on personal support. “Family” or “relative” was used in a more comprehensive sense than usual. It was not only applied in its legal sense, but in the sense of emotional and close relationship. Only 60 % of the cared-for in our study get benefits from the LTCI, the so-called “persons in need of care”. The other cared-for in our sample are defined as “persons in need of help”. This will be reflected by building groups of cared-for for further analysis.

In the following part we present the frequency distributions related to the supplementary questions. Using a newly built variable, which divides the sample into the subsamples of persons in need of help and persons in need of care, analyses of burdening factors to which family carers are exposed will then be carried out. In addition, we investigated differences related to the utilisation of LTCI benefits on the one hand and kinds of benefits and grades of dependency on the other hand. The concepts “need of help” and “need of care” and the newly built variable as well as the subsamples will be commented later.

For a better overview, the ten original questions of the questionnaire for family carers are listed hereafter. The questions will then be addressed in turn. Each will be preceded by introductory explanations on the topic.

1. Does your RELATIVE currently draw benefits from the LTCI?
2. If no application has been made so far, what is the reason?
3. Is your RELATIVE insured by a statutory or a private LTCI?
4. What is the grade of dependency currently assigned to your RELATIVE??
5. Are you or your RELATIVE currently planning to apply for a higher classification of the grade of dependency because of worsening or is such an application under consideration? (Application for a higher classification of the grade of dependency)
6. Since when is your RELATIVE in need of care?
7. Since when has your RELATIVE been assigned the current grade of dependency?
8. What types of benefits does your RELATIVE draw from the LTCI?
9. Which other benefits according to SGB XI did you or your RELATIVE utilise in the course of last year?
10. Are your care or nursing efforts remunerated in any way, e.g. pro rata constant benefits (cash or other), allowances from the RELATIVE?

### **8.3.1 Does your RELATIVE currently draw benefits from the LTCI?**

To qualify for benefits in terms of the SGB XI, the grade of dependency must be assessed by the medical review board of the health insurance (MDK). This must be preceded by the recognition of need of care according to the procedure laid down in § 18 SGB XI, which will not be further commented here. The criteria ruling the recognition of need of care are defined in § 14 SGB XI. According to them, persons are in need of care “if, due to physical, mental or psychic illness or handicap, they require a considerable or high degree of help (§ 15) in their normal and regular activities of everyday life for an indefinite period of time, but a minimum of six months” (§ 14 I 1 SGB XI). Point two of the same paragraph describes the diseases and handicaps that might lead to a state of needing care, e.g. paralyses, functional disorders of sense organs etc. Point three lists the kinds of benefits that can be granted for persons in need of care.

“Help in terms of point 1 consists in supporting, in partial or complete performing of tasks of everyday life or in supervising or guiding with the goal of re-assuming autonomy in performing these activities” (§ 14 III SGB XI). The latter in particular refers to the above mentioned goal of “priority of rehabilitation over care“. Point four of § 14 defines the tasks of everyday life, where various degrees (according to level of care) of help must be required in order to

recognise need of care in terms of § 14 SGB XI. This will be commented in the context of grades of dependency (cf. question 4).

Table 73 presents the frequency distribution of the answers given to question 1: “Does your RELATIVE currently draw benefits from the LTCI?”

**Table 73: Benefits of the LTCI**

Benefits of the LTCI	Number	% of given answers
Yes, assessment positive decided on	579	58.3
No, no assessment filed yet	318	32.0
No, assessment rejected	43	4.3
No, but assessment procedure still lasts	48	4.8
No, but objection was entered	5	0.5
Total of given answers	993	100

More than half of the interviewees reported a positive decision of the cared-for persons' application for benefits of the LTCI. One third stated that they had not made an application so far. The reasons will be discussed in the context of question 2. 4.3 % of the applications were rejected. In 4.8 %, an application was under consideration. Only in 0.5 % of cases, an objection was made.

### 8.3.2 If no application has been made so far, what is the reason?

In addition to the question whether benefits are drawn from the LTCI, it is also of interest to know the reasons for not applying for benefits.

Out of the 1,003 interviewed family carers, 21.0 % were of the opinion that there is not yet a state of need of care (in terms of § 14 SGB XI) and (presumably) therefore did not apply for benefits through the LTCI (see table 74).

The two categories “no application, will be made soon“ (1) and “no, but application or objection is under consideration“ (3) were stated by 12.8 %. In these cases, the need of care is at least perceived from the perspectives of those providing care / nursing and / or the persons in need of care. In 4.3 %, the interviewees perceived the need of care, but, according to the assessment by the medical review board of the health insurance (MDK), the criteria of need of care according to § 14 SGB XI were not met and the application therefore rejected. These results are summarised in table 74. This table shows the number of persons in need of care in each of the assigned grades of dependency (ten persons who assigned to grade of dependency III with hardship provision were integrated into grade of dependency III).

**Table 74: Benefits of the LTCI and grades of dependency**

Benefits of the LTCI and grades of dependency	Number	% of given answers
No need for assessment, no need for care	211	21.3
No, but assessment planned, filed or objection was entered	126	12.8
No need for assessment, other reasons	30	3.0
Assessment rejected	43	4.3
Grade I	193	19.5
Grade II	240	24.3
Grade III	146	14.8
Total of given answers	989	100

An analysis of the response category “other reasons” shows that the decision to apply for benefits of the LTCI not only depends on the degree of need of care, but is also influenced by the attitudes both of the person needing care and the carers’ (1 = person in need of care refuses, 2 = family carer refuses). There also seem to exist information deficits and bureaucratic barriers in individual cases, highlighting one of the areas where action is needed in order to improve the situation of family carers and the persons in need of care. In section 8.4, some activities meant to improve the situation of family carers will be presented and discussed.

### 8.3.3 Is your RELATIVE insured by a statutory or a private LTCI?

There should be made a difference rather between social and private LTCI, as both types are referred to as statutory LTCI. The insurance of the members of statutory health insurances is called **social long-term care insurance** according to § 1 Abs. 1 SGB XI (Simon 2005).

Min our sample more than 90 % of the persons in need of care or nursing are insured by the social LTCI (5.7 % of them private additional insurance). Almost 8 % are insured by the private compulsory LTCI (table 75).

**Table 75: Type of insurance**

Type of insurance	Number	%
Social LTCI	855	86.5
Social LTCI with additional private insurance	56	5.7
Privat LTCI	78	7.9
Total	989	100

The distribution of social and private LTCI is almost identical with the results of the German representative survey “Possibilities and limits of an autonomous lifestyle in private households of persons in need of care or nursing” (MuG 3) by Infratest Sozialforschung (Schneekloth & Wahl 2005). According to this study, 93 % are insured by the social LTCI and 7 % by the private compulsory LTCI. As the benefits of both types of insurance are identical, this differentiation will be dropped hereafter.

### 8.3.4 What is the grade of dependency currently assigned to your RELATIVE?

The legislator defined three levels of care plus one extension for cases involving particular hardships in the LTCI (§ 15 SGB XI). The grades of dependency are characterised, in ascending order according to the required degree of care, as grade of dependency I (needing considerable care), grade of dependency II (needing a high degree of care), grade of dependency III (needing a very high degree of care) and grade of dependency III with hardship clause. As mentioned above, the assignment of grades of dependency must be preceded by the assessment of **need of care** by the MDK according to § 14 SGB XI. In order to assess the need of care in terms of the law, the time required for carrying out the above mentioned activities must be recorded. According to the legislator, the assessment is based upon the amount of time “needed by a relative or some other person not qualified as nurse for the required basic care and household activities” (§ 15 III SGB XI).

For a better understanding, two terms vital for the classification will be commented, viz. **basic care** and **household care**.

The legislator defines **basic care** as the three areas described in § 14 IV Nr.1 to 3: **personal hygiene, nutrition and mobility**.

- **Personal hygiene** includes “... washing, showering, bathing, dental care, combing, shaving [and] defaecation or urination” (§ 14 IV Nr.1).
- **Nutrition** includes “...bite-sized preparation of food or feeding” (§ 14 IV Nr.2).
- **Mobility** includes “... autonomous getting up and going to bed, dressing and undressing, walking, being upright, climbing stairs or leaving or returning home” (§ 14 IV Nr.3).
- **Household care** includes “shopping, cooking, cleaning of the rooms, washing the dishes, changing and washing of linen and clothes or heating the rooms” (§ 14 IV Nr.4).

Time spent on basic care and household care must reach following “daily averages per week” in each of the grades of dependency (§ 15 III Nr. 1-3 SGB XI):

- In **grade of dependency I** at least 90 minutes, more than 45 minutes must be spent on basic care.
- In **grade of dependency II** at least three hours, at least two hours must be spent on basic care.
- In **grade of dependency III** at least five hours, four of them must be spent on basic care.

However, the classification is not only based on the expended time but also on the areas, in which basic care was required, when and how often.

- In **grade of dependency I**, help must be required for “at least two activities” of basic care and “additionally several times a week” for activities of household care (§ 15 I Nr. 1 SGB XI).
- In **grade of dependency II**, help must be required “at least three times a day at different times of day” in basic care “and additionally several times a week in household care” (§ 15 I Nr.2 SGB XI).

- In **grade of dependency III**, help must be required in basic care “daily round the clock, also at night“, “and additionally several times a week for household care” (§ 15 I Nr.3 SGB XI).

Grade of dependency II is most common and includes 41.5 % of those getting benefits, grade of dependency I: 33.3 %, grade of dependency III: one quarter of the persons in need of care and grade of dependency III with hardship clause 1.7 % (table 76). The Federal Ministry for health and social protection (Bundesministerium für Gesundheit und Soziale Sicherung (BMGS) 2003) reports following distribution of grades of dependency of the LTCI for 2004: grade of dependency I 50.6 %, grade of dependency II 35.6 %, grade of dependency III 13.2 % and grade of dependency III with hardship clause 0.6 % receivers of benefits (BMGS). It appears that the cared-for in the EUROFAMCARE sample, compared to the classification of the LTCI, is in greater need of care than the basic population. This is probably due to sampling effects.

**Table 76: Grades of dependency**

Grade	Number	% of given answers
Grade I	193	33.3
Grade II	240	41.5
Grade III	136	23.5
Grade III+	10	1.7
Total of given answers	579	100

### 8.3.5 Are you or your RELATIVE currently planning to apply for a higher classification of the level of care because of worsening or is such an application under consideration?

No less than 98 persons applied for a higher classification of the grade of dependency, 47 of them currently in grade I and 46 in grade II. Five persons in grade III applied for the highest grade of dependency (grade of dependency III with hardship clause). This shows that the need of care is assessed higher by those in need of care and / or their family carers compared to the view of the MDK.

### 8.3.6 Since when is your RELATIVE in need of care?

The given answers reveal that the concept “need of care” is understood differently by the family carers from the definition set down in § 14 SGB XI, as was to be expected. In individual cases, need of care was stated to exist since the 1960s and 1970s. A total of 12.4 % stated that need of care existed prior to 1995, the year of the introduction of the LTCI. 7.7 % stated that need of care existed since the first two years of the introduction of LTCI (1995 / 1996). According to 10.2 %, need of care dates back to 1997 and 1998, 10.3 % mentioned 1999 and 10.7 % 2000. 2001 was reported by 14.3 %. 17.0 % were reported for the following year. 2003 and 2004 combined a total of 17.3 % of new cases of need of care. This survey could not explore the criteria according to which the relatives assessed need of care.

### 8.3.7 Since when has your RELATIVE been assigned the current grade of dependency?

Table 77 shows the beginning of current grade of dependency assignments. In the year of introduction of the LTCI, 5.4 % were assigned to a grade of dependency. In the subsequent year, the percentage dropped to 1.6 %. From then on until 2001, there was a continuous increase up to 11.6 %.

**Table 77: Beginning of the current grade of dependency**

Beginning of the grade of dependency	Number	% of given answers
1995	30	5.4
1996	9	1.6
1997	13	2.3
1998	16	2.9
1999	31	5.5
2000	44	7.9
2001	65	11.6
2002	122	21.8
2003	182	32.6
2004	47	8.4
Total of given answers	559	100

A considerable increase occurred in the following two years: in 2002 up to 21.8 % and in 2003 up to 32.6 %. The low percentage of 8.4 % in 2004 is partly due to the fact that the survey period ended in June 2004.

Table 77 can also be interpreted as the length of time of the current need of care according to SGB XI (without considering potential higher assessments). At the time of investigation, 8.4 % had been assigned to a grade of dependency for less than one year, one third for up to one and a half year, one fifth for up to two and a half years, one tenth for up to three and a half years. However, it is possible that a state of needing care has been existing for much longer (irrespective of the SGB XI criteria), as described above. The mentioned groups represent 74.4 % of the sample. Thus, only 25.6 % have been needing care for more than three and a half years according to SGB XI.

The question, "How long have you been taking care of your relative?" indicates the length of time of care giving irrespective of the SGB XI criteria (table 78).

**Table 78: Length of time of care / nursing**

Length of time	Number	% of given answers
Up to 1 year	221	22.3
Up to 2 years	227	22.9
Up to 3 years	153	15.4
Up to 4 years	85	8.6
Up to 5 years	95	9.6
Up to 6 years	36	3.6
Up to 7 years	38	3.8
Up to 8 years	30	3.0
Up to 9 years	17	1.7
Up to 10 years	37	3.7
More than 10 years	52	5.2
Total of given answers	991	100

It appears that the length of time stated by family carers tends to be somewhat higher than the assignments to LTCI. Two thirds of the interviewees report up to five years of caring and no less than 5.2 % report more than 10 years of caring.

A recent leading decision of the Federal Social Court (BSG) (Az: B 3 KR 8 / 04 R und B 3 KR 9 / 04 R) could cause some changes with respect to the assessment or higher assessment of grades of dependency. It implies that the insured person can choose whether nursing activities narrowly related in time and kind to tasks of basic care, should be born by the health insurance or by the LTCI. Putting on compression hosiery is an example for nursing care related to basic care. According to the judges, the choice is exercised indirectly. The LTCI is responsible for persons in need of care, who draw exclusively constant attendance allowance, i.e. the time for basic care would increase and would have to be considered in the MDK assessments. The adding-up of care minutes could lead to a first assessment of need of care or a higher LTCI grade. For those who receive benefits in kind, the health insurance would be responsible for nursing care (Wortmann 2005).

### 8.3.8 What types of benefits does your RELATIVE draw from the LTCI?

The legislator decided that people in need of care, who have received an LTCI grade by the MDK, can basically choose between **home care** and **institutional care**. The **kinds of benefits** related to each of these domains are described hereafter.

#### Home care

Home care offers a choice between following kinds of benefits: benefits in cash, benefits in kind, or a combination of the two.

**Benefits in cash** are transferred monthly, provided that the person needing care uses the money to ensure that the required basic care and household care are adequately performed. In order to warrant the quality of home care and of the professional assistance of the persons giving home care, the persons who draw benefits in cash have to request advice by an approved care institution or professional nurse, who is mandated but not employed by the LTCI. In the LTCI grades I and II, this monitoring occurs at least once every half year, in LTCI grade III at least every three months.

The advisory service is paid by the LTCI (up to 16 € in LTCI grades I and II, and up to 26 € in LTCI grade III).

The benefits in cash amount to (according to § 37 SGB XI)

- 205 € in LTCI grade I;
- 410 € in LTCI grade II;
- 665 € in LTCI grade III.

### **Benefits in kind**

Persons in need of care are entitled to basic care and household care by qualified nursing staff, who are employed either by the LTCI or an ambulant skilled nursing service. They are entitled to these benefits even if they do not live in their own home but e.g. with their children, but not in case of institutional care. Benefits in kind are not paid to the person in need of care but settled directly with the care provider (skilled nursing service).

Benefits in kind amount to

- up to 384 € in LTCI grade I;
- up to 921 € in LTCI grade II;
- up to 1,432 € in LTCI grade III.

If the patient requires an exceptionally high amount of care, “exceeding by far the extent of LTCI grade III“, e.g. the final stages of cancer, if help is also required several times a night, the LTCI might grant benefits in kind amounting to a total of 1,918 € per month (hardship clause). This exception may only be granted in three percent of the persons assigned to LTCI grade III by each LTCI (§ 36 SGB XI).

### **Combination of benefits**

Persons in need of care can draw a combination of benefits in cash and benefits in kind.

In that case, the benefits in cash will be reduced by the part drawn in kind. If e.g. 50 % of the benefits in kind have been claimed, only 50 % of the benefits in cash are payable. In LTCI grade I, this would correspond to benefits in kind by a skilled nursing service amounting to 192 € and 102.50 € benefits in cash (§ 38 SGB XI).

### **Institutional care**

Persons in need of care are entitled to fulltime institutional care, if home care or parttime care is not possible or not suitable for specific reasons of the individual case. The LTCI covers the expenses for nursing and social care.

The allowances for inpatient care amount to

- up to 1,023 € in LTCI grade I;
- up to 1,279 € in LTCI grade II;
- up to 1,432 € in LTCI grade III.

If an exceptionally high degree of nursing is required and exceeds by far the extent of LTCI grade III, e.g. in apallic persons or in case of severe dementia, the LTCI may grant allowances up to a total of 1,688 € per month (§ 43 SGB XI).

Table 79 represents the distribution of the above described kinds of benefits in the EUROFAMCARE sample. **Monthly benefits in cash** ranges highest with 55 %, followed by a **combination of benefits** drawn by one fifth of the persons in need of care. **Nursing home care** is chosen by 15% while **benefits in kind** are utilised only by about 10 % of the persons in need of care.

**Table 79: Kind of benefits**

Kind of benefit	Number	% of given answers
Cash benefits	314	54.9
Kind benefits	59	10.3
Combined benefits in cash and kind	113	19.8
Nursing home care	86	15.0
Total of given answers	572	100

For 2004, the BMGS reports following annual averages for the distribution of the kinds of benefits in the population of all ages. Benefits in cash is also the most frequently drawn benefit with 48.4 % though clearly less frequent than in the EUROFAMCARE sample – not surprisingly as it is a sample of family carers. A somewhat lower percentage (8.5 %) chose benefits in kind, and combined benefits are utilised only by about half as many persons (10.3 %). On the other hand, almost three times as many persons (31 %) received nursing home care (including 3.3 % in homes for disabled people). The remaining 1.8 % account for day and night care (0.8 %), short time care (0.5 %) and home care to replace the carer in case of prevention (0.6 %).

### 8.3.9 Which other benefits according to SGB XI did you or your RELATIVE utilise in the course of last year?

In addition to the **kinds of benefits** described above, the LTCl offers further benefits (supplementary benefits), which are meant to relieve either the person in need of care or to relieve or support the carer. Carers are, according to § 19 sentence 1 SGB XI “persons, who – not gainfully – care for a person in need of care in terms of § 14 SGB XI in his or her own home“.

These benefits cannot always be claimed additionally but must also be considered as part of the optional benefits.

#### Utilisation of supplementary benefits

The utilisation of supplementary benefits in the EUROFAMCARE sample is summarised in table 80. Unlike previous descriptions, this table can only include the group of persons whose care needing relatives have a certified grade of dependency. The family carers of the 579 persons in need of care, who draw benefits from the LTCl, delivered a total of 602 answers regarding the utilisation of supplementary benefits. Nursing courses for relatives form an exception although it could be utilised by all persons. However, only 32 persons (5%) have utilised them.

**Table 80: Supplementary benefits and number of drawers (multiple answers)**

Supplementary benefits	Number	% of given answers
Nursing aids	287	47.7
Short time care	96	15.9
Activities to improve home environment	56	9.3
Contributions for the social security of the carer	53	8.8
Respite care	51	8.5
Nursing courses for family carers	32	5.3
Part time inpatient care (day care)	27	4.5
Total of given answers (from n=579)	602	100.0

For the following description of these different supplementary benefits, they will be subdivided into benefits, which relieve family carers directly or indirectly. This will be followed by an analysis of the utilisation according to LTCI grades and kinds of benefits.

**Indirect relief** of the family carer or the professional carer can be expected by utilising the supplementary benefits described hereafter.

**Nursing aids** represent almost half of the mentions and are by far the most frequently utilised supplementary benefits. The nursing aids had not been further differentiated in the questionnaire.

Persons in need of care are entitled to nursing aids by the LTCI, which should provide relief for the carer or ease discomforts or allow the person in need of care to live a more autonomous life (unless the nursing aids must be born by the health insurance or other purchasers because of illness or disability). Expenses for consumable material such as incontinence material must not exceed 31 € per month.

For non-consumable aids, co-payments of 10 % are due for persons older than 18 years, but not more than 25 € (to avoid hardships, part or total exemption is possible according to §§ 61, 62 SGB V) (§ 40 I to III SGB XI).

**Short time care** was also frequently utilised and mentioned by 15.9 %. However, since short time care is granted only in a very narrow frame (see above), it provides only limited relief to the carer.

Short time care is granted by the LTCI in those cases, where home care can not, not yet or not sufficiently be provided for a certain time, and day care is not sufficient. It is only provided **subsequent to inpatient treatment** of the person in need of care or in a **crisis** when home care or day care is not possible or sufficient. The LTCI bears the costs related to nursing and social care. Short term care is limited to **four weeks per calendar year** and the total amount is limited to 1,432 € (§ 42 SGB XI).

Almost every tenth mention was related to **activities to improve the home environment** (e.g. rebuilding of the bathroom). The LTCI can subsidise improvements of the individual home environment, e.g. technical household aids, if they permit or considerably relieve home care or restore autonomous living. The amount depends upon the costs incurred. The person in need of care must contribute according to his income. The subsidy must not exceed 2,557 € for each action (§ 40 IV SGB XI).

