EUROFAMCARE

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

The National Survey Report for Sweden

(Deliverable N^o 18)

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Content

1 Introduction

Content

1.1 Aims of the national survey report

The aim of the national survey report (NASURE) is to describe the situation of family carers of elderly people in the individual country in relation to the existence, familiarity, availability, use and acceptability of supporting services.

The EUROFAMCARE project is exploring the characteristics, coverage and usage of services supporting family carers and older people in Europe.

1.2 Methodology

The NASURE describes a part of the EUROFAMCARE project that is based on a survey study. A core research group[1] have been conducted studies at a trans-European level to examine different care arrangements for older people and family carers in six countries: Germany (co-ordination); Greece; Italy; Poland; Sweden and the UK. The main focus is on the perspective of family carers. Following a common study protocol the individual countries have conducted:

- A baseline survey study including interviews with approximately 1000 family carers per country
- A one-year follow-up study with family carers from the baseline study that accepted to be contacted
- A service provider survey study including interviews with approximately 20-50 service providers

1.3 Overview of the chapters

Chapter 2 gives a short overview on the state of the art of the literature on support services for family carers of older people in Sweden.

Chapter 3 describes the EUROFAMCARE Common Assessment Tool (CAT) and the Follow-up Questionnaire (FOQ) concerning the development of items and instruments, questionnaire pilots, items' transformation, scale development and psychometric characteristics of used scales. This chapter is the same as chapter 3 in the EUROFAMCARE, Trans-European survey report (TEUSURE), 2005.

Chapter 4 present the sampling and recruitment procedures and discusses the question of representativeness.

Chapter 5 gives an overview of the main characteristics of the national sample. It shows the profile of the cared-for older people: socio-demographics; financial situation, living and household situation, health and need for support. The profile of the family carers is also described:

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socio-demographics; education and employment; financial situation; family caring situation; health and quality of life.

Chapter 6 is a summary of chapter 6 in the Trans-European survey report (TEUSURE). It gives a short description of a typology of caregiving situations in Europe, using a cluster analysis approach.

Chapter 7 focus on service. It describes need of support; use of services and allowances; experiences of service use and costs; family carers' preferences and if services meet the needs.

Chapter 8 presents the service provider survey study. The aim and methodology is described. The results focus on coverage, usage, access and costs from the provider’s perspective. Additionally the importance of types of service and quality characteristics as well as future developments in services are described.

Chapter 9: describes the results from one-year follow-up study and shows the changes for the older people and for the family carers between the baseline study and one year later.

2 State of art in literature in Sweden

Content

2.1 Carers of older people in Sweden

Care responsibilities of dependents vary