Family carers can find **direct relief** by utilising the supplementary benefits described below. However, the interviewees report a very low degree of utilisation.

**Part time inpatient care (day care)** can be considered as a direct relief, because the family carers spend less time with the person in need of care. However, since this benefit is not granted additionally, e.g. in addition to the constant attendance allowance, the relief period is very limited without spending additional money. This might be the reason why only 4.5 % of the mentions were related to part time inpatient care.

Persons in need of care are entitled to part time inpatient care in institutions providing day and night care, if home care cannot be provided to a sufficient extent or if required in addition or support of home care. Table 81 shows the extent of parttime inpatient care utilised by the interviewees. The claim includes transport to the institution and back. The LTCI covers the costs for nursing and social care.

The allowances for each grade of dependency per calendar month are as follows:

- up to 384 € in LTCI grade I;
- up to 921 € in LTCI grade II;
- up to 1,432 € in LTCI grade III.

If part time inpatient day or night care is claimed in addition to **benefits in kind** (professional care by skilled nursing service), the **total** costs per calendar month must not exceed the above amounts, i.e. this service is not additionally remunerated.

If part time inpatient day or night care is drawn in addition to **benefits in cash**, the total amounts must not exceed the monthly constant attendance allowance, viz.

- up to 205 € in LTCI grade I;
- up to 410 € in LTCI grade II;
- up to 665 € in LTCI grade III (§ 41 SGB XI).

**Respite care** was mentioned almost twice as often, by 8.5 %. If the carer is prevented because of vacation, illness or other reasons, the LTCI pays for the necessary respite care for at most four weeks per calendar year, on condition that the carer had been nursing the person in need of care for at least 12 months prior to the first prevention. The expenditure of the LTCI must not exceed 1,432 € per calendar year in any individual case. If the substitute carer is related or related by marriage up to the second degree to the person in need of care or if he or she lives in the same household, it is assumed that care is not given gainfully. In that case, the amount granted by the LTCI must not exceed the constant attendance allowance for the respective grade of dependency. Additional expenses related to the respite care can be reimbursed upon evidence; the costs for respite care and additional expenses must not exceed 1,432 € (§ 39 SGB XI).

**Contributions for the social security of the carer** were mentioned by 8.8 %. The LTCI pays contributions to the social pension fund, if the carer is not gainfully employed more than thirty hours per week. The amount of the contributions depends on the time spent nursing. The carer or the person in need of care must produce evidence of this time upon request, in particular when drawing benefits of kind. For the period of nursing, the carer is protected by the statutory accident insurance (§ 44 SGB XI). However, these rights only exist “if he or she [the carer] takes care of a person in need of care at least 14 hours a week“ (§ 19 2 SGB XI).

The LTCI can offer training courses for family carers and unsalaried carers. These training courses can also be offered in the homes of the persons in need of care. They are meant to

relieve nursing and caring activities and reduce physical and mental strains of the carers (§ 45 SGB XI). Participation in training courses is normally free of charge.

Only 5.5 % utilised the **nursing courses for family carers**. These courses provide on the one hand physical relief, e.g. by learning techniques that spare the back, on the other hand by providing knowledge, e.g. on care financing, on application procedures, etc. Moreover, meeting other family carers is an important emotional relief. It is important to advertise these courses to a broader public in order to reach a greater number of persons.

Relating supplementary benefits to LTCI grades as shown in table 81 reveals that **respite care** (8,8%) is claimed with growing frequency from grade I (5,7%) to grade III (12,4 %). **Nursing aids** show the same tendency and account for about half of the answers in all LTCI grades with a slight predominance in grade III. **Activities to improve home environment** are claimed by every 10<sup>th</sup> person in need of care. **Part time inpatient care** is mentioned most often for LTCI grade II (6.7 %), though the overall number is rather low (4.7 %). **Short term care** is mentioned by 16.6 %, most of them having LTCI grade II and III. **Contributions to the social security of the carer** (9,2%) are found to a lower degree in grade I. **Nursing courses for family carers** are mentioned almost exclusively in LTCI grades II and III. It can be assumed that family carers perceive the usefulness of this relief offer only when need of care is progressing. As the reasons for not utilising such courses had not been explored, there is need for further investigation. This is also made clear by the overall low number of 5.5 % of utilisers.

**Table 81: Supplementary benefits and grades of dependency, numbers and percentage (multiple mentions)**

Supplementary benefits	Grade of dependency I	Grade of dependency II	Grade of dependency III	Total
Respite care	11 5.7 %	22 9.2 %	18 12.4 %	51 8.8 %
Nursing aids	79 40.9 %	124 51.9 %	84 57.9 %	287 49.7 %
Activities to improve home environment	22 11.4 %	22 9.2 %	12 8.3 %	56 9.7 %
Part time inpatient care (day care)	4 2.1 %	16 6.7 %	7 4.8 %	27 4.7 %
Short term care	19 9.8 %	49 20.5 %	28 19.3 %	96 16.6 %
Contributions to the social security of the carer	12 6.2 %	25 10.5 %	16 11.0 %	53 9.2 %
Nursing courses for family carers	2 1.0 %	19 7.9 %	11 7.6 %	32 5.5 %
No supplementary benefits at all	78 40.4 %	73 30.5 %	35 24.1 %	186 32.2 %

Relating the supplementary benefits to the chosen kinds of benefits yields interesting results, as shown in table 82.

Not surprisingly, all supplementary benefits are claimed with a clear majority by those family carers or persons in need of care who draw a **benefit in cash**. Drawers of **combined**

**benefits** or their relatives range second in utilising supplementary benefits, with a considerable distance to the other kinds of benefits.

Only 62 mentions were made by persons who draw **benefits in kind** or their family carers. Supplementary benefits were mentioned only occasionally by person living in **nursing homes**, with the exception of nursing aids. As supplementary benefits claimed during the last year had been asked, respite care, part time inpatient care etc. are also mentioned for persons now living in nursing homes. Claiming supplementary benefits can also be influenced by direct payments to the person in need of care. On the other hand, requirements might be less, if the person in need of care receives benefits in kind or professional support by institutional care.

**Table 82: Supplementary benefits and kinds of benefits (multiple answers)**

Supplementary benefit	Benefits in cash	Benefit in kind	Combination of benefits	Nursing homes	Total
Respite care	27 (54.0 %)	6 (12.0 %)	16 (32.0 %)	1 (2.0 %)	50 (100 %)
Nursing aids	153 (53.9 %)	29 (10.2 %)	75 (26.4 %)	27 (9.5 %)	284 (100 %)
Activities to improve home environment	34 (60.7 %)	7 (12.5 %)	14 (25.0 %)	1 (1.8 %)	56 (100 %)
Part time inpatient treatment	13 (48.1 %)	2 (7.4 %)	9 (33.3 %)	3 (11.1 %)	27 (100 %)
Short term care	43 (44.8 %)	14 (14.6 %)	30 (31.3 %)	9 (9.4 %)	96 (100 %)
Contributions to the social security of the carer	25 (48.1 %)	4 (7.7 %)	15 (28.8 %)	8 (15.4 %)	52 (100 %)
Nursing courses for relatives	19 (59.4 %)	0 (0 %)	10 (31.3 %)	3 (9.4 %)	32 (100 %)
No supplementary benefits at all	105 (56.8 %)	19 (10.3 %)	18 (9.7 %)	43 (23.2 %)	185 (100 %)

### 8.3.10 Are your care or nursing efforts remunerated in any way, e.g. pro rata benefits in cash or other allowances from the RELATIVE?

A total of 38.4 % of those family carers who care for a person in need of care with a grade of dependency I, II or III reported that they receive remunerations for their nursing / caring efforts (table 83). Almost all persons in need of care (92.7 %), whose family carers reported receiving a remuneration for their nursing or care efforts, receive benefits in cash or combined benefits from the LTCl, i.e. allowances where money is paid directly by the LTCl to the person in need of care. This suggests that the choice of the kind of benefit is also influenced by the wish (or even enforcement?) to remunerate the family carer.

This underlines the importance of cash benefits for the maintenance of home care by family carers.

**Table 83: Remuneration of care / nursing efforts and kind of benefit**

Kind of benefits	Payment of care		Total
	No	Yes	
Cash benefits	164 52.4 %	149 47.6 %	313 100 %
Kind benefits	51 86.4 %	8 13.6 %	59 100 %
Combination of benefits in kind and cash	55 49.1 %	57 50.9 %	112 100 %
Nursing home care	81 94.2 %	5 5.8 %	86 100 %
Total	351 61.6 %	219 38.4 %	571 100 %

#### **8.4 Effects of nursing and care giving on the family carers in consideration of the input of time and the self-help abilities of the persons in need of care or nursing**

In section 8.3 we described the ten additional questions related to the LTCI under special consideration of the LTCI grades and the kinds of benefits; in this section, they are considered under the aspects health and quality of life of the family carers. Health and quality of life have been selected as important outcome criteria indicative of the strain on the main carers.

For this aim, the newly built variable introduced in question one regarding the assignment to a grade of dependency, has been modified again. Thus, category 2 (subjective need of care, but no LTCI grade) was constituted from the former categories “no application, will soon be made”, “no application, other reasons”, “no, but application or objection is under consideration”, and “application was made but rejected”. In these categories, at least a subjective need of care as perceived by the family carers and / or the persons in need of care can be assumed though the criteria according to § 14 SGB XI are not met. In category 1, (“no application, no need of care yet”) there is no need for care or nursing from the perspective of the family carers but need for support or care amounting to at least four hours a week (see definition of target group). Persons of the categories 1 and 2 will hereafter be referred to as “needing help” (Schneekloth & Wahl 2005). Those persons, who have been assigned an LTCI grade according to SGB XI will be referred to as “needing care”. The main carers, independent of the degree of support or care required by the person in need of cares, will be called family carers.

Each of the two groups of persons needing help make up about one fifth (21.3 % and 20.1 % respectively) of the persons cared for by the interviewed family carers. The persons in need of care represent a total of 58.6 %. The ranking order presented in figure 8 reveals an increasing need of help and care, with category 1 (“no application, not yet need of care”) displaying the lowest and category 5 (LTCI grade III) the highest need of care.

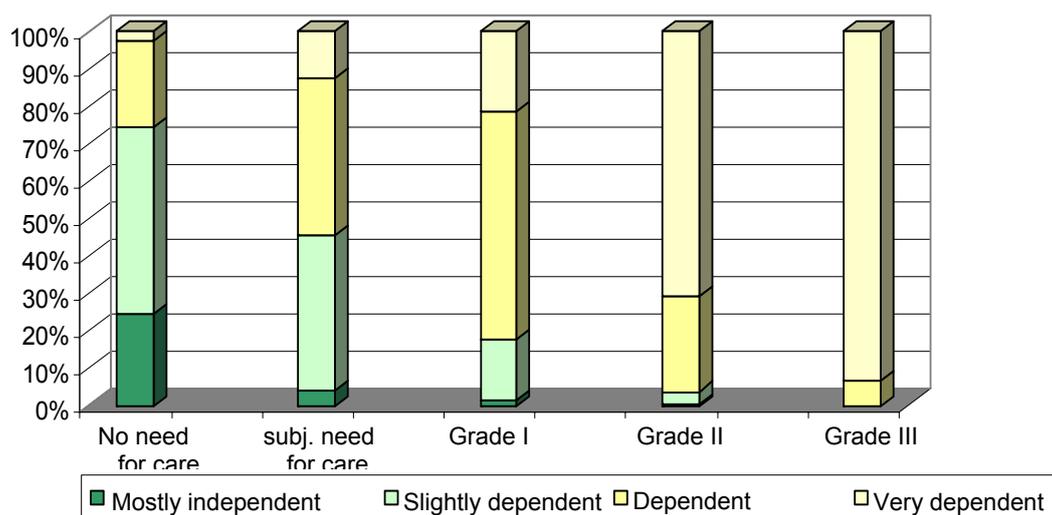
Figure 8 contrasts the subjectively assessed degree of dependency of the persons in need of help and care by family carers with the five categories described above (no need of care to LTCI grade III).

The subjective assessment of dependency is based on the following support needs as defined in the survey instrument:

- **Independent** – Able to carry out most activities of daily living, but may need some help occasionally
- **Slightly dependent** – Able to carry out most activities of daily life, but requires help with some instrumental activities (e.g., shopping, cooking, housework, etc)
- **Moderately dependent** – Able to carry out some basic activities of daily life (e.g. bathing, feeding, dressing) but unable without help to carry out most instrumental activities of daily living (e.g. shopping, cooking, housework)
- **Severely dependent** – Unable to carry out most activities of daily living, without help (e.g. feeding themselves, or going to the toilet).

It becomes apparent that, according to the family carers, older people's need for help increases in the above sequence. While in category 1 (no need of care) two thirds of the family carers assess their care needing relative to be "predominantly autonomous" or "needing slight care", in grade of dependency III, nearly 100 % of the family carers report "moderate" to "extensive need of care" of their care needing relative. The assessment of the family carers and the assessment by the MDK are most often in agreement apart from the 43 persons whose application for a grade of dependency has been rejected. It should be pointed out that the described categories clearly show the decrease of autonomy of the persons in need of care, which will result in an increasing burden on the family carers.

**Figure 8: Need of care through the eyes of the carers and LTCI grades**

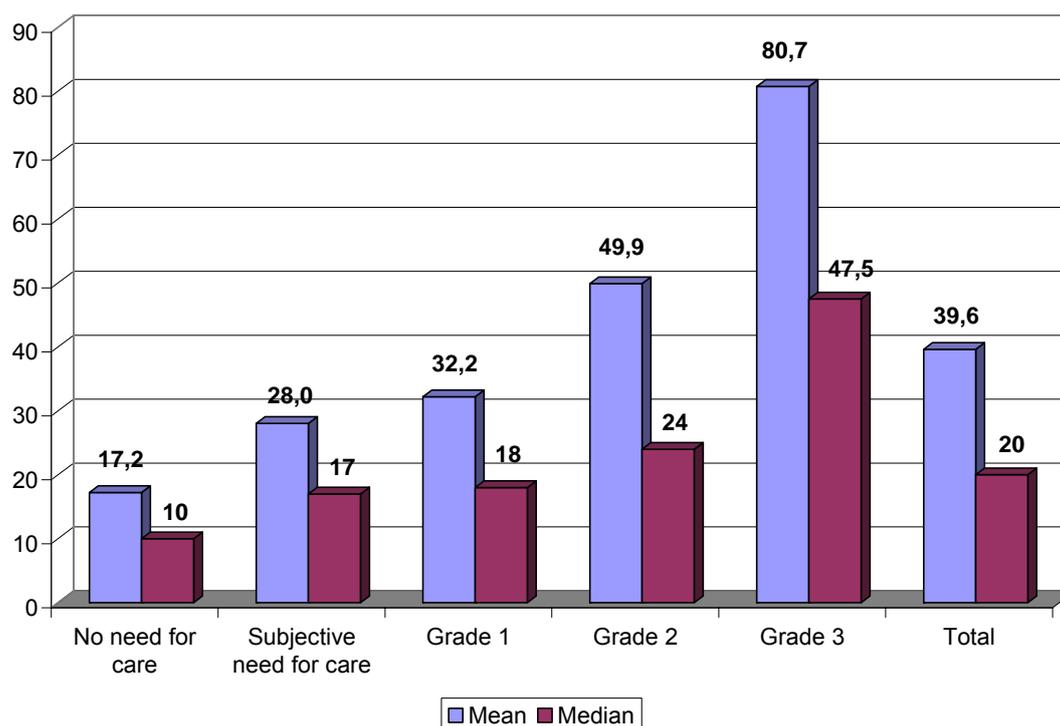


Other factors, which might exercise an influence on the health and / or quality of life of family carers, are the time required for caring or nursing and the self-help abilities of the person in need of care and nursing.

### 8.4.1 Time required for caring or nursing by family carers

As expected, figure 9 clearly shows that the weekly average time required increases with the degree of needed care. It is noteworthy that family carers of the group, where no need of care is yet perceived, still spend on average 17 hours a week supporting their care needing relatives. The median value is presented in addition to the average, because the values exhibit a relatively broad scattering with outliers at the high end of the scale. Overall, the minimum time expenditure is 4 by definition, the maximum 168 hours a week which meant 24 hours a day (round the clock).

**Figure 9: Average time expenditure for caring / nursing in hours**



When analysing the individual kinds of benefits, it is surprising that the time required for nursing is overall highest for the drawers of benefits in kind in all of the LTCl grades (table 84). It seems that professional skilled nursing services do not bring considerable time relief to family carers. It is possible that there is a shifting to rather organisational and administrative activities, since, in this group, nursing itself is taken over by professionals of ambulant services. The collected data do not allow a greater differentiation of the activities. It is particularly conspicuous that family carers, whose charges draw only benefits in cash and are assigned LTCl grade III, report a distinctly lower average of hours spent on care giving (87 hours). The average of hours is clearly higher in the groups drawing combined benefits and benefits in kind (117 and 126 hours respectively). The median value of 168 hours for the family carers of the beneficiaries of combined benefits in LTCl grade III is due to the fact that 56 % (19 out of 34 persons) reported this value. Assuming that the classification by the MDK is sufficiently reliable and does not vary between evaluators, it is necessary to detect other reasons for the unexpected differences of time reported for nursing.

**Table 84: Kinds of benefits by LTCI grades and average time required for nursing in hours per week**

Kinds of benefits	Grade I		Grade II		Grade III		Total	
	Mean	Me-dian	Mean	Me-dian	Mean	Me-dian	Mean	Me-dian
Benefits in kind only	41	25	62	21	126	150	77	50
Combinated benefits only	19	15	40	24	117	168	59	28
Benefits in cash only	37	21	64	35	87	60	56	30
Nursing home care	9	5	12	10	11	9	11	8

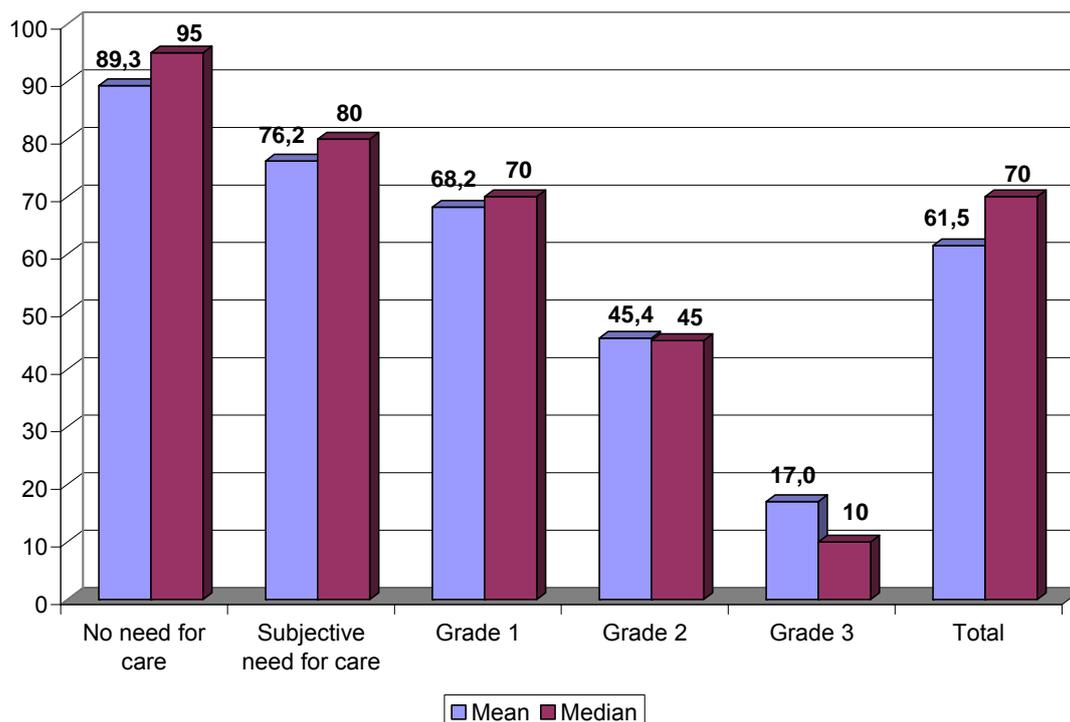
The group of family carers of persons in need of care, who draw only benefits in cash and are assigned LTCI grade III, is composed of 49 women and 15 men. On average, the men of the group spend more hours nursing than women (88 versus 74 hours on average). The median value for men is 60, for women 40 hours. That seems to refute the prevailing assumption that men more often utilise outside help. This assumption is also rejected by a metaanalysis of more than 40 studies (Pinquart & Sörensen 2005).

All the same, informal help networks play a part in the time used for the care of relatives. This is shown by the comparison of family carers of the mentioned group, who “have no problem” or who “have some difficulties” finding somebody to care for their relatives if they need relief time with the group, who would have nobody to relieve them. The latter spend on average 115 hours (n = 19, median value 140). The first two groups only spend slightly more than half of that time, viz. 64 and 59 hours respectively (n = 22, median value 33 and 40 respectively). These differences are also found, though less pronounced, when analysing all the LTCI grades. Here, the average time (mean value) spent by family carers of persons drawing benefits in cash and who can get relief “without problem” or “with some difficulties”, is 42 and 47 hours respectively. The carers, who do not have this option, spend considerably more time caring, viz. an average of 76 hours.

As expected, this shows that those family carers whose older relatives charge only benefits in cash and who cannot fall back on informal support, have a particular need of support, at least with respect to the time factor.

#### 8.4.2 Self-help abilities of persons in need of care or nursing

Apart from the time required for caring, the limitation of self-help abilities of the person in need of care is well suited to describe the burdens of family carers. These limitations were assessed by the frequently used Barthel Index. However, the ascertained values must be qualified as subjective assessments of family carers, whose answers were converted into points. Moreover, professional classification of self-help abilities with the Barthel Index normally requires a clearly comprehensible manual, well structured according to the individual items of daily life, such as the “Hamburger Einstufungsmanual zum Barthel-Index“, and in a clinically relevant application, the users would have to be specially trained (Lübke 2002).

**Figure 10: Average Barthel-Index and LTCI grades**

As the EUROFAMCARE study is not concerned with clinical accuracy but with the detection of trends, the instrument may be assumed to be sufficiently valid (Döhner & Kofahl 2000).

The question related to the individual items of activities of daily life is, “If ELDER was alone, would they be able to carry out following activities“ (e.g. using the bath or toilet)? The answer categories are, “unable“, “with some help“ and “without help“. The maximum value for a person without limitations of self-help abilities is 100 points. The Barthel index only allocates points for those activities that the patient really performs (figure 10).

Despite these limitations, a very clear picture emerges showing how self-help abilities of the person in need of care or nursing decreases with the LTCI grade. This expected result shows again very clearly the basic concordance of self-assessments of support and nursing needs by family carers and by the MDK.

### 8.4.3 Family carers’ health and quality of life

Family carers’ state of health and quality of life reflect the strains they are exposed to. The state of **health** of family carers was explored by the question, “In general, would you say your health is ...“. The available answer categories were “excellent“, “very good“, “good“, “fair“, “poor“. The answers were dichotomised in a new variable. The first three potential answers were merged into the new category “better“, the last mentioned answers into the category “worse“. The stated answers are presented in table 85. Despite the great simplification, a clear distribution trend emerges: With increasing need of help and nursing, family carers describe their general health state increasingly as “worse“ (from 16 % in the category “no need for care“ to 39 % in LTCI grade III). The proportion of answers in the category “better“ decreases accordingly (from 84 % to 61 %). However, two thirds of all interviewees assess their health state as better.

**Table 85: Family carers' state of health and need of care (dichotomised)**

Degree of dependency	Health		Total
	Better	Worse	
No need for care	175 84.1 %	33 15.9 %	208 100 %
Subjective need of care	161 82.6 %	34 17.4 %	195 100 %
Grade I	143 74.9 %	48 25.1 %	191 100 %
Grade II	169 71.0 %	69 29.0 %	238 100 %
Grade III	89 61.0 %	57 39.0 %	146 100 %
Total	737 75.4 %	241 25.6 %	978 100 %

Taking into account the family carers' age, it is shown as expected that, with increasing age, family carers report their state of health as "not so good". In the group of family carers up to 64 years of age, 82.4 % report their health state as "good" and 17.6 % as "not so good". In the group of those older than 65 years, the relationship is 59.4 % vs. 40.6 %.

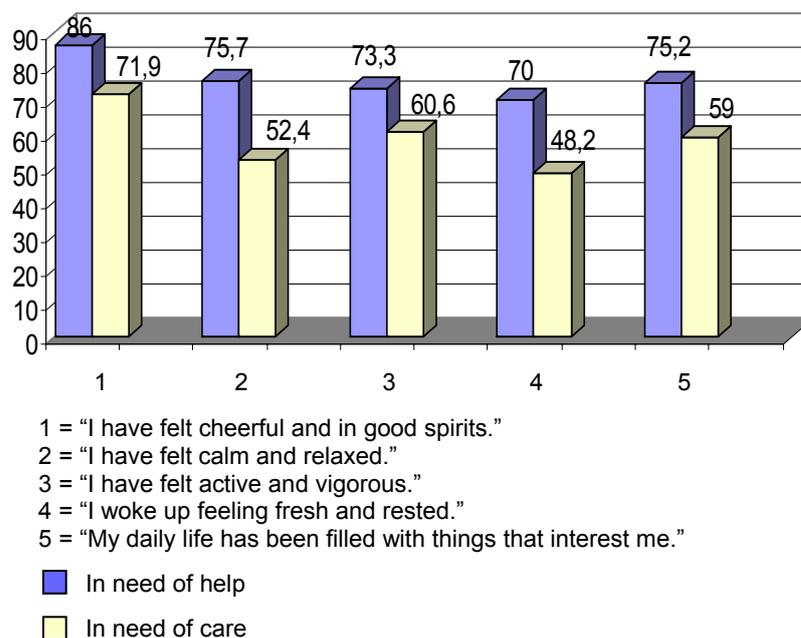
The question related to the **quality of life** of the family carer was, "How would you assess your overall quality of life during the last two weeks?" (cf. SF-36, Brazier et. al. 1992). The original five categories "very good", "good", "moderate", "bad" and "very bad" were combined to form the categories as presented in table 86. "Good" and "very good" were merged into "good", the procedure was the same for the category "bad". The same trend became apparent that prevailed for health. With increasing need of help and nursing, the quality of life of family carers decreases. The number of replies in the category "good" decreases from 67.8 % to 39.7 %. Replies in the two other categories continuously increase (from 29.4 % to 46.6 % in the category "moderate" and from 2.8 % to 13.7 % in the category "bad"). However, the small number of cases has to be taken into account. Only 6.6 % of the interviewees report a "bad" quality of life. More than half report a "good" quality of life and 38.2 % "moderate" life quality.

**Table 86: Quality of life and LTCI grades in %**

Degree of dependency	Quality of Life			Total
	Good	Average	Bad	
No need for care	143 67.8 %	62 29.4 5	6 2.8 %	211 100 %
Subjective need of care	134 67.3 %	56 28.1 %	9 4.5 %	199 100 %
Grade I	108 56.0 %	76 39.4 %	9 4.7 %	193 100 %
Grade II	103 43.1 %	115 48.1 %	21 8.8 %	239 100 %
Grade III	58 39.7 %	68 46.6 %	20 13.7 %	146 100 %
Total	546 55.3 %	377 38.2 %	65 6.6 %	988 100 %

The expected trend is confirmed that the quality of life of family carers decreases with the increasing need of care and nursing of older people.

For further assessment of the quality of life of family carers, conditions “within the last two weeks” have been explored as presented in figure 11. The answers have been dichotomised and assigned to the two categories “more than half of the time” and “less than half of the time”. 86 % of the family carers of persons “needing help” stated that they were “cheery and in good spirits” in the last two weeks. Of the family carers of persons “needing care” (LTCI grade I to III), this was stated only by 71 %. In general, it is shown that the subjective quality of life of family carers is partly clearer lower if they take care of persons in need of care then in the case persons in need of help.

**Figure 11: Quality of life and need of help and care in %**

Despite the simplifications, relationships can be detected between the extent of the need of help or care on the one hand and health and quality of life of family carers on the other hand. Of course, it must be kept in mind that a great number of other determinants exercise an influence on health and quality of life.

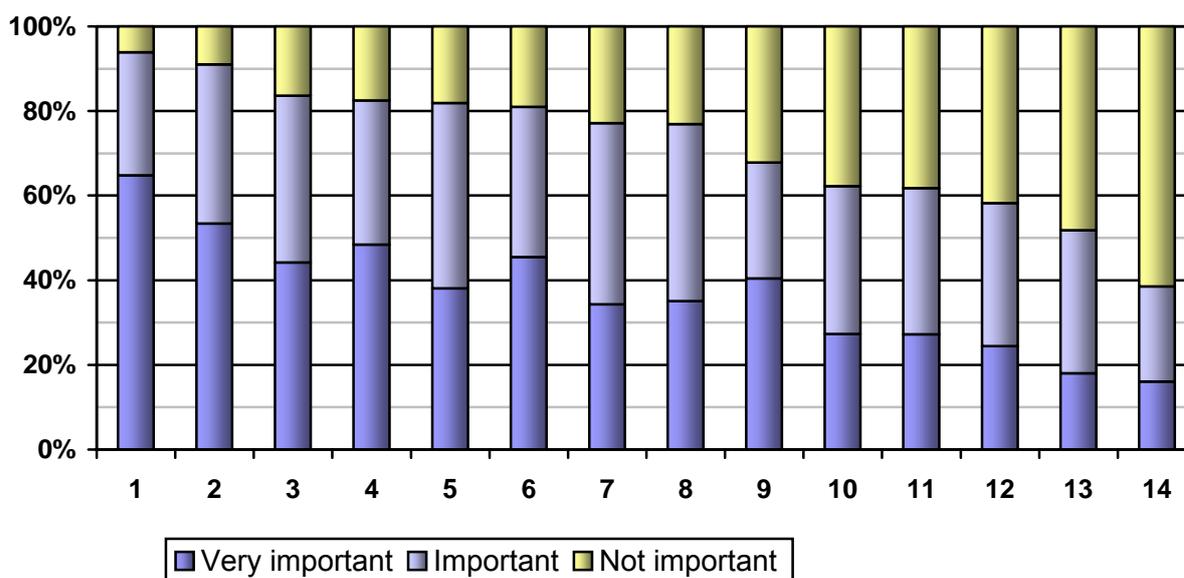
As (in most cases) need of help and care increases with age, so does the burden of family carers and his health related strains and other strains, and the situation calls for early interventions.

To conclude, which are the kinds of support important to the family carers and is it possible for the LTCI to cover these needs?

## 8.5 Kinds of support for family carers

In addition to the supplementary benefits of the LTCI described in section 8.3.9, which offer support and relief for family carers, the following will describe the kinds of support that family carers consider most important, and the characteristics that support services and offers should have (Döhner & Lüdecke 2005). Out of 14 forms, family carers selected following support offers as most important in the indicated sequence. There is only a slight difference between the first two mentions concerning information.

**Figure 11: The most important support offers for family carers**



1. "Information about the disease that elder have."
2. "Information and advice about the type of help and support that is available and how to access it."
3. "Opportunities for elder to undertake activities they enjoy."
4. "Opportunities to have a holiday or take a break from caring."
5. "Opportunities to spend more time with my family."
6. "Opportunities to enjoy activities outside from caring."
7. "Help with planning for the future care."
8. "The opportunity to talk over my problems as a carer."
9. "The possibility to combine care giving with paid employment."
10. "Training to help me develop the skills I need to care."
11. "More money to help provide things I need to give good care."
12. "Help to make elder's environment more suitable for caring."

13. "Help to deal with family disagreements."

14. "Opportunities to attend a carer support group."

Understandably, the LTCI can only comply in a very limited way with the wish to learn more about the illness of the person in need of care (point 1). This falls rather into the doctor's responsibility, subject to the patient's consent. General information on certain illnesses can also be conveyed to family carers in training courses (§ 45 SGB XI). As concerns the low level of utilisation: see table 81. The activities of nursing services regarding counselling according to § 37 III to V SGB XI for beneficiaries of constant attendance allowances should also be mentioned. These counselling assignments were strengthened in terms of their quality assuring role by the addendum to the law on care provision (Pflegeleistungsergänzungsgesetz (PflEG)). According to it, counselling is improved by federal standard procedures. Counselling assignments should be carried out by professionals of licensed nursing services or by other qualified nurses charged by the LTCI. The counselling nurses should "be skilled in counselling and have specific knowledge about the respective disease or handicap pattern". This is particularly true for persons with a "particularly high need of care" (e.g. in case of dementia). In such cases, counselling nurses "should be versed in pertinent knowledge, in particular geronto-psychiatric knowledge and experience in the dealing with people suffering from dementia" (Statistisches Bundesamt 2005).

As concerns point 2, the legislator clearly charged the LTCIs to inform and counsel as put down in § 7 II 1 SGB XI: "LTCIs have to inform and counsel the insurant **and his relatives and partner** in questions pertaining to the need of care, in particular with respect to benefits of the LTCIs and benefits and services by other agencies". The fact that this issue ranks very high on the priority list of family carers reveals a great deficit of information. The LTCIs are required to better fulfil their obligation to inform.

The wish for "opportunities for elder to undertake activities they enjoy" cannot be fulfilled by the LTCIs.

For the wish to get "opportunities to have a holiday or take a break from caring", the SGB XI offers respite care (§ 39 SGB XI) under certain conditions described above (for a maximum of four weeks per calendar year).

The points 5 and 6 ("opportunities to spend more time with my family" and "opportunities to enjoy activities outside from caring.") can be provided by the LTCIs to the family carers of persons, who have "a considerable need of general supervision and caring" (§ 45a SGB XI), e.g. in case of dementia. Under certain conditions, they can dispose of an amount of 460 € per calendar year to be used for this specific purpose. For instance, low-threshold care offers can be utilised, who supervise the person in need of care by the hour.

Point 7, "help with planning for the future care", is answered by what has been said under point 1.

Concerning the "opportunity to talk about the problems as a carer" (point 8), the LTCIs can only refer to the training courses for family carers or to self-help groups.

The wish for "possibilities to combine care giving with paid employment" (point 9) is a challenge to the employers, e.g. by providing flexible working hours.

Point 10 ("training to help me develop the skills I need to care") is again a matter of the above mentioned training courses.

“More money to help provide things I need to give good care“ (point 11) is, in a restricted way, certainly a question of the kind of benefits chosen, the total amount being fixed by the legislator.

The wish for “help to make elder’s environment more suitable for caring“ (point 12) can be met by the LTCIs by subventions for the improvement of the home environment as stipulated in § 40 SBG XI.

“Help to deal with family disagreements“ (point 13) cannot be given by the LTCIs. As for the last point on the priority list (“opportunities to attend a carer support group”), the LTCIs could help by referring to self-help organisations as well as contact and information centres for self-help groups (Kontakt- und Informationsstellen für Selbsthilfegruppen).

To summarise, the LTCIs are able to provide certain possibilities to comply with the kinds of support desired by the family carers. This concerns most of all needs for information and counselling, but also the need for time off. Of course, there are limits set to the LTCIs. Therefore, the providers of services, e.g. nursing services and doctors, are also required to support the family carers in those areas.

In addition to the LTCIs and the service providers, various counselling services for older people and their relatives should be mentioned. In Hamburg, this is for instance the “Hamburgische Brücke e.V.“ ([www.hamburgische-bruecke.de](http://www.hamburgische-bruecke.de)) or, on the federal level, the BAGA (Bundesarbeitsgemeinschaft für Alten- und Angehörigenberatungsstellen e.V. / [www.baga.de](http://www.baga.de)).

A basic problem is the accessibility to the group of family carers. Almost all supporting benefits by LTCIs and providers of services are only granted upon request by the family carers or the persons in need of care. The reason is probably a lack of possibilities to remunerate activities of counselling and preventive measures by the service providers.

It is conceivable to improve the situation by introducing an accessing counselling e.g. by the MDK in the course of the assessment situation.

## 8.6 Discussion

Even though the LTCI had primarily been developed for those in need of care, its professed aim is also to maintain care at home by offering relief and support to the family carers (ambulant care rather than institutional care). In the light of the fact that “more than 90 % of the persons in need of care and living in private households are supported by their close relatives”, this is also of high societal relevance (Runder Tisch Pflege 2005).

Therefore, we conclude by summarising the various forms of support provided by the LTCI to family carers on the one hand, and the utilisation of these services on the other hand. The LTCI does offer a number of services that could adequately meet the support needs of family carers. These are most of all services that could meet various information needs and the desire for “time off”, e.g. by respite care. However, there are great differences between the stated needs or the assessment of importance of certain support services and their actual utilisation. Beside psychological reasons, the relatives’ statement that they learned too late of such offers, must be considered. A positive result is that the actually utilised offers met the support needs in almost all cases (Kofahl & Mnich 2005).

It is a basic problem that the LTCI only grants relief and support offers upon request of the family carers. But the latter are already heavily burdened with care (on average 40 hours a week) and professional activities (average working time 32 hours a week) and are hardly able to hunt for information. Here, the LTCI is challenged and should be reminded of their duty to provide information as required by the law. But service providers such as hospitals, nursing services and doctors should also feel responsible, also in view of the concept of health prevention, which takes increasingly root in the public health system. The potential role of the “Medical Service of the health Insurances” concerning accessing counselling in the evaluation context should again be stressed.

As expected, the degree of family carers’ burden seems to be related to the degree of required care by their charge. As mentioned, this is reflected by the time spent on caring, by the degree of autonomy of the person requiring care and by the reduced health state and quality of life of the family carers. According to a study by the Friedrich-Alexander University Erlangen-Nürnberg (Gräßel 1997), the burden of family carers is most of all the result of little flexibility of time and the physical demands of care activities.

This highlights the great importance of preventive measures to relieve family carers and improve their state of health. It means that support services for family carers should be offered as early as possible, in order to decrease their burden and thus prevent health problems and also to encourage them to continue caring in the home environment of the person in need of care.

Support services must recognise that their clients are (or should be) not only the persons they care for but also the family carers. The providers should consider how they can reach family carers, how they can learn about their needs and calculate the market value of this target group. It is a decisive question how family carers can be induced to utilise the existing offers. When combining formal and informal help networks, professional helpers should realise that their task consists in “strengthening weak domestic arrangements and compensating missing resources, without debasing proffered efforts and damage the self-perception of the persons concerned”. Which means that professional helpers are supplementary and not replacement of family carers and should blend “as a resource into the arrangement of the non-professional helpers [family carers and other informal helpers]” and not conversely (Zeman 2005, 104-108). When exploring and covering the needs of family carers and their charges, the perspectives of support providers and representatives of the social and health care system should always focus on the individual situation.

Last not least, the improvement of the situation of family carers not only requires actions on the micro level, but also supportive actions on the meso and macro levels. This could be for example a better co-operation of individual counselling and support services on the communal level, better basic conditions on the federal level, better compatibility of care and employment. This is a challenge both to the representatives of the social and health care system and the policy makers on the national as well as on the European levels.

At the national level the LTCI itself is under heavy discussion. In 2002 two legislations supplementary to the law have been introduced:

- Care Quality Improvement Bill (“Pflege-Qualitätssicherungsgesetz”)
- First Bill to Improve the Care of People Suffering from Dementia (“Pflegeleistungs-Ergänzungsgesetz”)

The new government put this law high on the agenda for 2007. Between experts there is a consensus that the legal definition of “in need of care” has to be broadened to open the benefits more to people with gerontopsychiatric problems, especially dementia. Relatives caring for this group, that will increase in the future, are higher burdened as other carers. This is also a result of this study. They are more in danger stopping care for the older person and give their cared-for to a nursing home. This is a main challenge for politicians if they will be able to realise their own goals described for the LTCI.

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## 9 The Service Providers' Survey

*Daniel Lüdecke, Susanne Kohler*

### 9.1 Purpose of this chapter

A major concern of the EUROFAMCARE study is to analyse services for supporting family carers of older people in Europe. The needs and demands for services from the family carers' perspective were obtained by face-to-face interviews with family carers at their home (see chapter 7). The purpose of the Service Providers' Survey was to add the views of service providers to those of the family carers. The intention of further analysis is to describe possible differences in the views on service provision between those persons who receive help and those who offer it, i.e. completing the picture of two different views on help services and their existence, familiarity, availability, usage and acceptability. Furthermore the current and future perspectives on challenges concerning the services provided for carers of older people was conducted, to identify gaps in service provision and to show examples of good practice through the eyes of the providers.

### 9.2 Method and sample

In the period from September 2004 to December 2004 in Germany, data was collected in general by postal questionnaires and as an exception by telephone interviews, both using a semi-structured questionnaire which was identical in each of the six core countries of the EUROFAMCARE study. The questionnaire contains four sections: A) Background information about the service provider organisation (see 9.3.2 and table 87 to 95 in section 9.3.2.5); B) open questions dealing with services offered for carers (see 9.4.1 – 9.4.7); C) open questions which are about help for the older, dependent people (see 9.4.1 – 9.4.7); D) and finally a section where the service providers were asked about their opinion on family carers' views on service importance and characteristics (see 9.4.8 – 9.4.9).

#### 9.2.1 Sample size

The intention of the sampling procedure was to reach a good mixture of different types of providers offering services for family carers or for older people, which at least relieve the family carers. To achieve high response rates it was tried to identify highly motivated service providers. Furthermore to reach the aimed sample size of about 60 to 80 interviews, 315 questionnaires were dispatched, calculating with a response rate of at least 25 %. From the original sample 78 of the services did not fit to our sampling criteria, i.e. their work was not concerned with older people in general. As a consequence a new, cleaned sample size of 237 was the result. Unfortunately only 35 of these 237 questionnaires were finally filled in and sent back (see table 87).

#### 9.2.2 Pre-test

In Germany we made a pre-test to see whether and which problems could occur to the providers when answering the questions. As the providers chosen for the study were all expected to have special offers for family carers, the service providers complained that parts B

and C were almost identical. Both parts have exactly the same questions with part B referring to family carers and part C asking about older persons – due to the situation in some countries, where no special offers are available. Usually the questioned service providers would have filled in the same answers in part B and C, thus they considered it as repetitive and redundant. Due to the need for identical questionnaires in all core countries this questionnaire structure was not changed. Although we were aware of the fact that the length of the questionnaire might deter the questioned service providers, we decided to use postal interviews for time and personal exposure reasons. In the covering letter the research team offered to call the service providers and do the interviews by phone. Only two of the 35 providers accepted the offer of phone interviews while the rest used the postal method of answering. 28 of the 33 providers who used the written form gave answers to the open questions. Including the two telephone interviews we gathered data for the open questions by 30 service providers.

### 9.2.3 Sampling

Data was collected in four different regions of Germany, being the same areas where in the first phase the family carers' survey has been carried out before having widened the study to the whole country, because of recruitment problems. To identify potential providers who fit in our sample, local coordinators in each region were asked to put together an address list of providers offering services for family carers or for cared-for older persons which relieve family carers. This list should contain addresses of several types of service providers weighted according to their availability in each locality type, thus representing the typical structure of service coverage in each metropolitan, urban and rural areas. The aim was to take in

- 30 selected providers from a metropolitan area,
- 35 selected providers from an urban area,
- and 15 selected providers from a rural area.

To cover a wide range of service types, at least one of the following types of services should be included in each type of area:

- advisory centres
- self help and carer support groups
- Alzheimer society
- Telephone help lines
- nursing homes
- day care centres
- respite care
- domestic care services
- geriatric departments
- general practitioners
- care insurances

To avoid a too unbalanced sample, the amount of certain types of services to be included in our sample was meant to be limited to the total number of four.

The address lists from the four regions were delivered from the local co-ordinators to the Hamburg research team where the service providers' survey was co-ordinated and realized. Due to good relationships with the service providers in Hamburg and northern Germany, relatively high response rates were reached in the northern region while we had very low return in the other three regions. Therefore, the initial aim to cover a broad spectrum of different services in each region could not be reached. As a result the final sample is biased by the contacts of the local co-ordinators and the effort they could give to the recruitment.

### **9.2.4 Representativeness**

As the core of this study was a qualitative approach, the aim was not to collect representative data. It was rather planned to cover up a broad spectrum of different service providers to get manifold providers' views on family carers' situations. A theoretical sampling procedure was applied to include all relevant types of service offers for both family carers and cared-for older persons. Due to the low response rates not all the different service types are represented in the sample, and of those included most are only 'represented' by very few cases or just a single case. However, the analysis of the open questions showed, that the answers frequently point out important aspects of service providers. These aspects, of course, cannot be generalised for all service providers, but still many problems and concerns of providers are reported about and are helpful to understand and approach the views of service providers on the family carers' situations.

### **9.2.5 Methods of data analysis**

The structured parts of the questionnaire were analysed with frequency description while a content analysis approach has been used to deal with the open questions. Quantitative data was filled out by 35 persons while 30 persons gave answers to the qualitative sections.

The service providers survey focuses mainly on the qualitative, open questions which should obtain detailed information about usage, existence, familiarity, availability and acceptance of different services. This data was analyzed with in-depth content analysis. The structure of the questionnaire was used as a guideline for building a deductive category scheme. Using this scheme, the content of all answers belonging to each category were analyzed to inductively build several subcategories. The subcategories found in the data have been used to structure the analysis part of this report.

## **9.3 Background Information**

### **9.3.1 Background on the German situation**

It is a characteristic of the German welfare system, that services are mostly operating on a local level and therefore the coverage of the different service types varies a lot over all localities. By law, ambulatory services have high priority compared to stationary (Döhner 1999, 2002; Glaeske 2002).

In the care sector a broad spectrum of ambulatory services for either carers or dependent elder people is provided. This includes not only nursing care or household work but also services like mobile hairdressers, care sitting, meals on wheels, shopping, mobile physiotherapy, mobile rehabilitation services, social home visits and so on (for more details see chapter 7). A deficit in the system is a gap in co-ordination and co-operation of services on the individual, as well as structural level.

Since 1995 the Long Term Care Insurance (LTCI) gives personal and financial support to carers and cared-for persons with a preference of ambulatory care at home over long term residential care (for more information regarding the LTCI see chapter 8). Dependent elder persons are provided allowances if a certain degree of disability was ascertained by the medical service of care insurances (MDK). The guidelines for evaluating the dependency and the resulting extent of help needed are obliged by law. Cared-for older persons can be classified into four different grades of dependency, determining the amount of benefits. Most of the urgently needed professional help for elder persons can be paid by the amount of benefits given by the LTCI. Further help or care is supposed to be realized by informal networks, i.e. family members, friends, or neighbours etc. In this case, the LTCI also provides allowances for selected help offers (e.g. training courses, respite care, measures for adapting the home environment to ease care work). Further details about the LTCI can be found in the German National Background Report (NABARE) which is available for free download at the EURO-FAMCARE web site (<http://www.uke.uni-hamburg.de/eurofamcare>).

### **9.3.2 Sample description**

#### **9.3.2.1 Locality type**

To get information from providers with different structural backgrounds the interviewees were recruited from different localities. 22 providers had their office in a metropolitan area, 7 in an urban and 6 in a rural area (see table 88).

#### **9.3.2.2 Role of interviewed persons in their organisation**

18 responders were the main responsible person in their organisation. A quarter of them, nine persons, were on a managerial level, i.e. closer to the practitioners. 5 were practitioners while the rest (2 persons) assigned themselves into other categories. One service provider did not respond to this question (see table 89).

#### **9.3.2.3 Type and size of organisation**

Most of the interviewed persons worked for voluntary (13) (e.g. the Alzheimer Society) or private business organisations (10). Religious denomination (5), was the third largest type of organisation. Only five of all organisations employ more than 50 people, while small organisations with up to 10 employees or medium companies with 11 to 50 employed people are represented almost equally with a total of 16 and 14 cases of the sample (see tables 90, 91, 94, 95).

### 9.3.2.4 Amount of work concerned with family carers and / or older people

29 of the 35 service providers specified the amount of their work concerned with older people with more than 50 % or nearly 100 %. Even more than half of the interviewed providers offered special services for family carers (see tables 92 and 93).

### 9.3.2.5 Overview of tables 87 to 95

**Table 87: Overview of sample size and response rates**

	North	West	South	East	Total	Percentage
No. of sent questionnaires	89	66	65	95	315	100 %
“Does not apply” (i.e. provider did not fit into sample)	18	25	9	26	78	24.8 %
“Cleaned” sample size	71	41	56	69	237	100 %
<b>Total return (by phone)</b>	<b>21 (2)</b>	<b>5</b>	<b>5</b>	<b>4</b>	<b>35</b>	<b>15.8 %</b>

**Table 88: Number of service providers by locality type and kind of organisation**

Locality Type	What kind of Organisation				Total
	Local	Local but part of National Organisation	Regional	National	
Metropolitan	9	2	11	-	22
Urban	3	1	2	1	7
Rural	-	-	6	-	6
Total	12	3	19	1	35

**Table 89: Interviewed person’s role in his / her organisation**

Role	Total Number
Head	18
Manager	9
Practitioner	5
Other	2

Missing Values: 1

**Table 90: Number of service providers by locality type and type of organisation**

Locality Type	Type of Organisation						Total
	Public social care	Public health care	Relig. denomination	Volunt. organisation	Privat business	other	
Metropolitan	3	1	4	8	5	1	22
Urban	-	-	-	4	1	2	7
Rural	-	-	1	1	4	-	6
Total	3	1	5	13	10	3	35

**Table 91: Number of service providers by locality type and number of employed people**

Locality Type	Number of employed People			Total
	Small (10 or less people)	Medium (11-50)	Large (more than 50)	
Metropolitan	12	6	4	22
Urban	1	5	1	7
Rural	3	3	-	6
Total	16	14	5	35

**Table 92: Number of service providers by locality type and percentage of activity concerned with older people**

Locality Type	Percentage of Activity concerned with older People			Total
	Less than 50 %	More than 50 %	100 % or nearly 100 %	
Metropolitan	4	2	16	22
Urban	1	1	5	7
Rural	-	1	4	5
Total	5	4	25	34

Missing Values: 1

**Table 93: Number of service providers by locality type and percentage of activity concerned with family carers**

Locality Type	Percentage of Activity concerned with Family Carers			Total
	Less than 50 %	More than 50 %	100 % or nearly 100 %	
Metropolitan	7	3	-	10
Urban	1	1	2	4
Rural	3	1	-	4
Total	11	5	2	18

**Table 94: Number of service providers by type of organisation and provision of services for family carers**

Type of Organisation	Provision of Services for Family Carer		Total
	Yes	No	
Public social care	3	-	3
Public health care	1	-	1
Relig. denomination	3	2	5
Volunt. organisation	5	8	13
Privat business	4	6	10
Other	2	1	3
Total	18	17	35

**Table 95: Number of Types of Service Providers by Locality Type**

Type of Service	Metropolitan	Urban	Rural	Total
Advice Centre	5	1	-	6
Carer Support Group	2	2	-	4
Day Care Centre	-	-	1	1
Domestic Care Service	7	1	4	12
General Practitioner	3	-	-	3
Geriatric Department	1	-	-	1
Hospice	-	2	-	2
Nursing Home	1	-	1	2
Respite Care	1	-	-	1
Telephone Helpline	1	-	-	1
Temporary Residential Care	1	-	-	1
Training Course in Caring	-	1	-	1
Total	22	7	6	35

The assignment of cases to the above listed service provider types follows the European list of services which was already used in the national family carer's survey (see chapter 7).

## 9.4 Results

On the following pages the results of the analysis of the open questions are presented. Due to the experiences from the pre-test of the service providers survey only a small amount of information and data in part C - with the questions concerning older people - were expected. In Germany many service providers considered the complete second part of open questions as duplicative and misunderstanding and mostly answered with "see above", if they answered the questions at all, or the answers were fairly congruent. Furthermore, many support services often help both the carer and the cared-for, for instance the care sitting service for people suffering from dementia. In these cases, the questions related to the carer have been answered while the questions related to the cared-for would have been identical, thus the questions of part C mostly were left out. Therefore, the results of both parts are presented as integrated text together in the following paragraphs and whenever necessary, information or results which explicitly refer to part C are additionally indicated as such.

There are two tables with the quantitative overview of the provided services (see table 96 and 97). It was intended to use this list of provided services for a quantitative description of certain questions as introduction into the qualitative analysis steps. By numbering the amount of given answers in relation to the type of service provided, the importance of each aspect (e.g. problems in access, customers' satisfaction, problems with costs etc.) should have been emphasized, thus showing the relations of problems according to the service type as stated by the service providers. In our German sample we had several difficulties with the adequate usage of this quantitative overview. As already mentioned, our service providers do not strictly separate services which target carers and those targeting older people. They usually have a more holistic picture of the care situation, and therefore they see their offers as helpful for both the carer and cared-for. This is supported by the fact that then LTCI pays only to the cared-for, even if the offer is directed to the family carer. As a result, part C of the questionnaire mostly contained fairly similar answers or wasn't filled in at all. That means, services already mentioned in part B also appeared in part C of the questionnaire. Another

problem are the short answers, in some cases even just one single word. When asking for “Do you charge for your service? Does this cause any problems?” and getting “yes” as answer, it is problematic to associate this answer with the concrete question, hence this case could not be used for a quantitative overview of certain categories found in the data. As a consequence we decided not to use explicit numbers when we describe our results. Instead, it was only indicated which type of service mainly refers to the described results and whether there are certain service types to which the results apply or if there are services which did not answer at all, thus having no relation to a found category according to our data.

As the described results represent the service providers’ opinion it is not surprising that they might use the chance of answering open questions to give an overly positive picture of themselves.

### **9.4.1 Goals and benefits**

As there was an overlapping between goals and benefits in the answers to the questionnaire in the following we analysed the two questions together. The objectives and benefits declared by the service providers are mainly to relieve the carers from the burden of caregiving, to prevent physical and psychical exhaustion and improve carers quality of live and even so allow the person in need to stay at home as long as possible.

#### **9.4.1.1 Information and advice**

One basic necessity as stated by many service providers is to enable carers to have relief from the burden of care. This includes the need for the provision of information and advice about the clinical picture and the course of the diseases, the interaction with the special behaviour of persons suffering from dementia, the possibilities of financial support, like the Long-Term Care Insurance application, the availability of services and the existing opportunities.

*“In the training courses the family carers get many information about the progression of certain diseases, especially under consideration of diagnostic and therapy measures, how to cope with strange disease-related behaviour, which kinds of support are available and what legally possibilities they have.”*

This information is seen as a necessary precondition for making further decisions and finding access to service providers.

#### **9.4.1.2 Physical support and relief**

Teaching (training courses) caring techniques and impart knowledge of the caring process is one way to prevent carers from physical exhaustion and improve their confidence in the care situation.

*“I think, family carers have the advantage of learning useful techniques, which make life easier for them when they care.”*

Another alternative is to maintain the autonomy of the person in need as long as possible by providing activating care.

### 9.4.1.3 Emotional support and relief

Carers do not need only physical but also emotional relief. This opinion is shared by almost all of our questioned providers. One possibility to give emotional support is the offer to talk about one's own experiences, fears and sorrows in an atmosphere of trust. That may happen with the aid of professionals or in self-help groups for family carers.

*“The participants of carer support groups can exchange experiences with other concerned persons, can build up co-operation help networks and by that spare new carers down wearing experiences.”*

The knowledge of not being alone and not being the only one trying to cope with the care situation may mean a great relief to many carers. Arranged meetings with other carers also prevent isolation from social contacts outside the family.

### 9.4.1.4 Spare time and the possibility to recreate

It is known that many carers of highly dependent older people feel as though they have to look after the person in need 24 hours a day (Meyer 2006). If so, they need the option to take a break every now and then, to attend to their own interests, to find some time on their own and relax from the burden of care. Carers need support to care also for themselves and draw new strength again. This is what the service providers reported and what in their opinion seems to be necessary for family carers.

### 9.4.1.5 Immediate crisis intervention

Sometimes situations come up which overextend the carer, especially in the care of persons suffering from dementia, like increasing aggression and violence, difficult behaviour, or runaway tendencies. Sometimes troubles just accumulate during several months. Excessive demands like these can even cause a collapse of the carer. Then carers need the possibility of immediate crisis intervention in the form of professional advice and support.

*“We also offer very immediate advisory conversations. Support for everyday life, developing next steps of what to do and how to cope with problems, getting back a bit of normality in everyday life.”*

For the service providers it is important that there is always a contact person available, at least on the phone in these cases of emergency and that this service is free of charge.

### 9.4.1.6 Terminal care

In the case that carers do not want to put their dying relatives in hospital but accompany their terminally ill relative on his last way at home, they might need professional support. In our sample, hospice initiatives and also some domestic care services reported about the provision of this support and offer palliative and terminal care and assistance at the process of mourning.

### 9.4.1.7 Enabling a life in a familiar environment

The previous aspects mentioned by the service providers mainly focus on the carer's relief which again has positive effects for the quality of life of the cared-for. By unburdening the carer, the older person gets the chance to stay at home longer. Many of the service providers, primarily the ambulatory services, see this aspect as one of the main benefits for the

cared-for person. Enabling a life in a familiar environment can be achieved by reducing stressors and burden of the carer, and the service providers think this will lead to an improvement of the cared-for as well as the carer's quality of life.

*“The support of autonomy has almost always positive effects on the psychological constitution. Enabling a life at home can be prolonged by the above mentioned measures [usage of technical aids, training in caring, changes in home environment for care work, emotional support: the authors].”*

## 9.4.2 Usage and Access

### 9.4.2.1 Access of family carers to services

One of the most important support for family carers stated by our service providers was information about the type of help that is available and how to access it (see section 9.4.8). As these aspects affect all types of services, nearly all of the questioned providers shared this opinion. Considering this, it is interesting to know which ways and means service providers set in order to make their offers more known to their target group. How do family carers usually access the provided services and how do they get to know of different existing types of help?

#### *Word-of-mouth recommendation*

According to our service providers, the most common way family carers find out about available support seems to be word-of-mouth recommendation. This applies to all types of services. Certain service providers have evaluated the channels of recruitments and how their customers get to know about their services and the results validated the way of word-of-mouth-recommendation to be most effective. An advantage in this way of access is seen to be the higher acceptance of using external help.

*“We did a customer evaluation and the results were that our support offers get the highest acceptance when they were recommended by word-of-mouth.”*

Provisos against support services seems to narrow when the type of help was recommended by a good friend, neighbour or well known person, thus encouraging the family carer to take the initiative to ask for help.

#### *Newspapers and brochures*

Word-of-mouth recommendation cannot be the only way of spreading information about their offers for the service providers. It is getting more and more important to inform family carers about available as well as existing help to reach those carers who have less or no contact to care experienced persons in their circle of acquaintance. One method to achieve this is advertisements in newspapers, local press or brochures. All of the questioned service providers – except the general practitioners – use these media to promote their offers. The advantage is wide spread advertising which can also be noticed by people who are not in a carer role, but know someone else who is. To a certain degree advertisement in newspapers or brochures can strengthen the effect of word-of-mouth recommendation.

#### *Advice centres and other information networks*

In Germany there is an increasing co-operation between hospitals and ambulatory support services. One of the tasks of the so called “Social Services in Hospitals” is the preparation of

the discharge of patients from the hospital. This includes the supply of family carers with necessary information concerning how to arrange the care at home, which types of support are available and how to access them (Caritas 2005; Bräutigam et al. 2005). The same way of informing inpatient older persons who will be in need of care when they come back home applies to other in-patient institutions in our sample like geriatric departments, respite care or rehabilitation hospitals. Another co-operation network, according to the answers mostly given by domestic care providers and general practitioners, is established between general practitioners and ambulatory service providers. Like Social Services in Hospitals, the general practitioners in our sample described the information of family carers and their depend elder persons when certain diseases have been diagnosed as one of their tasks. Both of these types of recruiting new customers were specified quite often by the questioned service providers. But especially the frequent mentions of co-operation between ambulatory services and general practitioners can be reduced to the sample bias, i.e. the sample contains mostly very committed general practitioners. Common experiences show that in practise these networks are not very well developed.

#### *Other ways of accessing services*

Other ways of how family carers access services were internet, telephone directory, open house day events or parish priests but these seem to be rarer ways of access.

#### **9.4.2.2 Problems in accessing services**

Although the service providers' effort to enable easy access for customers is high, there are still different barriers which detain family carers from accessing or using support services. Although particularly in rural areas structural conditions, like the amount and variety of service types, were expected by the questioned service providers, most of the given answers dealing with barriers were linked to family carers' attitudes or related problems.

#### *Sense of shame*

One of the most frequently mentioned reasons that could keep customers away from using help was the sense of shame of family carers. This attitudinal barrier seems to apply to all types of providers in our study with the exception of general practitioners, who generally faced no problems with shame of their patients. According to the answers of the service providers shame can have several causes, for instance, the privacy and possible problems within families. People are afraid to let foreign persons look into their households when family crisis or conflicts have been kept inside the domesticity for many years. This is true for violence in families, independent of who resorts to violence, either the carer or the dependent elder person. Another reason for sense of shame might be the behaviour of the elder person due to illness. Especially people suffering from dementia behave unusually and unpredictably the more the disease progresses.

*“What we know is, that in our rural area, many people simply have a huge sense of shame when someone external wants to look into their households. Things which were kept secret for decades might be revealed.”*

Friends and neighbours often have problems coping with such situations, which affects family carers in a way that they are ashamed for their older relative and retract. This results in social isolation and complicates accessing support services. Care is tabooed (Lüdecke 2007). How can service providers report about such problems when they usually do not reach these persons? One solution was the already above mentioned advisory work from the

hospital social services, where carers are recommended to use professional help services in order to better cope with the care situation. Accepting the advices from social service workers seems to be one way to eliminate access barriers.

#### *No available time*

Further major barriers of accessing services mostly reported by providers with offers like carer support groups or training courses is the (non-)available time to look for adequate types of help. Especially in care situations where the carer burden is quite low at the beginning people see no need for support at that time. The approaching problems are often underestimated. But with increasing effort for caring, the time available to inform oneself about support services diminishes rapidly and finally, particularly when carers have no informal support network, they find themselves in a situation where they missed the opportunity to look for help offers.

*“The specialties within the process of care for people suffering from dementia makes the search for help difficult. Due to the slow and sneaking progress of the disease the carers can not estimate the upcoming problems, and later the high burden complicates the search for help.”*

The high degree of burden makes it difficult to take time for information search.

#### *Using help means failure*

Some service providers – mainly those offering training courses, carer support groups and domestic care services – reported about family carers who have a very pronounced will of managing the care situation alone. The carers' ambition is that they have to cope with the problems themselves, using external help is seen as failure.

*“They have a strong sense of ‘autonomy’. They equate help usage with failure.”*

This aspect is related to the family carers' attitude that they often do not want to relinquish from caring for their relative: It has always been their task and there is no reason why they now should concede this duty to other persons.

#### *Uncertainty about the adequate type of support*

People in need of help also might be uncertain of which types of help will bring the most adequate support and meet their needs. There are doubts about the benefits of the help and whether it is really supporting them and their cared-for relatives. It was mostly providers offering carer support groups and domestic care services who reported about such statements made by carers. Furthermore, family carers are afraid that the cared-for will reject the offered support anyway and do not even try to use help services, a problem which mainly affected the domestic care services in our sample.

#### *Humility detains people from using help*

Another aspect mentioned by the service providers was humility. Some family carers do not want to burden others, not even the health care or Long-Term Care Insurance even though they have legal claims for financial and / or professional service support.

#### *Other barriers*

Care is often seen as a taboo, especially if death, dying or serious diseases are involved. Beside the sense of shame related to strange behaviour of the cared-for person, the taboo

generally concerns aspects of dying or illnesses. It costs family carers many self-conquests to ask for information or help. Other reasons mentioned by the service providers for not using help result from being unaware of available or existing services or carers don't find supports that can be combined with paid employment or fits in their daily routines.

#### **9.4.2.3 Extent of service use by family carers and older people**

Independent from the type of service, most of the service providers reported satisfying usage rates of their offers.

Domestic care services mostly offer several different types of help and all of them seem fully utilised. The advantage for domestic care services of providing a wide range of service types is that they can bind their customers due to comprehensive help offers, which enables service providers to build up coordinated service structures. This again seems to affect high utilization.

Some domestic care service providers report about higher usage of services for older people which are paid for by the Long-Term Care Insurance. In contrast to help offers for carers which are not financially supported to such an extent and are used slightly less.

The carer support groups are in general well accepted, independent of whether they are part of a comprehensive domestic care service or standalone offer. However, in most of the groups there is still place for new members. Only some providers report outstanding utilization that make the development of further carers supports groups necessary, as the maximum number of participants have been reached.

Providers offering phone and personal advisory services also report high utilization. Particularly the fact that these services are in general free of charge makes the usage for customers attractive. Moreover, these offers provide fast and useful advices and are usually the first step of compiling several needed help offers for a stable care arrangement.

### **9.4.3 Coverage**

#### **9.4.3.1 Services provided for family carers and older people**

##### *Domestic care*

As known domestic care is quite a well known and accepted offer which is also reflected in the German sample and data. It provides primarily nursing, caring and domestic work in the homes of the persons in need and often relieves the relatives from a heavy physical burden. Domestic care services are visiting their clients from several times a week up to three times a day and often provide tele rescue alarm also over night. The services are widespread all over the country and in the sponsorship of the community, charities or private provider. Their benefits are partly subsidized by the Long-Term Care Insurance and the health insurance company (Busse & Riesberg 2004).

##### *Advice service for older people in need of care and their families*

Special services for counselling inform carers about available services, like domestic care, day care centre, respite care, care groups, meals-on-wheels or emergency help-lines and about the possibility to apply for care facilities and financial support to do necessary home modifications. In our sample these services are mainly provided from advice centres of chari-

ties and communities, but also from domestic care services. Advice services deliberate along with the relatives on applications of guardianship, give advice on financial facilities like the Long-Term Care Insurance or social aid and help to acquire it. They provide information about the special clinical pictures and course of diseases and often also manage the placement of nursing homes. They give immediate advice to carers in case of need and sometimes even accompany consultants for several months. Advice centres also organize events and perform public relations.

#### *A Crisis intervention by telephone*

These phone services provide immediate crisis intervention for 24 hours a day. That enables worn out carers to contact the advice service from home whenever they need assistance. They can ask for assistance without needing someone to look after the depending older and can ask for advice also anonymously.

#### *Training courses for non-professional carer*

Training courses on caring are especially offered by domestic care services to qualify carers to perform a care which is up to the standard the dependent elder needs and simplifies the caring for the provider. There are, but only few, cases in our sample where this offer is provided by persons or organisations not belonging to a comprehensive domestic care service. Carers acquire not only specific care techniques, but also learn how to regain their own strength. The aim is to prevent the carer from exhaustion and to assure that the person in need can stay at home as long as possible. These courses are either given for groups of carers or especially in rural areas individually in the homes of the person in need.

#### *Self-help groups for family carers of people suffering from dementia.*

These groups are meanwhile quite well established all over the country and offered by self-help organizations like the Alzheimer Society, charities or domestic care services. Normally the relevant relatives meet once a month, often supervised by a professional social worker or a practiced relative and exchange their experience, talk about their current problems and look after individual solutions all together. These offers are usually for free.

#### *Training courses for the carers of people suffering from dementia*

In addition to the self-help groups some of our providers, independent from the type of service they are, established training courses for the carers of people suffering from dementia. A special program "Assistance to help" was developed from the German Alzheimer Society. The intension is to impart knowledge about the clinical picture and the course of dementia, to better understand the sometimes difficult behaviour of the older person and to appropriate strategies on how to cope with critical situations.

*"The seminars, as well as the carer support groups work against the considerable burden and the increasing social isolation of carers from people suffering from dementia."*

These courses also get through to people who have problems to explicitly talk about their difficulties. For those carers it seems to be easier to search for practical support in hope of additionally getting emotional relief.

#### *Care groups for people suffering from dementia*

The original aim of these groups according to the service providers' given answers was to allow relatives to join the self-help group for family carers which is organized in the mean-

time, knowing their dependent older person is cared for. Meanwhile, these groups are also offered to relieve the relatives and enable them to enjoy spare time. These groups take place about once a month up to once a week for several hours supervised by a professional carer and assisted by special trained unsalaried volunteers. The major part is financed by the Long-Term Care Insurance. The providers are the ones announced above.

#### *Terminal care and mourning courses*

In addition to domestic care services, special hospice initiatives offer terminal care and palliative care with the aim to not only support the dying but also accompany the whole family. These enable terminally ill people to die at home and prevent families from putting their relatives in hospital. It allows families to stand by their cared-for person and enables them to take leave. Hospice initiatives also offer mourning courses to the surviving dependant. These services are mainly provided by trained unpaid volunteers.

### **9.4.3.2 Customers' needs which are not covered by the provided services (gaps)**

#### *9.4.3.2.1 Additional personal contacts*

The telephone help-line service provider sees an increasing demand of personal contacts and conversation. One of the reasons customers use the telephone help-line service is the opportunity to stay at home because they can not leave the dependent older person alone. The personal contacts between the service provider's staff and the carer can not take place in a form like an advisory conversation in the service provider's facilities or offices.

*“For example home visits. That would be a completely different situation for the concerned person, but we hardly can provide this service right now.”*

The only chance to enable the required personal contact is to visit the customers at their home. But this can only be realized if more employees are available. That means, personnel capacities need to be increased. The demands for more personal help at home is also true for advisory centres who cannot always cover the service of home visits.

#### *9.4.3.2.2 Night care and care around the clock*

As known, domestic care services usually provide nursing help during the day. During the night the carer is depend on him or herself. For a short period, some of our questioned domestic care service offer help at night but it is not possible for them to provide night care over long periods. One solution is the co-operation with in-patient care centres although some of the ambulatory care providers in our sample would like to offer this service on their own. In certain cases where the dependent elder person is highly disabled the questioned ambulatory services would like to provide an additional care around the clock, this is financially not manageable at the moment.

#### *9.4.3.2.3 Flat-sharing community for people suffering from dementia*

Quite a new type of service in Germany is flat-sharing communities for people suffering from dementia. Small groups of about eight to ten persons with dementia live together in a flat and are accompanied and cared for by professional staff in cooperation with the family carer. This kind of segregated care tries to meet the needs of persons suffering from dementia by responding to the special demands of this clientele, namely offering a safe and familiar environment and the opportunity of having enough time for every single inhabitant.

*“Our future visions are to establish more flat-sharing community groups in our area for people suffering from dementia. About 10 people with the dementia disease shall live there in family-like structures and cared-for individually.”*

The questioned service providers see more demands for this type of service than is currently being met.

#### 9.4.3.2.4 *More time for conversation*

Many older people have less social contacts when they are less agile and their mobility is reduced. The personnel of our questioned ambulatory services is often one of the few opportunities for the elder person for a chat. Yet this need can not be met by the service providers due to the tight time frame which is available for the offered services. The care time being paid for by the Long-Term Care Insurance does not include longer personal contacts and conversations.

*“The need for chat and conversations often exceeds our available time frame. These services are not included in the service catalogue (of the LTCI). The law rule makers are requested to give this aspect more consideration. Mostly we take our free time for conversations with our customers.”*

### 9.4.4 **Quality**

#### 9.4.4.1 **Assessment of customers’ needs**

One aspect which features in high-quality services is the preparation of support types before the actual help is provided. This is mainly done by elaborate assessments of the carer’s and cared-for person’s needs.

##### 9.4.4.1.1 *Home assessments*

Especially for domestic care services it is necessary to be familiar with the situation of carers and their families face-to-face at home. To achieve this aim many of our service providers have certain assessment procedures based on flexible guidelines. With this basic scheme typical daily routines, rooms and facilities, family habits and the special demands and needs of the customers are being assessed. The service providers can get an impression of the condition of the domestic environment and estimate the necessary help.

*“Well, we do home visits and advise our customers to use some services on trial, because we tend to bolster the carers up, saying ‘you can’t cope with everything, you need some help for certain tasks’, when they obviously need external help.”*

After assessing the needs advisory conversations about the extent of support are conducted.

##### 9.4.4.1.2 *Conducting advisory conversation*

The most important, or at least most frequent used method of needs assessment according to our providers is to conduct an advisory conversation. These personal discussions are either made subsequent to home visits or when people in need of support arrange personal contacts with service providers. The domestic care service providers try to ascertain the type and extent of necessary help by evaluating information about the medical history and biographical information of the person in need. With well elaborated information the likings of

the cared-for person can be taken into account when planning the support, which is very important to service providers. This shows the importance of the customers focus and emphasizes the high quality standard service providers want to abide.

*“Yes, we do care planning, which is individually customized for the cared-for. The demands of the carer are, where possible, taken into consideration, e.g. at what time the help shall arrive, so it fits into the daily routine. We have to align ourselves to the local conditions, not the other way round.”*

Conversations are also conducted with involved general practitioners to increase the knowledge about the cared-for persons. Usually this information is received in advance, so service providers can prepare their advisory conversation with their customers.

#### *9.4.4.1.3 Permanent assessment of needs*

Once a person's needs are ascertained, our service providers' employees permanently monitor the development of the care situation and the physical, psychological and emotional constitution of the family carer and the dependent older people. This applies to our questioned domestic care services, who observe the situation at home, as well as to carer support groups or advisory centres, who permanently try to find out which problems are important to talk about. Thereby providers can validate positive and negative effects of their support and detect areas of needs which are not covered by the provided help. Thus, necessary changes to the extent of the support needed by either the carer or the cared-for person can be induced immediately.

#### *9.4.4.1.4 Other assessment methods*

Further methods of assessing the customers' needs are not mentioned, although certain scales like IADL or MMSE for measuring the degree of dependency or dementia are common tools for nurses for the older people and social worker. This doesn't mean that these instruments are not familiar to the questioned service providers, it just could be that they take these assessment tools for granted.

### **9.4.4.2 Evaluation of customer satisfaction**

Another important aspect of service quality is to meet the customer's needs and wishes. Satisfied customers will not only continue using the offered help but could also recommend the service provider by word-of-mouth. To measure customer satisfaction, their opinions about certain characteristics of the service type and the inset care workers are evaluated.

#### *9.4.4.2.1 Customer survey*

Many of the questioned service providers have professional evaluation methods to obtain information about the satisfaction of their customers. The data is collected with questionnaires which are handed out to the family carers. In some cases, where appropriate, e.g. domestic care services, the dependent older person is also involved and asked for his or her opinion. The results accrue by detailed data analysis, thus provide useful statistics about the customer's satisfaction profile. Some providers use methods which are less precise and complex and “only” based on short feedback from the customers.

#### 9.4.4.2.2 Existing problems in quality

Although from the service providers' view most customers were very satisfied with the used services, still some problems in quality remain. For example, for economic reasons, when planning their trip routes to visit all patients, domestic care services often can not take into account customer's demands that the help arrives at a time it fits most in the family carer's daily routine. Especially when due to the cared-for person's habits this aspect becomes most important, disaffection arises.

*"The changing personnel who visits our customers and that we can't always arrive at the time the carers want us most, that were points of critique. In our rural area we sometimes have routes of more than 60 kilometres, from village x over y to z. You can imagine, if you have a customer in each small village, you can't just say 'I drive to the next villages and then come back to you again later'. That is not affordable for us."*

The only solution for both parties if the carer's demands and service provider's capabilities mismatch seems to be a compromise on a time which is acceptable for all involved persons and still manageable for the care worker. The service providers pointed out that they usually are very open-minded towards criticism and take it as a chance for further development of their offers.

#### 9.4.4.3 Examples of good practise

In the following section we present several models of good practice described by the interview services providers. It turned out that the providers offer a wide range of different support services for family carers and their cared-for.

##### *Telephone help-lines*

The service provider offering telephone help-line reported about their attempt to organize a carer support group but experienced several problems with this try. The main problem for the family carers was the lack of time available or the inept dates when the meetings took place. Thus the service provider established a telephone help-line offering the carers the use of this help according to their time management. Employed family carers for example could call the help-line from their office, others who feel confined indoors can use this help without needing to leave their home. These advantages were seen by carers and thereby the usage of this offer highly increased to the service provider's complete satisfaction. But there are still more particular features pointed out by the questioned provider. Family carers can stay anonym if they wish. There are no personal face-to-face contacts necessary to use this kind of help. This lowers the barrier of usage for potential customers. Furthermore people in need of advice can use his help secretly, e.g. alongside the shopping. This case is true for carers who feel the urgent need to talk about their problems but can not do this in presence of the cared-for, if this person does not want others to know about the care situation.

*"We wanted to offer a service for those who are employed and for carers at home, who just want to go to the pharmacy, so they can talk to us without the cared-for realizing that other persons talk about him or her or care-related problems. And that works quite well. We often have situations like someone saying 'I'm on my way to the pharmacy and just wanted to call...'"*

### *Care sitting for people suffering from dementia*

It is often reported that people who care for older persons suffering from dementia have the problem that they can not leave them home alone. Especially when the disabled person has high cognitive but few physical impairments, run away tendencies and uncontrolled behaviour can be very dangerous for the dependent older person. Carers in such situations have nearly no opportunities to manage other necessary things beside caring. To help persons with such demands, some of our service providers – preponderant domestic care services – offer care sitting for people suffering from dementia. Carers do not need to use day care centres or similar services and thereby have no problems with organising shuttle transports and related procedures. Employees from the service providers visit and stay at the family carer's house, looking after the depend older person, thus enabling the family carer to have some free time. The reasons for taking this opportunity is not always the need of free time, sometimes the family carers just want to talk over problems with the service employees. The carers usually should order this help in good times although some providers can make this help in urgent cases available immediately, i.e. from one day to another. The spontaneous help is usually provided by trained volunteers or subcontracted employees.

Similar good working examples of good practise found in our sample are day care centres which offer shuttle services, thus causing no extra effort for the carer to bring his or her dependent older relative to the service provider's buildings. The advantage of day care centres are the customer-focused facilities enabling comfortable care and activities with the cared-for. Furthermore, the professional staff is well versed with all facilities, which might not always be true when the staff is at the family carer's home. Hence certain activities can be realised more effectively.

### *Carer support group "Living with Dementia"*

Another example of good practise is carer support groups dealing with a special topic, mainly targeting family carer who have a dependent elder person suffering from dementia. The cruel thing about this disease are the changing of the affected person's mental state and behaviour. Life long established intimatenesses and interpersonal relations are being destructed by the dementia disease. To cope with such a difficult situation, carers can attend carer support groups and can exchange experiences and develop coping strategies.

*"The problems of the carers are the centre of interests during that evening. They receive understanding for their problems, support and suggestions for solving their problems. An important aspect is: the carers open themselves to the group, they discuss problems and find solutions together."*

Within these groups family carers all share the same sorrow which makes it easier for each participating person to open up towards others and talk about problems. The moderation by the service provider is passive, only giving advice to special questions or when else necessary.

### *Training courses*

Well running services as stated by service providers are training courses. The attendees learn a lot about theoretical backgrounds of caring and different diseases and about practical assistance they need for caring. In addition to this many participants of training courses grow together to a friendly coexistence and continue meeting at informal gatherings. These meetings are comparable to carer support groups but without professional moderation.

### *Campaign and information days*

One of the service providers who usually does advisory work also organises twice yearly campaign and information days about the Alzheimer's disease ("Hamburg Alzheimer Days") in co-operation with the local Alzheimer Society. This campaign lasts for five days and aims at informing and enlightening the concerned family carers and interested people, who are not necessarily caring for someone else, about all facts related to the disease and its possible consequences for the care situation. The Alzheimer Days have many interested visitors and contribute to a better understanding of Alzheimer's disease.

### *Comprehensive offers within one facility*

Nursing homes usually have more offers for older in-patient people than for family carers. One of the service providers puts the facilities of a nursing home at disposal and offers several services like having lunch, training courses, physiotherapy and other free time activities for people living in the area.

#### **9.4.4.4 Things that could be improved**

Although the service providers are very satisfied with the extent of the service use by their customers and get mostly positive feedback on their offers, they still strive for further development and quality improvement of their services. This is necessary due to the increasing competition which means that the highlight of help offers is their quality and their outright service.

### *Home visits and personal contacts*

As stated in chapter 9.4.3.2.1 the questioned providers offering telephone help lines want to meet the increasing demands of their customers of personal contacts and conversation. This aspect is both perceived as a gap of service provision and something to be improved.

### *Expansion of existing offers*

Some providers have initiated certain services to test out the acceptance and how these offers are running. During these test phases service structures are not completely developed, thus more expansion is needed when the services run well and customers express increasing demand. Some service providers experience difficulties by realizing these aims due to the rural structures of their occupation area. For example, care sitting provided by domestic care services means long ways to customers, thereby high driving costs arise. Furthermore, only personal with driving license can carry out these tasks. These problems must be solved by the service providers to reach their goals.

### *Public relations*

Although the service providers offering carer support groups or training courses report good attendance, they still experience difficulties in reaching the carers attention and their motivation to participate in such help offers. These services are not used as readily as other help, e.g. domestic care. Therefore more public relations like information activities, opinion polls or advertisement seem necessary, measures which mostly refer to chapter 9.4.2.1

### *Further aspects*

Most of the service providers' ideas and plans of what could be improved are linked to personnel capacities. As employees make the most of the costs but are frequently the only pos-

sibility of realizing the development and improvement of existing or new help offers, many service providers try to build up a mixed structure of both qualified professional and (qualified) voluntary employees. Here lies one of the main problems for service providers, as many of them report a lack of voluntary staff. Personal costs and the lack of volunteers are the main barriers for further service development.

### **9.4.5 Attitude towards family carers and older persons**

With reference to chapter 9.4.4.1 one can say that the various types of customers' needs assessment emphasize the importance of care-givers' experience and knowledge within the whole care and support process. The opinions of the family carers are listened to and the special demands of the dependent elder people are taken into consideration. These results are strengthened by the analysis of possible partnership approaches as stated by the service providers, i.e. family carers are treated as partners during the whole assessment and monitoring process.

#### **9.4.5.1 Involvement of family carers and older persons**

The advisory conversations our service providers have with family carers in the run-up to potential usage of their offers usually involves both family carers and cared-for persons, and should the occasion arise, the other family members are involved as well. Single talks behind one's back are exceptions of this procedure which occur when someone – usually the carer – wants to relief him- or herself by talking over problems. That means the care process normally is planned by all involved parties with the family carers and dependent older people bringing in their opinions and demands and the service providers giving advice and hints on how to organise the care and which supports are possibly needed. Normally the service providers let the customers express their wishes and try to judge the needed type and extent of support. The customers are then being shown possible solutions to their problems including which type of help fits most to round off the care arrangement. This also means that the necessary work and care is divided between all supporting persons, i.e. family members and professional carers, and both parties complement one another.

*“The objectively ascertained extent of help needed often does not match with the subjective perception of help needed. Here we first have to show an interest in the subjective needs of support, and then little by little have to approach the necessary extent of support. We do this by trust achieving measures and valuing and accepting dealings with the older person.”*

The questioned service providers believe that only a partnership relation between them and their customers leads to effective and satisfying results. Especially domestic care services emphasized the need for partnership and involvement of both the carer and the cared-for person because they enter their customers' privacy each day which should only happen in reciprocal approval and acceptance.

The involvement of the persons concerned by support services does not stop after the first home assessment or advisory talks. Rather the assessment and monitoring process is being continued during the whole time the help is provided. This may lead to adjustments of help type or amount always depending on the needs and demands of carers and cared-for.

According to the statements of a few service providers, sometimes the partnership approach turns out to be complicated or nearly impossible, especially when family carers do not allow

co-operation and refuse suggestions or support for planning the care arrangement. Service providers then only have the opportunity to fulfil the customer's demands, independent from whether they have a different point of view with regard to the necessary type and amount of help. Only in those cases where the service providers think that the carers act against the interests of the cared-for persons, measures are initiated against the wishes of family carers.

#### **9.4.5.2 Family carers and older persons as experts**

Beside the family carers' and cared-for persons' expertise according to their biographical background and the connected special demands and opinions of service provision as described in the previous paragraph, family carers can also hold another role as experts. This applies to carer support groups where the attendees do not need certain kinds of support but more take the opportunity to talk over problems and exchange experiences.

*"The title 'partner' doesn't fit for my work. In the seminars and carer support groups I see the carers as experts of their every care situation while I am the one who just provides the carers with the requested information, but sometimes inspirations as well. In my opinion carers need above all respect for the work they do."*

Here the moderating service provider sees the carer as expert and only supplies the participants with technical or professional information and in some cases, if necessary, with advice. From the service providers' point of view, carers predominantly deserve more credit for the good job they do. This underlines the expert status of family carers in the opinion of some service providers.

### **9.4.6 Costs**

#### **9.4.6.1 Services which are free of charge**

Not all services are being paid for by the user. Of course these types of support have the least problems with service costs. In general the advisory services are free of charge independent from whether they are being offered by ambulatory care services or advisory centres. The same applies to carer support groups or telephone help-lines where family carers as well do not have to pay for the usage. Costs are mainly covered by the German LTCl or in case of some voluntary organisations the services are financed by charitable donations.

#### **9.4.6.2 Services with fees required**

There are several services which require fees to cover the upcoming costs. Services which belong to the basic care supply are usually being (partly) paid for by the German Long-Term Care Insurance. If a certain degree of disability was ascertained by the medical service of care insurances (MDK) the Long-Time Care Insurance gives allowances for care service support. The services which are being paid for are normally connected to the kind and extent of help and support demanded by the cared-for person. Moreover, types of services are being financed that help the carer to sustain the care situation at home. This is derived from the principles of the Long-Term Care Insurance which say that ambulatory care at home is preferred as opposed to long-term residential care. That means, beside the typical types of support by domestic care services other support services are also subsidized. For instance, customers usually must pay for using care sitting for people with dementia, other ambulatory sitting services or day care centres. Other often stated types of help requiring fees are train-

ing courses for family carers. The major part of the arising costs is paid for by the Long-Term Care Insurance while for some types of support the customers have to pay little equity ratios. Usually the small amount of required fees does not seem to be an obstruction for usage and acceptance of those services, at least the questioned service providers stated that they experienced no problems with the service costs.

## 9.4.7 Future development

### 9.4.7.1 Most important future challenges

Service providers face various challenges according to future development of existing or new help offers in order to close uncovered gaps or according to meet legal prevailing circumstances. Some plans might be realised more easily than others. In the following paragraphs the most important future challenges for service providers are discussed.

#### *Enhancements of services*

Many of our questioned service providers see the enhancement of their help offers as one of the most important future challenge, independent from what type of help they offer. Service providers mainly want to enhance their existing offers which are well used. Moreover the establishment of new offers is seen as major challenge to those providers who experienced service provision gaps which could be covered by themselves. But also the improvement of quality, for instance by qualifying the service staff, is a popular concern.

*“It’s not only about developing the honorary post. We also want to strengthen the professional services. That’s a major concern for us.”*

#### *Managing the costs*

Although the Long-Term Care Insurance prefers the primacy of ambulatory services over residential care, many domestic care service providers report problems with getting along with sufficient financing. This applies above all to service providers who are active in rural areas. As a consequence of the circuitousness of rural areas more additional expenses arise like higher driving costs and thereby fewer customers that can be visited in a work day.

#### *Reaching more people*

Another major concern of all of our service providers is to increase the familiarity and acceptance of potential customers. Some service providers, especially those offering advice, see a lack of information regarding the manifold range of services and help utilities which bring relief to care situations.

### 9.4.7.2 Strategies for future developments

#### *Consideration of needs*

According to the statements made by the service providers in the interviews, the permanent assessment and monitoring of the care process as discussed in chapter 9.4.4.1 and the regular evaluations of customers’ satisfaction is seen as a part of a strategy for future development. With this information service providers try to foresee the future needs of their current and potentially new customers, which helps to adjust the service offers by considering changing needs. These changes in needs occur for instance due to changes in family struc-

tures, especially in rural areas where the informal support network for carers seems to disperse more and more.

*“At the moment we have families with three or four generations but these large families also die out in rural areas. The number of single households increases, and those people are getting older, too, are alone and have no support from family members.”*

#### *Consideration of legal developments*

To cope with the expenditures for services many providers, especially the domestic care services, have to keep an eye on the development of legal prevailing circumstances. This ensures the right development of service structures in good times. As most of the services are mainly paid for by the Long-Term Care Insurance planning help offers need to consider modifications or additions of those laws which bear on the financiers.

#### *Other strategies*

Other strategies refer to the development of co-operation networks between complementary services. Especially those service providers who can not offer a large number of needed support services try to specialize in their special field and co-operate with other providers who complement the service offers with their special help.

**Table 96: List of specific services provided for family carers**

Specific services for family carers (to be used in connection to section B of SPQ)	Provision (Q16)	Access (Q19)			Problems with car- ers' sat- isfaction (Q22)	Good prac- tice (Q23)	Need for improve- ment (Q24)	Uncover- ed ser- vices (gaps) (Q25)
		Prob- lems in access (Q19a)	Full utilisa- tion (Q19b)	Prob- lems with costs (Q19c)				
Training courses on caring	9	6	6	3	1	4	3	1
Telephone service offered by associations for family members	5	4	4	0	1	1	1	1
Internet Services	1	1	1	0	0	1	1	0
Support or self-help groups for family members	10	8	7	1	0	3	8	4
Counselling services for family carers	16	11	12	0	2	3	8	6
Regular relief home service (supervision of the elderly for a few hours a day during the week)	10	6	6	4	2	2	6	5
Temporary relief home service (substitution of the family carer for brief periods of time, for example, a week)	6	5	5	1	1	1	4	1
Assessment of the needs	2	2	2	0	0	0	2	0
Monetary transfers	0	0	0	0	0	0	0	0
Management of crises	2	1	1	0	1	0	0	0
Integrated planning of care for the elderly and families at home or in hospital	1	1	1	0	0	0	1	0
Services for family carers of different ethnic groups	0	0	0	0	0	0	0	0
Information campaigns	6	4	4	0	0	3	6	3
Excursions	1	1	1	0	0	0	1	0
Ambulatory hospice	2	2	2	0	0	0	2	1
Home and family care	1	1	1	0	0	0	1	0

**Table 97: List of specific services provided for older people**

Services to Older People (to be used in connection to section C of SPQ)	Provision (Q28)	Access (Q19)			Problems with carers' satisfaction (Q34)	Good practice (Q35)	Need for improvement (Q36)	Uncovered services (gaps) (Q37)
		Problems in access (Q31a)	Full utilisation (Q31b)	Problems with costs (Q31c)				
<b>Social services at home</b>								
Housekeeping (cooking, shopping etc.)	4	2	2	1	2	1	2	2
Cleaning and laundry	0	0	0	0	0	0	0	0
Meals on wheels	2	1	1	1	1	1	0	0
Transport services	1	1	1	0	0	0	1	1
Domestic care service (minor repairs, gardening etc.)	3	2	1	1	2	1	1	2
Social home visits (e.g. by pastor, social worker etc.)	3	2	2	1	1	2	2	2
Safety monitoring system (tele-alarm, telemedicine etc.)	1	0	1	0	0	0	0	0
<b>Medical care services at home</b>								
Medical treatment (medication, nursing etc.)	3	1	1	2	2	2	1	2
Rehabilitation (occupational therapy, physiotherapy etc.)	0	0	0	0	0	0	0	0
<b>Other care settings</b>								
Partly inpatient care (day care centre etc.)	8	4	2	5	2	3	4	5
Residential care (long-term care, sheltered housing etc.)	0	0	0	0	0	0	1	3
Counselling (technical aids, financial supp.)	3	0	2	0	0	0	2	2
Mobile services (hairstylist, pedicure...)	1	0	1	0	0	0	0	0
Excursions	1	1	1	0	0	0	1	0
Ambulatory hospice	1	1	1	0	0	1	1	0
Training courses and information seminars	2	0	0	2	0	0	0	0

#### 9.4.8 Analysis of types of support and their importance to service providers

In the last section of the questionnaire the service providers were asked about *their* views on the family carers' needs and demands. They had to rate the importance (14 questions with each 3 possible items: "very important", quite important "not important") (see Table 98) and characteristics (12 questions with each 3 possible items) (see Table 101) of several services for carers. The same questions were also asked to family carers in the main part of the EUROFAMCARE project (see chapter 3 and 7). Because of the low number of interviewed service providers a direct comparison between these two groups was not possible.

The most important service for family carers in the service providers' opinions is "Information and advice about the type of help and support that is available and how to access it". Almost all providers (32) rated this type of support as very important, two as quite important while no one classified this help as not important. The second item mentioned as very important was "Opportunities to have a holiday or break from caring" (29). While 33 of the service providers could offer "information and advice about the type of help that is available", only half of them could provide services that might relieve family cares by making holiday or break from caring possible to them. Services for carers that help them develop training skills is the third important type of support (23) among those stated as very important. More than half of all questioned providers could offer this kind of help.

Information about the type of help that is available seems to be the key element for providers for absolute necessary types of support services for family carers. Asked for the ranking as first, second and third most important types of services of those rated as very important, this kind of help was also the top answer by most providers (see Table 99). Training skills needed for care giving (4) and opportunities to have a break from caring (3) do also belong to the three most important types of support.

**Table 98: Importance of types of support for family carers judged by service providers in absolute numbers**

How important do you think it is that family carers have the following types of support?				Do you provide this type of support?
Kind of Service	Very important	Quite important	Not important	Yes
Information and advice about the type of help and support that is available and how to access it	32	2	-	33
Information about the disease that the older person has	16	16	1	22
Training to help family carers develop the skills they need to care	23	10	-	18
Opportunities to enjoy activities outside of caring	17	16	-	16
Opportunities to have a holiday or take a break from caring	29	4	-	17
Opportunities for the older person's to undertake activities they enjoy	21	12	-	18
Help with planning future care	18	13	1	28
The possibility to combine care giving with paid employment	9	16	1	12
The opportunity to talk over their problems as a carer	22	10	1	28
Opportunities to attend a carer support group	15	17	1	15
More money to help provide things they need to give good care	10	15	6	9
Opportunities to spend more time with their family	14	17	1	14
Help to deal with family disagreements	12	18	3	17
Help to make the older person's environment more suitable for caring	21	13	-	25

**Table 99: The three types of support most frequently rated as “most important”**

Of those types of support you have stated as “very important” for carers, which would you state as the most important to carers?	
Information and advice about the type of help and support that is available and how to access it	19
Training to help family carers develop the skills they need to care	4
Opportunities to have a holiday or take a break from caring	3

**Table 100: The three types of support most frequently rated as “most important” by locality type**

Of those types of support you have stated as “very important” for carers, which would you state as the most important to carers?	Metro-politan	Urban	Rural
Information and advice about the type of help and support that is available and how to access it	14	2	3
Training to help family carers develop the skills they need to care	3	1	-
Opportunities to have a holiday or take a break from caring	2	-	1

#### 9.4.9 Analysis of characteristics of services and the service providers’ view on their importance to family carers

In this section the service providers were asked to judge the importance of service characteristics to family carers. The service characteristic which was most frequently rated as “very important” is that “Care workers treat older person with dignity and respect” (30). Both second most rated important characteristics are that “Help is available at the time they need it most” and that “Care workers treat carers with dignity and respect” (27 answers to the item “very important” each). Customer-friendly personnel and the aim to provide help when it is most necessary needed are from the service providers point of view characteristics of high priority for family carers.

Timeliness (25) and adequate skilled personnel (24) are the next most important rated characteristics by almost three quarter of the questioned providers. All of the above mentioned characteristics could mostly be met by nearly all providers, except of “Help is available at the time they need it most”, which was ‘only’ mostly met by 26 providers.

Furthermore, there seem to be characteristics of services, which are taken for granted by the providers and therefore, in their opinion not necessarily seen as “very important” for family carers, as the service has this characteristic anyway. For example, “Carers views and opinions are listened to” has a high rate of item response to “quite important” (15), thus only half of the questioned providers rated this characteristic as “very important” (17). But nearly all services met this characteristic (30).

In only three cases a characteristic was rated as “not important”. Comparing the results shown in table 98 to those shown in table 101, it is noticeable that the responsiveness according to importance of service types was much more differentiated than the importance of characteristics. This becomes interesting when comparing these results with the results from the National Survey with Family Carers and look at the differences in the perspectives of service providers and family carers on these aspects.

**Table 101: Importance of characteristics of services in absolute numbers**

How important are the following characteristics of a service for family carers, do you think?				Do your services mostly meet this needs?
	Very important	Quite important	Not important	Mostly Yes
Help is available at the time they need it most	27	6	-	26
The help provided fits in with carers own rou-tines	18	15	-	25
Help arrives at the time it is promised	25	8	-	29
Care workers have the skills and training they require	24	8	1	28
Care workers treat older person with dignity and respect	30	3	-	29
Care workers treat carers with dignity and respect	27	5	-	30
Carers views and opinions are listened to	17	15	-	30
The help provided improves the quality of life of the older person	20	11	1	28
The help provided improves the carers' quality of life	15	17	-	24
The help provided is not too expensive	15	17	-	17
Help is provided by the same care worker each time	14	17	1	22
Help focuses on the carer's needs as well as those of the older person	17	14	-	27

**Table 102: The three characteristics of services most frequently rated as most “important”**

Of those characteristics you have stated as “very important”, which would you state as the most important to carers?	
Help is available at the time they need it most	10
Care workers treat older person with dignity and respect	4
Help focuses at the carer's needs as well as those of the older person	4

**Table 103: The three characteristics of services most frequently rated as “most important” by locality type**

Of those characteristics you have stated as “very important”, which would you state as the most important to carers?	Metro-politan	Urban	Rural
Help is available at the time they need it most	6	3	1
Care workers treat older person with dignity and respect	3	-	1
Help focuses at the carer's needs as well as those of the older person	4	-	-

## 9.5 Final remarks

The purpose of the Service Providers' Survey was to add the views of service providers to those of family carers. The aim was to describe possible differences in their views on service provision, to identify gaps in offers and to show examples of good practice through the eyes of the providers.

Unfortunately the response rate to the questionnaire was very low. 35 out of 237 questionnaires were sent back, only 30 also answered the open questions. That means that the results are based on the opinion of 30 service providers.

For family carers of older people in Germany various services are provided. Most of these services are ambulatory offers. The same applies to services for elder people, but these offers are predominantly focusing medical or caring aids while the services for family carers frequently focus psychological and physical relief.

The goals and benefits declared by the service providers are mainly to relief carers from the burden of caregiving, prevent physical and psychical exhaustion and improve carers' quality of life. Therefore service providers underlined the importance of information and advice, the supply of physical and emotional support, respite care, immediate crisis intervention and the offer of palliative and terminal care.

The precondition for carers to enable them to use several kinds of support is the information about the offers. The most common way for carers to find available support seems to be word-of-mouth recommendations, followed by advertisements and articles in newspapers and brochures, advice centres and information networks, open-house day events, or parish priests.

Although the service providers' effort to enable easy access for carers is high. There are still different barriers which detain family carers from using support services. Providers stated that most of the barriers are linked to family carers attitudes or related problems, like sense of shame, no available time, the idea that using help means failure, uncertainty about the adequate type of support, humility and a taboo concerning aspects of illnesses and dying.

Even so most service providers are satisfied with the usage rates of their offers. Especially domestic care service providers who offer a range of support services mentioned higher utilisation. Generally providers state higher usage of those offers paid for by the LTCI. Providers have the impression that support groups for carers are in general well accepted.

Service providers offer a wide range of support for family carers (and the cared-for) like domestic care, advice service, crisis intervention telephone, training courses for family carers, self-help groups, care groups for people suffering from dementia, and terminal care and mourning groups. Asked about gaps in the service provision providers stated especially additional personal contact, night care and care around the clock, flat sharing communities for people suffering from dementia and more time for conversation.

The preference of ambulatory services over residential or in-patient care is prescribed by law, i.e. the structural development of ambulatory service provision is increasing rapidly. These tendencies can also be found in the data from this survey. More and more providers are expanding their range of services and especially domestic care service approach towards a comprehensive service provision. The development of the ambulatory sector comes closer to the needs and demands of family care, as the different types of services allow a

prolonging phase for dependent older people to stay at home because the carers are better supported.

As a consequence of the development towards a comprehensive service range it is getting more and more difficult to distinguish between which services especially focus on older persons' needs and which are directed straight towards carers. It can rather be said that there are reciprocal influences between those services meant for elder people and those meant for carers. Many help offers support both the carer and the older person, independent from who was originally targeted by the service. This became a problem for the data analysis of the open questions, as many service providers mixed up both aspects, i.e. services both targeting older people as well as carers, and did not respond to the second part of open questions (C) concerning offers for older persons. Hence it was the better solution to combine both separate analysis steps to one for this report.

Yet there are still certain problems for service providers and problems in service provision in general. Although there is an increasing effort for co-operation between different complementing services and although networks of service provision are well developing, both aspects are still lacking in Germany. As a high decentralised welfare-system, which means that there is no central co-ordination instance which organises a comprehensive mixture of services for well compiled care arrangements, many service providers do not know of each other and thus family carers do not know about possible offers. This problem is less urgent in metropolitan areas, but might be more problematic for urban or rural areas. These problems were not mentioned by the questioned service providers to such an extent. This might be simply due to the fact that they tended to give an over positive picture of themselves and their organisation.

The tendencies to comprehensive ambulatory service provision are clearly recognizable and the advantages of holistic service offers, either offered by few providers with a wide range of services or by many providers with different service types, are very obvious: Preservation, support and further development of family care at home. These tendencies are also forwarded by lawgiver not only in the current legislation but, also in the trial of new approaches according to ambulatory service structure development.

Finally, one problem still remains, at least it is currently a major effort for many service providers to deal with: the costs. As intended by the lawgiver, the future care arrangements will increasingly be a mixture of professional and informal help, thus the importance of informal support services will increase, as this help is much more affordable for family carers because the allowances can only finance service support to a certain extent. As a consequence for service providers, this means that beside the professional help and personnel they have to take the development of voluntary and informal support structures into account, if they want to keep high utilization of their offers.

As conclusion it has to be underlined, that this chapter gives a more positive picture than we would find in reality. The advantage is that we have got a lot of innovative examples that could push changes in those institutions that are not that open to new challenges till now.

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## 10 Preliminary results of the one year Follow-up Study in Germany

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### 10.1 Aims of the chapter

In the present chapter we report preliminary results of the changes in care giving situations in Germany after approximately one year. We want to examine the patterns of change that occurred in the 12 months between baseline data (T1) and follow-up data (FU or T2). We are particularly interested in answering following questions:

- What are the socio-demographic changes in the studied population of care-givers and the cared-for older persons after 12 months of care giving, especially in terms of:
  - mortality rates in the sample of cared-for?
  - Institutionalisation rates among the cared-for and the possible reasons for stopping care?
  - rates of professional help for the cared-for and possible reasons for carers to stop giving care?
  - changes in care intensity?
  - changes in living arrangements, such as the distance between the carer's place of living and that of the cared-for?
  - changes in carers' occupational status, restrictions deriving from caring activities and possible effects on professional career?
- What are the changes in the older peoples' psycho-physical functions in the 12-month follow-up? In particular:
  - What are the changes of memory and behavioural disorders after one year? How have cognitive functions changed over time?
  - What are the changes, in the carers' subjective situation in terms of positive and negative impact from care giving, quality of life and her/his willingness to continue care in the future, in the whole sample and for each country?
  - What impact did services have on modifying/improving the carers' situation?

### 10.2 Methods

#### 10.2.1 Study design and procedure

In Germany, baseline data (T1) were collected (with face-to-face interviews) by means of the Common Assessment Tool [CAT], i.e. the extensive EUROFAMCARE questionnaire. Baseline data were collected between December 2003 and June 2004. In that period, we interviewed 1003 people, who were providing care or support to their older relatives (age 65 or

older) for more than four hours a week. 273 of the interviewees were recruited by the Hamburg team and 730 by a subcontractor.

The follow-up study [FUS] was carried out in Germany 12 months after the baseline study, i.e. between December 2004 and March 2005 (T2). All care givers, who participated in the first study, were to be approached again, with the exception of those who refused to be contacted again.

The FUS was carried out using the FU questionnaire (see also chapter 3) distinguishing between “ex-carers” (i.e. those who were no longer carers for different reasons, e.g. the older person's death) and carers, who were still caring for the same person. Former carers were asked to complete a short version of the FU questionnaire, with a special paragraph focusing on reasons and circumstances related to the ending of the caring role. Active carers were asked to complete a longer questionnaire that included several items from the baseline questionnaire [CAT], especially items related to the time flow, supplemented by new ones.

### 10.2.2 Subjects, sample size, response rates and reasons for non response

For the follow-up study, 603 care givers, who had participated in the study at T1, were contacted again in writing and invited to participate in the follow-up. The other 400 carers from the baseline study were excluded from the follow-up because they had already previously refused to participate again.

In addition to the care givers who refused participation in the baseline study, another 152 care givers did not respond for different reasons. The response rate (not counting the first 400 refusals) was 74.8%, i.e. 451 care givers were reached in the follow-up.

The reasons for non-successful contacts, including refusals, were: wrong address; carer not at home; no recollection of first interview and refusal of re-interview (no time, busy); moved away; lack of cooperation between older person and their husband/wife as a carer; illness of carer; lack of belief in the effectiveness of study for the carer's situation.

**Table 104: Size of T1 and T2 samples: Reasons for non response, and response rates**

Country	T1: Sample Size	A priori excluded from resurvey <sup>(1)</sup>	Reasons of for non response						Lack of contact or response from respondent	Successful inter-views		Response Rate (in %) <sup>(2)</sup>	T2: Final FU Sample Size
			Carer died			Carer refused to take part in FU				Short interview	Full interview		
			Elder alive	Elder died	Lack of data about Elder	Elder alive	Elder died	Lack of data about Elder					
Germany	1,003	400 <sup>(1)</sup>	0	0	3	5	4	89	51	179	272	74.8	451

<sup>(1)</sup> These carers refused in the baseline study to take part in the follow-up.

<sup>(2)</sup> Cases excluded from resurvey were not included in the calculation of the response rate.

In case of unsuccessful contacts, an attempt was made to find out whether carers and elders were still alive at T2, registering information in a special annex to the FU study (see table 104). Considering the above mentioned contacting problems, information thus acquired was

scarce (indicating for instance that only 4 family carers and 5 older persons died between T1 and T2), and not included in the final FU dataset. In case of successful contacts, the short form of the FU questionnaires provided more in-depth information on older persons' death rates. Table 2 presents the changes that occurred between T1 and T2 of our study.

The 451 remaining care givers were asked whether they still provide support to their older relative for at least four hours per week. Those who had stopped caring were asked to answer the short version of the FU questionnaire, and those still caring the full version of it. 39.7% of the care givers answered the shorten version of the follow-up questionnaire and 60.3% the long version (table 105).

**Table 105: Transition of the T1 sample into the T2 sample**

	Germany	The whole sample
Size of the T1 sample	1,003	5,923
No of dropped cases	552	2,561
Size of the T2 sample	451	3,362
% of T1 sample resurveyed in time T2	44.9	56.8
With short interview	179 39.7 %	914 27.2 %
With full interview	272 60.3 %	2,448 72.8 %

### 10.2.3 Representativeness of the national T2 samples compared to T1 samples

We tried to answer the question whether the re-surveyed carers represent the German initial sample. After one year, a certain degree of weariness was found in the initial sample as well as technical difficulties in approaching all initial responders, and both samples (T1 and T1', i.e. T2 in the FU study)<sup>12</sup> have been compared with regard to selected demographic features that are derived from the baseline study.

Looking at demographic characteristics like residence and gender of the care giver and the cared-for and at the cohabitation status we found no significant differences between the T1 and T2 samples in Germany. However, in the T2 sample, caregivers of more severely dependent older people, who experienced a more negative impact from caring and who mentioned a worse quality of life, were more often willing to participate in the follow-up study (table 106). All distributions of the compared variables, between T1 and T1', were tested with Chi-square Pearson's test.

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<sup>12</sup> T1 sample refers to the baseline sample; T1' sample is a sub-sample of T1 sample, which was accessible for the follow-up study. It is an equivalent of T2 sample.

**Table 106: Comparison of sample T1 with sample T1' with regard to the distribution of the chosen CAT characteristics (in %)**

	Germany		The whole sample	
	T1 N = 1,003	T1' N = 451	T1 N = 5,923	T1' N = 3,362
<b>Locality</b>				
Metropolitan	32.8	36.8	22.0	25.0
Urban	45.2	39.0	47.2	37.8
Rural	22.0	24.2	30.8	37.2
	NS		<b>P = 0.00000</b>	
<b>Elder's gender</b>				
Male	31.5	29.3	32.5	31.2
Female	68.5	70.7	67.5	68.8
	NS		NS	
<b>Carer's gender</b>				
Male	23.8	22.6	23.7	22.1
Female	76.2	77.4	76.3	77.9
	NS		NS	
<b>Cohabitation with the cared-for person</b>				
Other place	49.5	46.6	43.8	40.3
The same building	50.5	53.4	56.2	59.7
	NS		<b>P = 0.001</b>	
<b>Cognitive disorders in elder</b>				
No	28.7	22.9	39.3	36.9
Yes	71.3	77.1	60.7	63.1
	<b>P = 0.023</b>		NS	
<b>Negative impact of care</b>				
Lower	44.8	37.7	45.9	46.1
Higher	55.2	62.3	54.1	53.9
	<b>P = 0.011</b>		NS	
<b>Quality of life</b>				
Worse	44.3	54.1	49.8	51.7
Better	55.7	46.9	50.2	48.3
	<b>P = 0.0022</b>		NS	

#### 10.2.4 The Follow-up Questionnaire and the mode of its administration

The questionnaire used for the follow-up was developed as a shortened form of the CAT instrument. The idea was to repeat as few of the CAT's questions, which were necessary in order to discern any possible changes in the care arrangements of the family carer and their cared-for person in the course of one year.

The follow-up questionnaire included following sections:

- Identifying data (number of questionnaire as in initial study, interviewer's details, date of interview);
- Method of administration of follow-up questionnaire;

- Filter question identifying "present carers" still caring for their older relatives (for whom the full version of the FU questionnaire was used) and "ex-carers" who had stopped caring (who completed the short version of the FU questionnaire);
- Time, reasons and circumstances of withdrawal from the caring process (only for "ex-carers");
- Current quality of life (for "present carers" and "ex-carers");

The section for "present carers" included following topics:

- Living arrangements;
- Occupational status and economic consequences of caring;
- Restrictions on carers and on their professional career;
- Level of psycho-physical disability of the older person;
- Subjective outcome of caring, measured with COPE Index;
- Older persons' and carers' utilisation of services (the same as at the baseline study)
- Helpfulness of services in carers' opinions;
- Willingness to continue care.

The FU questionnaire consisted of 36 questions (compared to the 193 questions of the CAT applied in the baseline study) and used the same wording of similar questions in the CAT.

Concerning the mode of administration in Germany, postal interviews were made; only if the care giver did not want to complete the questionnaire in written form, we conducted the interview by phone. Only 2.2% of the interviews were conducted by phone call, 97.8% by postal service. The FU intended to resurvey the family carers 365 days after the baseline study with 1 month of tolerance. This aim was achieved with a short delay of 4 days (table 107).

**Table 107: Mode of administration of the FU questionnaires and interval between T1 and T2**

Mode of administration	N	%
Postal	441	97.8
Phone call	10	2.2
Total	451	100
Intervall between T1 and T2 (Days)	369+27.5	

### 10.2.5 Analyses and Statistics

All the FU data were entered using a common template created in SPSS software. The cleaning procedures were performed twice – at national and European levels – and the merging and matching procedure allowed to create the integrated CAT-FU dataset.

The main aim of the follow-up study was to detect those carers whose characteristics "changed to a better state" (and/or those unchanged) versus those reporting a "worse" situation with respect to each of the analysed variables. The purpose was to examine carers' transitions from one to the other modalities within the T1 - T2 timeframe, in order to address

some crucial questions: What are the changes over time in the chosen characteristics? What are the predictors of changes (both positive and negative)?

In order to explore these issues, we performed following analyses: The same syntaxes as for the baseline dataset, but adapted to the FU records, were run on the merged CAT-FU dataset to create the FU derived variables, thus ensuring comparability between T1 and T2 analogous variables. To reveal changes over time, the analogous T1 and T2 ordinal variables/measures were subtracted (e.g., scores on the scales), and the obtained values dichotomised/trichotomised into two/three modalities, those which improved/stayed the same and those which worsened. To reveal the dynamics of change over time with regard to nominal variables, cross-tabs (T1 by T2 within analogous variables) were created.

## 10.3 Main findings

### 10.3.1 Socio-Demographical changes in the care-giving situation

#### 10.3.1.1 Continuity versus discontinuity in care: Mortality and other reasons

In Germany, 60.3% of the original family caregivers continued caregiving after one year. This is the lowest rate in the European comparison, where the overall average of “still caring” is about 73%. The most common cause of withdrawal from caring in all participating countries was the death of the cared-for. In Germany, this reason applied to 25.5% of re-surveyed carers, which is also the highest mortality rate in the whole sample (table 108). A higher mortality is found especially amongst the older group of cared-for elders and those with higher functional and/or cognitive impairments in metropolitan localities.

**Table 108: "Continuity" versus "discontinuity" in care-giving over one year**

	Germany N = 451	The whole sample N = 3,362
Still caring	272	2,446
% by country	60.3 %	72.7 %
Stopped caring*	179	916
% by country	39.7 %	27.3 %
Due to:		
Elder's death	115	577
% by country	25.5 %	17.2 %
Other family member provides care now	13	100
% by country	2.9 %	3 %
Professional carer provides care now	5	41
% by country	1.1 %	1.2 %
Transferred to nursing home	40	153
% by country	8.9 %	4.6 %
Lack of data, or other reason	6	45
% by country	1.3 %	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.

Table 109 shows other reasons of withdrawal from care than the death of the older cared-for. Apart from this circumstance, the reason most often mentioned in Germany for stopping care was the placement of the cared-for in a nursing home (62.5% withdrawals in the German sample), followed by another family member taking over caring for the older person (20.3%). The first mentioned reason is above, the second one below the European average. The transfer of care to professional carers plays a minor role in Germany.

**Table 109: Reasons for withdrawal of care, other than older person's death**

	<b>Germany N = 64</b>	<b>The whole sample N = 339</b>
Transfer to nursing home % by country	40 62.5 %	153 45.1 %
Transfer to professional carer % by country	5 7.8 %	41 12.1 %
Transfer to other relative % by country	13 20.3 %	100 29.6 %
Other events / missing data % by country	6 9.4 %	45 13.2 %
Total % in column	64 100 %	339 100 %

### 10.3.1.2 Institutionalisation rates in the German sample

In Germany, the rate of institutionalisation increased by 8.9% within one year and is considerably higher than in the European average. In the European sample, the rate increases with higher age and especially with stronger cognitive and functional impairments of the cared-for and higher burden (measured by the negative impact) for the care giver. In Germany, higher functional impairments of the cared-for leads to higher rates of institutionalisation; the age of the cared-for and also the higher burden of the care giver do not play a special role. The greatest increase occurred when the caregiver was working; the institutionalisation rate then reduplicates (table 110).

In Germany, it is therefore to a lesser degree a question of the perceived burden, if a care giver places the cared-for into a nursing home. Institutionalisation is rather dependent on the carers' professional work.

**Table 110: Institutionalisation rates in Germany per year [in % of category within country]**

	<b>Germany N = 451</b>	<b>The whole sample N = 3,362</b>
In whole sample % of country	40 8.9 %	153 4.6 %
In age < 80	16 9.7 %	53 3.6 %
In age > = 80*	24 8.6 %	99 5.3 %
<b>Type of locality</b>		

	<b>Germany N = 451</b>	<b>The whole sample N = 3,362</b>
Metropolitan	14 8.4 %	24 3.4 %
Urban	16 9.5 %	82 5.1 %
Rural	10 9.2 %	45 4.3 %
<b>IADL dependency</b>		
Low to moderate*	4 5.1 %	16 1.6 %
More severe*	36 9.7 %	136 5.9 %
<b>Cognitive disorders</b>		
Intellectually able	7 6.9 %	21 1.7 %
Probable / suspected	33 9.6 %	132 6.3 %
<b>Working conditions of carer</b>		
Nonworking	17 5.9 %	90 4.3
Working	22 13.9 %	62 5 %
<b>Negative impact of care in T1</b>		
Lower negative impact	15 8.9 %	41 2.3 %
Higher negative impact	25 10 %	111 6.2 %
<b>Carer's self-perceived health in T1</b>		
Better health (1-3)	26 8.5 %	98 4.9 %
Worse health (4-5)	14 9.8 %	55 4.1 %

### 10.3.1.3 Changes in the living arrangements after a year

The distance between the care giver's and the 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 sometimes it might be a result of other factors e.g. a shortage of apartments, carers' or elders' financial situation, better access to service networks, etc.

In the German sample, we found only small changes in the living arrangements. Concerning the cohabitation status, 82% of the arrangements did not change. In most of the cases, care givers, who had lived in a different building, moved from his/her own home to the older person's household/building or the cared-for moved to the carers' household/building during the last year (31.3%). Only in few cases (3.9%), people who had shared one household, separated to live in their own home. The first mentioned direction of change was much more

prevalent than the second one (from the same house to different houses) (table 111). That may support the hypothesis that lapse of time and the progress of disability in older persons may lead to cohabitation. It should be explored in further analyses.

Concerning the place of living, most of the cared-for live in their own household (82%) at the time of the follow-up, only a small number now live at another place. In most of the cases these other places are nursing homes or sheltered housing.

**Table 111: Living arrangements**

Cohabitation		T2		
		Same building	Other place	Total n (%)
T1	Same building	96.1	3.9	129 (100)
	Other place	31.3	68.7	134 (100)
	Total n (%)	166 (63.1)	97 (36.9)	263 (100)
Place of living		T2		
		At home	Other place	Total n (%)
T1	At home	88.4	17.4	23 (100)
	Other place	11.6	82.6	232 (100)
	Total n (%)	209 (82.0)	46 (18.0)	255 (100)

#### 10.3.1.4 Change in the intensity of caring

Intensity of care giving after one year was measured as occurred in the baseline study, namely, as an average number of hours per week for supporting or helping an older person. Comparison of these two numbers shows changes in the intensity of caring. The comparison was carried out on the FU sub-sample of "still caring" carers interviewed with the extended version of the FU questionnaire.

For the whole German sample, intensity of care after one year was lower than at the time of the baseline study, by on average 7.8 hours per week. One explanation of this result can be that caregivers became more accustomed to their role and responsibilities and can better cope with everyday tasks.

The distributions of categories of carers in terms of an increase, maintenance or decrease in the number of hours for care after one year, is presented in table 112. There we can see that in the whole German sample the proportion of those who decreased and those who increased their hours of care is nearly the same.

Looking for an explanation for the lower intensity of care after one year in the German sample, the amount of care was compared within two sub-categories: (1) a group of cared-for with the same or improved ADL dependency (measured with numbers of the Barthel dysfunctions) *versus* (2) a group of cared-for with worsened ADL dependency during one year. For the German sample this comparison shows a different picture. On the one hand the average number of hours per week decreased by 9.4 hours in the sub-group of cared-for with "better or the same IADL dependency than at T1". But on the other hand, the average number of care hours per week increases only by 0.1 hours in the sub-group of cared-for with "Worse IADL dependency than at T1".

**Table 112: Hours of care per week, changes after one year**

Difference	Hours	[SD]
Mean differences in hours of care per week	- 7.8	+ / - 51.4
Distribution of carer		
Less hours of care per week	43.6	
The same hours of care per week	16.1	
More hours of care per week	40.3	
Difference in hours per week divided by the level of IADL dependency after one year	Hours	[SD]
Better or the same IADL dependency than at T1	- 9.4	+ / - 54.2
Worse IADL dependency than at T1	+ 0.1	+ / - 37.9

### 10.3.1.5 Changes in the carers occupational status, restrictions and career

Most of the German care givers did not change their employment status (93.3%). 66.2% of them are still not working, 33.8% are still working. 4.1% of the German sample started to work and almost the same proportion stopped her/his employment. When looking at the changes within the sub-groups of initially non-working carers and initially working carers, we see that ending employment prevails at the beginning of a new job. This difference is lower in Germany than in the European sample (table 113).

**Table 113: Transition of the employment status between time T1 and T2**

	Germany	The whole sample
No of valid	N = 268	N = 2,400
Began work between T1 and T2	11 4.1 %	135 5.6 %
<i>% of initial non-workers within country</i>	6.0 %	9.2 %
Stopped working between T1 and T2	7 2.6 %	124 5.2 %
<i>% of initial workers within country</i>	8.1 %	13.4 %
No change (% of country)	250 93.3 %	2,141 89.2 %

In all countries and also in Germany the combination of employment and care for an older relative might be a problem. Sometimes, the necessities of care demand a reduction of working hours or, in the worst case, quitting the job. Table 114 presents the care givers' opinions on possible restrictions of the professional life due to caring, amongst the sub-groups of currently working and currently not working carers (at T2).

In Germany, the majority of currently working carers (74.4%) is struggling with caring responsibilities without any reduction of their working hours (table 114). This rate is relatively low compared to the European sample. On the other hand, the number of those who expressed that there were restrictions on their professional career is above the European average. Here, more than every fifth carer had to reduce her/his working hours mainly because they cared for their older relative.

Looking at the currently non working carers we see that most of them stopped work for another reason than care giving (73.3%). This might be an effect of unemployment (the rate in

Germany is 12.1%). But a major reason might also be that we had interviewed care givers, who care for an older relative aged 65 and more; as a rule, these care givers are themselves often old and retired (the rate of retired person in Germany is 33%). But even in this group of non working care givers, a high proportion had to give up their job because of the caring situation (14.8%).

**Table 114: Restrictions on professional career in the groups of "current workers" and "current non-workers" (at T2)**

	Germany	The whole sample
<b>Working at T2</b>		
No of valid cases	N = 78	N = 860
Despite caring, my working hours are unchanged	58 74.4 %	758 88.1 %
Because of caring I had to reduce my working hours	17 21.8 %	82 9.6 %
I had to reduce my working hours for another reason than caring	3 3.8 %	20 2.3 %
<b>Not working at T2</b>		
No of valid cases	N = 135	N = 1092
Because of caring I could not carry out my job at all	16 11.9 %	314 28.7 %
Because of caring I had to give up my job	20 14.8 %	42 3.9 %
I stopped work for another reason than caring	99 73.3	736 67.4 %

Concerning other restrictions on professional life than those mentioned above, only a minority of the whole sample (8%) had been affected. In Germany, 12.3% of the care givers mentioned difficulties in developing their professional career or studies, and a proportion of 15.9% could only work occasionally (table 115).

**Table 115: Other restrictions from caring (at T2)**

	Germany	The whole sample
<b>I can / could not develop my professional career or studies due to caring (at T2)</b>		
No of valid cases	227	2,280
YES	28 12.3 %	188 8.3 %
<b>I can / could work only occasionally (at T2)</b>		
No of valid cases	227	2,186
YES	36 15.9 %	174 8 %
<b>If you needed a break from your caring role is there someone who would look after ELDER for you (at T2)</b>		
No of valid cases	262	2,395
Yes, quite easily	69 26.3 %	997 41.6 %
Yes, I could find someone, but with difficulty	115 43.9 %	917 38.3 %
No, there is no one	78 29.8 %	481 20.1 %

Restrictions related to the professional life of the care givers are not the only ones, many restrictions referred to everyday life. Nearly 75% of the care givers in the German sample complained about difficulties in finding someone, who would occasionally step in as carer just to provide them a break in care giving. Most of them could find such a person with difficulties but every third care giver in Germany could not find anyone at all.

Are these statements stable over one year? In table 116, we can see the changes in the individual statements over one year of longitudinal observation. At T2, only a minority of the care givers (42%) were convinced that they could easily find someone to step into the care giver's role. The majority had changed their mind to more pessimistic answers. Of those care givers who could not find someone at T1, about 54% confirmed their statement, the rest changed their mind to a more optimistic response. To summarize: 43% of the German care givers did not change their opinion of the year before (double frame boxes), 22% changed their mind to a more positive answer and every third care giver changed to a more negative answer. It can be concluded that the tendency is slightly negative.

**Table 116: Changes in the possibilities of making a break in caring for older person**

If you needed a break from your caring role is there someone who would look after ELDER for you?		T2			Total
		Yes, I could find someone quite easily	Yes I could find someone, but with some difficulty	No, there is no one	
<b>No of valid</b>		<b>N = 70</b>	<b>N = 115</b>	<b>N = 75</b>	<b>N = 260</b>
<b>T1</b>	Yes, I could find someone quite easily % of row	39 41.9 %	38 40.9 %	16 17.2 %	93 100 %
	Yes I could find someone, but with some difficulty" % of row	25 25.5 %	51 52.0 %	22 22.4 %	98 100 %
	No, there is no one % of row	6 8.7 %	26 37.7 %	37 53.6 %	69 100 %
Total N % of row		70 26.9 %	115 44.2 %	75 28.2 %	N = 260 100 %

### 10.3.2 Changes in the level of the cared-for disability

In the course of one year, there can be changes in the level of disability of the persons cared for, both physical and mental.

#### 10.3.2.1 Functional disability after a year

Table 117 presents the changes in IADL functioning of the cared-for, measured in terms of the number of IADL dysfunctions. Decrease of the number of dysfunctions between T1 and T2 were labelled as "improvement", new dysfunctions were labelled as "worsening", and the rest as "no change".

**Table 117: Changes in IADL dependency between T1 and T2 [in % from columns]**

	Germany	The whole sample
<b>Number of dysfunctions defined as "not able or able with help"</b>		
No of valid cases	N = 252	N = 2,339
Less dysfunctions: IMPROVEMENT	7.5 %	19.3 %
The same as in T1: NO CHANGE	65.5 %	48.6 %
More dysfunctions: WORSENING	27.0 %	32.1 %
<b>Number of dysfunctions defined as "not able"</b>		
No of valid cases	N = 252	N = 2,339
Less dysfunctions: IMPROVEMENT	22.2 %	22.7 %
The same as in T1: NO CHANGE	43.2 %	42.4 %
More dysfunctions: WORSENING	34.5 %	34.9 %

According to the assumed definition of IADL dependency, the groups of older people show different degrees of changes over the last year. Accepting a wider definition of dependency (number of dysfunctions defined not only as "not able" but also as "able with help" to perform one of six IADL functions) changes in the categories "improving" and "worsening" in IADL

dependency were fewer in comparison to the group with the more ambiguous definition "not able" (compare percentages in table 117).

In general, there are both negative and positive changes in the level of ADL-dependency of the cared-for, in Germany as well as in the whole sample, in the course of one year. The negative changes significantly prevailed. It is necessary to notice that the progress of changes depended primarily on the initial levels of disability.

We found the same directions of changes related to personal ADL measured by the number of dysfunctions ("not able or able with help") on the Barthel scale (table 118).

**Table 118: Changes in ADL dependency between T1 and T2 [in % from columns]**

Number of dysfunctions defined as "not able or able with help"	Germany	The whole sample
No of valid cases	N = 244	N = 2,277
Less dysfunctions: IMPROVEMENT	18.4 %	23.7 %
The same as in T1: NO CHANGE	29.1 %	27.6 %
More dysfunctions: WORSENING	52.5 %	48.7 %
DECREASE on "0-100 Barthel-Index Scale" (T1 – T2)	- 8.3	- 5.5

With the Barthel scale the progress in dependency of the cared-for is far more visible. In the German sample, the percentage of cared-for whose level of disability worsened was more than twice as high as the percentage of older people whose condition improved. The average decrease on the 0-100 Barthel scale in Germany was 8.3 for the whole year. This is higher than in the European sample.

### 10.3.2.2 Mental or cognitive disability after a year

In addition to the physical disability, also the mental abilities of the cared-for are susceptible to change over time. Table 119 shows the results concerning memory impairment during the year. Most of the cared-for in Germany were stable in terms of memory status, thus 29% of our sample did not manifest any symptoms within one year while in 52% of the cases the problem was stable over the last year. Approximately every tenth cared-for began to show memory problems while almost the same proportion stopped complaining of this problem. These proportions are about the same as in the whole sample with the exception that in Germany, the number of cared-for with memory problems is higher than in the European sample and accordingly, the number of cared-for with no memory problems is lower. The results confirm the findings that memory problems alone, without other cognitive dysfunctions, can be ascribed to a mild memory impairment syndrome, which can progress to dementia but can also improve.

**Table 119: Changes in memory problems [MP] between time T1 and T2**

	Germany	The whole sample
No of valid	N = 257	N = 2,409
Without MP at T1 & T2	28.9 %	41.8 %
MP retreated	9.3 %	10.6 %
MP newly appeared	9.7 %	11.9 %
MP persisted up to T2	52.1 %	35.7 %

Behavioural disorders co-existing with memory impairment usually indicate dementia if other cognitive functions are impaired. The proxy assessment of the cared-for applied in the study based only on an interview and therefore it is difficult to judge about the presence or absence of a disease. Nevertheless, it is interesting to recognise the dynamics of changes amongst the re-surveyed persons, even with these limitations.

The changes in the behavioural disorder scale between T1 and T2 are presented in table 120. The cared-for who showed lower scores on the behavioural disorder's scale [BDS] than in the baseline study were assigned to the category "Less BD", those who showed more disorders to the category "More BD", and those who kept the same score to the category "No change". Each category was described with an average score based on T2 results.

**Table 120: Changes on the Behavioural Disorder Scale [BDS] between time T1 and T2; average scoring on the BDS (T2) per category**

	Germany	The whole sample
No of valid	N = 238	N = 2,333
<b>Less BD</b>	26.5 %	23.5 %
Mean scoring	2.6	1.7
<b>No change</b>	27.7 %	42.7 %
Mean scoring	1.4	0.8
<b>More BD</b>	45.8 %	33.8 %
Mean scoring	4.0	4.0

In the German sample, 27.7% of cared-for had an unchanged behavioural status. Compared with the European sample this rate is very low. Some cared-for persons had an average score of 1.4 on the behavioural scale. 47.4% of them have no memory impairment which suggests cognitively health.

In the German sample, as many as 26.5% of the cared-for showed fewer disorders than at the time of the baseline study. The decrease of disorders over time, as well as a low BDS value (less than 3 on 0-9 BDS) rather does not suggest dementia. However, in about every sixth person of this category the memory problems persist and they may therefore be in risk of future dementia.

Nearly every second cared-for in our sample fulfils the criteria of probable dementia. Significantly higher results on the BDS (mean value = 4.0), a progression of behavioural disorders during the year as well as coexisting memory impairment (in 55% of this category) support this assumption.

It might be interesting to explore the changes of mental status in each of the baseline categories of the German sample: the group of intellectually able; the group with behavioural disorder-

ders only; the group with memory impairment only and the group with memory and behavioural disorders (with probable dementia). The results are shown in table 121.

**Table 121: Changes in older peoples mental status between T1 and T2 within categories from the baseline study (in % within categories)**

		T2				TOTAL
		Intellectually able	Behavioural disorders only	Memory impairment only	Memory and behavioural disorders	
No of valid		N = 49	N = 46	N = 10	N = 130	N = 235
T1	Intellectually able % of row	31 45.6 %	22 32.4 %	2 2.9 %	13 19.1 %	68 100 %
	Behavioural disorders only % of row	6 20.7 %	13 44.8 %	1 3.4 %	9 31.0 %	29 100 %
	Memory impairment only % of row	4 16.7 %	3 12.5 %	3 12.5 %	14 58.3 %	24 100 %
	Memory and behavioural disorders % of row	8 7.0 %	8 7.0 %	4 3.5 %	94 82.5 %	114 100 %

The double frame boxes in the table show the proportions of persons who were stable over one year, i.e. did not change their category. The boxes to the right of them show the proportions with progressing mental disorders, boxes to the left show decreasing disorders.

People assessed with memory and behavioural disorders i.e. with probable dementia in the baseline study proved to be the largest stable group in the German sample (82.5%). It is followed by the intellectually able (45.6%) and those with behavioural disorders only (44.8%). The smallest stable group are people with memory impairments.

Behavioural disorders and memory impairments are equally likely to evolve to dementia or to recovery. Nevertheless, memory impairment significantly more often predicts progress to probable dementia (in 58.3% of the German cases), than behavioural disorders as a single problem (31%). Every fifth person with behavioural disorders as reported by care givers at T1 had recovered after one year. In the case of memory impairment, this is true for nearly every sixth cared-for.

To summarise, as many as 60% of the cared-for in the German sample were in the same category with respect to their mental status after one year. 26% of them showed progress of their mental health disorders while 14% mentioned a regression in their mental health status. It should be noted that the study has some limitations. Beside a low number of cases in the German sample, one limitation could be seen in the fact that the data were collected from the caregivers only and not from the cared-for.

### 10.3.3 Changes in carers subjective situation

It is an undisputed fact that care giving to an older relative is connected with responsibility, stress, self-sacrifice and long-term dedication. On the one hand, it may be source of positive

feelings and satisfaction with care giving but on the other hand, it may be a source of anxiety, frustration, helplessness and sometimes even depression (McKee et al. 2003; Bien et al. 2001). These double-sided effects usually co-exist, but the caregivers usually run a higher risk of suffering from depression or becoming inefficient in their care giving, when the burdens of caring overwhelm the feeling of satisfaction with care. This sub-section describes changes in the subjective outcomes of care giving between the baseline study and the follow up in Germany. We used the COPE instrument to measure the positive as well as the negative effects of care giving, the quality of life of the care giver and her/his self-perceived subjective health status. The willingness to continue care giving can be regarded as an indication of how burdensome care giving is felt to be.

### 10.3.3.1 Positive value and negative impact

Most common outcome measurements focus on the care giver's burden. However, care giving also provides positive effects. In order to cover both, the positive and the negative effects of care giving, the COPE index was developed (McKee et al. 2003). This instrument consists of 15 items, 7 of which form a scale on "negative impact", while 4 items build a scale for "positive value" of care-giving and 4 items refer to the satisfaction with possible support.

Data at T1 and T2 show a trend towards worse in both impact measures in Germany. In half of the cases a higher negative impact is found than one year ago. The "positive value" is now lower for every second care-giver than one year before. Only in every fourth case in Germany, these two outcome measures show a positive development (table 122).

**Table 122: Changes in the COPE Index between T1 and T2 [in % from columns]**

	Negative impact	Positive value
No of valid cases	206	236
Change for better outcome in T2	24.8 %	28.0 %
No change	18.3 %	24.1 %
Change for worse outcome in T2	56.8 %	47.9 %

### 10.3.3.2 Quality of life and health status

One of the important aspects of the study was the evaluation of the care givers' quality of life (for detailed information about the measurements of this assessment see chapter 3). In this section we describe the changes which took place within one year in the care givers' self-perceived health and the self-rating of their overall quality of life in the last two weeks preceding the interview.

With the two outcome measures "quality of life" and "self-perceived health" we can differentiate two groups. One includes care givers who had stopped care at the time of the follow up, the other includes those who are still giving care. If the care giver stopped care, no trend is discernible for this group. If the care giver is still caring, a decrease of the quality of life can be noticed. In general, the subjectively perceived health status of the care givers in Germany tends to become worse. Here, however, care givers who had stopped giving care, are most affected (table 123).

**Table 123: Changes in the quality of life and health status between T1 and T2 [in % from columns]**

	Still care givers	Stopped care
<b>Overall quality of life</b>		
No of valid cases	269	169
worse	38.1	28.5
No change	49.1	40.2
better	11.4	25.7
<b>Self perceived health status</b>		
No of valid cases	267	166
worse	27.5	36.9
No change	59.0	39.7
better	11.4	16.2

If we want to investigate these results more in depth, we have to develop a complex model. This model must reproduce the internal coherences between the outcome measures and the care situation at both points in time. In addition, we have to consider events that occurred between T1 and T2 (e.g. death of the cared-for, more or less support in care giving etc.). However, such elaborate modelling cannot be done at this stage.

### 10.3.3.3 Changes in willingness to continue care

The follow-up survey, which took place one year after the baseline study, allowed to compare the care givers' willingness to intensify or reduce care in the future. To the question "In the next year, are you willingly to continue to provide care for the elderly person?" the care giver could answer by choosing one of five statements arranged from the most positive (Yes, and I would even consider increasing the care I give if necessary) to the most negative (No, I am not prepared to continue to provide care for the older person, no matter what extra support I receive). The comparison of these two views between two points in time allowed us to trace the opinions on this matter. It should be noted that, in the German analysis, we deleted the last option because this category included only two cases.

In the German sample, care givers' willingness to provide care in the future decreased from 60% to nearly 40% within the year between T1 and T2. In the category "yes, if the situation remains the same", four out of ten care givers reached the limits of their (care giving) capacities. Need for additional support in care giving tasks increased from about 4% to 8% of the care givers. On the other hand, the group of care givers who want to continue if the situation remains the same increased by 15%, and the group who needs more support increased by nearly 5% (table 124).

**Table 124: Change in the possibilities of making a break in caring for older person [T1 percentage, T1 - T2 row percentage]**

In the next year, are you willingly to continue to provide care for the elderly person?		T1	T2		
			Yes, and I would increase (incl. those who increase for a limited time)	Yes, but only the situation remains the same	Yes, but only with support
No of valid		N = 235	N = 97	N = 119	N = 19
T1	Yes, and I would increase (incl. those who increase for a limited time)	138 58.7 %	76 55.1 %	56 40.6 %	6 4.3 %
	Yes, but only the situation remains the same	88 37.5 %	20 22.7 %	59 67.1 %	9 10.9 %
	Yes, but only with support	9 3.8 %	1 11.1 %	4 44.4 %	4 44.4 %
Total		100 %	41.3 %	50.6 %	8.1 %

#### 10.3.4 Impact of services on modifying the carers' situation

In section 10.3 the „changes in the care givers' subjective outcomes of caring“ have only been described. In this section, we try to explain respective changes. Explanations focus on service use, i.e. the effects of service use on changes of outcome measures. If service use is dichotomised according to T1 and T2, four possible combinations result: 1) no service use at T1 but at T2, 2) service use at T1 but not at T2, 3) service use at T1 and T2; 4) no service use at T1 and T2.

The original aim of this section was to analyse service use in general. Due to the small sample size at T2 it is only possible to analyse the effects of “health needs” service use on carers' subjective outcomes of caring because this is the service mostly used at T1 and T2, so that we have sufficient cases in all cells of the tables and therefore enough statistical power.

As mentioned before, there are four possible combinations of service utilisation at T1 and T2. They build the modalities of the independent variable. For each of these combinations the change in the dependent variable, i.e. outcome measures is analysed. If we assume that service utilisation decreases the burden of care giving, we might expect worse results if service utilisation decreases between T1 and T2, i.e. service utilisation at T1 but not at T2. On the other hand, a change to the better could be assumed if service utilisation was started. In Germany, we have only slight effects in this direction (table 125). But positive changes are not really visible to a comparable extent. In all other outcome indicators we neither have effects with enough statistical power (see for details chapter 9 TEUSURE) and therefore cannot carry out this kind of in-depth analysis.

**Table 125: Effects of “health needs” service use of elders on changes of “negative impact” from T1 to T2 by elder from T1 to T2 in Germany**

Independent variable		Change of „negative impact“ (Dependent Variable)			
Service use		Positive change	No change	Negative change	
T1	T2	%	%	%	N
No	Yes	18.2	27.3	54.5	33
Yes	No	17.8	17.8	<b>64.4</b>	45
Yes	Yes	<b>29.0</b>	9.7	61.3	31
No	No	25.5	13.1	61.4	153

## 10.4 Discussion

The changes that occurred in the German sample in the year between the two surveys are in part remarkable. About 40% of the care givers stopped caring. The most frequent reason is the death of the older cared-for (ca. 25%) and, with nearly 10%, the placing of the cared-for into a nursing home. Both rates correspond to the average of the European sample. In the cross-national comparison, the working status of the care giver has the greatest influence on the decision to place the cared-for in a nursing home. But even in case of ongoing care, work restrictions for the care giver are more frequent.

In general, the functional and mental status of the cared-for was worse at follow-up. Therefore, a negative impact on the outcome indicators of the care giver is to be expected. This impact can be detected in the negative impact scale (COPE) as well as in the overall well-being of the care giver.

In parallel to that, the willingness to provide more care if needed declined. Relieving effects that may arise from the utilisation of services were found to be rather low.

# 11 Summary and final remarks

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## 11.1 Aim and Methodology

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

In this report the results of the German NASUR based on *three sub-studies* have been presented:

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

## 11.2 Results

The report starts with an *overview on the state of the art of the literature* on support services for family carers of older people in Germany, in particular focussing on the partnership approach. In the following chapter the EUROFAMCARE Common Assessment Tool (CAT) as well as the CAT-Follow-Up Questionnaire (CAT-FUQ) has been described in detail, including the *development of items and instruments*, the piloting of questionnaires, questionnaire item transformation, scale development and the psychometric characteristics of scales used. Then the *sampling and recruitment* procedures have been presented and discussed with a special focus on representativeness. The German EUROFAMCARE data seems to be quite reliable according to the reflection of different, typical care situations. Many distributions of family carer and cared-for criteria come very close to the representative INFRATEST-Study (Schneekloth & Wahl 2005).

The presentation of the results starts with showing the *profile of family carers and the cared-for older persons* in the German sample. The cared-for persons are on average 80 years old and about two thirds of them are female. While almost two thirds of the male cared-for are aged below 80 years, nearly 60% of the female dependent persons are 80 years or older. Most of the cared-for persons (63%) are widowed and even more (88%) live at home, which means that they either still live in their own house or they live at their children's house.

The three most frequent mentioned reasons for caring were mobility problems (28%), physical illness/disabilities (25%) and memory/cognitive problems/impairments (15%). 56% of the cared-for persons in the German sample suffer from memory problems. This group can be divided into three subgroups: Undiagnosed memory problems (21%), Dementia diagnosed by a doctor (61%) and other diagnosis or explanation than "dementia" by a doctor (19%).

The mean age of the family carers in our sample is 53 years. This is true for the female as well as the male carers. While one fourth of the male carers is more than 65 years old, only one fifth of the female carers is aged 65 and above. The higher proportion of younger female carers could be explained by the fact, that these persons might be the caring daughters or daughters-in-law.

43% of the carers were employed. One fifth of them had to reduce working hours due to the care situation, about 10% can only work occasionally and another 8% had such working restrictions due to caring that they could not develop their career or studies.

60% of our sample are care-giving children, about 20% are caring for their partner and another 20% are “other” relatives or friends of the older person. Almost half of all older cared-for persons live in the same household or at least in the same building as the family carers do.

The carers in our sample have a very close relationship to their cared-for older person, which can be seen in the fact that nearly half of all carers stated „emotional bonds“ as a principal reason for caring and even more than half of them are willing to continue to provide care, at least for a limited time, independent from increasing burden or amount of care.

Considering the coping resources, most family carers feel well supported by their families. About one third feel never well-supported by friends and/or neighbours, and even 41% state that they don't feel well-supported by support services. The majority of family carers state their quality of life as predominantly positive. On average, the family carers tend to give an answer between the items “good” and “neither good nor poor” with a slight tendency to the item “good”. It is noticeable that the older the carer is, the worse is the self-estimation of the health status and the quality of life.

To identify and describe different *types of care situations* we used selected variables. This has been done on the level of our six core countries. In Germany we found some specific patterns of care situations: (1) In all German care situations the caregivers live to a lower extent close to the cared-for (same building) and the cared-for in the Germany sample have more cognitive impairments. (2) If the caregiver is working the duration of care is in most of the cases lower than two years.

Between 20 % and 40 % of the caregiver receive informal or formal support if they need it, whereas the formal support is more concentrated to the health spheres. The largest need for additional support emerged in the emotional sphere. As a group, the working women with higher subjective burden have the biggest gap in getting support. Their perceived burden can also not be compensated if they cope well with their role as a caregiver. But such positive effects are to register for care-giving couples. Reinforcement in terms of more acceptance would consequently reduce the perceived burden in this group. On the other hand would this effect for working women with inter-generational care relations at least not to be due.

The the main questions of our project are focussing on availability, use and acceptability of *supporting services*. In the analysis we differentiate between special services for family carers and for the cared-for older people, although these services are sometimes directed to support both groups.

In nine out of ten cases, services for the cared-for relative are utilised. In the medical field, this corresponds to a large degree with the needs resulting from the older person's limitations. In the field of housekeeping services, this relationship between increased need and

increased utilisation does not exist. Services for family carers are utilised by slightly more than 20%. Caring husbands develop the greatest degree of utilisation, caring wives focus on self-help groups.

In the field of emotional/psychological or social support, there is a marked service gap. Since only few offers can be claimed, more than 40% of the interviewees wish to have additional support in this field. The existing service offers apparently focus on organisational problems that carers might encounter.

In general, information on service offers can be accessed through members of the medical system. In about 10% of cases, the informal network provided information. There are many barriers to service utilisation, but in many cases, they are cost related (in rare cases information deficits, long ways or quality problems). In addition, there is a German-specific reservation with respect to “strangers” meddling in one’s household.

When analysing the relief potential of services, services involving short home visits seem to bring the greatest relief to family carers. Nursing at home or mobile ambulatory rehabilitation at home are, on the other hand, examples for services that do not seem to have relief effects on the cared-for. Nevertheless, family carers expect the greatest support/relief by being able to escape the everyday routine of caring by pursuing special activities, either alone or together with the cared-for.

As the German care situation is extremely influenced by the *LTCI* we shortly described the law and analysed some *results based on the different grades of dependency*. We started giving an overview on offers especially for care-givers. Although in Germany there are many different services for family carers and they are sometimes widespread, the usage is very low. So the challenge for the future will be to make the offers more user-oriented.

Between experts there is a consensus that the legal definition (LTCI) of “in need of care” needs to be broadened to open the benefits more to people with geronto-psychiatric problems, especially dementia. Relatives caring for this group, that will increase in the future, are higher burdened as other carers. This is also a result of this study. They are more in danger stopping care for the older person and give their cared-for to a nursing home. This is a main challenge for politicians if they will be able to realise their own goals described for the LTCI.

In addition to the perspective of the family carers a special study deals with the *service providers’ view on support for family carers*, using a postal questionnaire. Unfortunately the response rate was very low. 35 out of 237 questionnaires were sent back in time; only 30 also answered the open questions. That means that the results are based on the opinion of 30 service providers, which shows clear limits for interpretation.

The goals and benefits declared by the service providers are mainly to relief carers from the burden of care-giving, prevent physical and psychical exhaustion and improve carers’ quality of life. Therefore service providers underlined the importance of information and advice, the supply of physical and emotional support, respite care, immediate crisis intervention and the offer of palliative and terminal care. The most common way for carers to find available support seems to be word-of-mouth recommendations, followed by advertisements and articles in newspapers and brochures, advice centres and information networks, open-house day events, or parish priests.

The service providers’ effort to enable easy access for carers is high. Although most providers are satisfied with the usage rates of their offers, they see barriers for usage and stated

that most of them are linked to family carers attitudes or related problems, like sense of shame, no available time, the idea that using help means failure, uncertainty about the adequate type of support, humility and a taboo concerning aspects of illnesses and dying.

One problem is currently a major effort for many service providers to deal with: the costs. As intended by the lawgiver, the future care arrangements will increasingly be a mixture of professional and informal help, thus the importance of informal support services will increase, as this help is much more affordable for family carers because the allowances can only finance service support to a certain extent. As a consequence for service providers, this means that beside the professional help and personnel they have to take into account the development of voluntary and informal support structures, if they want to keep high utilization of their offers. Therefore a future challenge is seen in more effort for co-operation between different complementing services and more co-ordination of offers available.

As conclusion to the provider study it has to be underlined, that this chapter gives a more positive picture than we would find in reality. The advantage is that we have got a lot of innovative examples that could push changes in those institutions that are not that open to new challenges till now.

The report ends with preliminary results of the one-year *Follow-up Study*. It provides a time-limited but important longitudinal dimension to the research, given the patterns of change in caregivers' and older people's situation and the need to understand the use and value of services.

The changes that occurred in the German sample in the year between the two surveys are in part remarkable. About 40% of the care givers stopped caring. The most frequent reason is the death of the older cared-for (ca. 25%) and, with nearly 10%, the placing of the cared-for into a nursing home. Both rates correspond to the average of the European sample. In the cross-national comparison, the working status of the care giver has the greatest influence on the decision to place the cared-for in a nursing home. But even in case of ongoing care, work restrictions for the care giver are more frequent.

In general, the functional and mental status of the cared-for was worse at follow-up. Therefore, a negative impact on the outcome indicators of the care giver is to be expected. This impact can be detected in the negative impact scale (COPE) as well as in the overall well-being of the care giver. In parallel to that, the willingness to provide more care if needed declined. Relieving effects that may arise from the utilisation of services were found to be rather low.

More in-depth analysis of the German data will follow in the future.

### 11.3 References

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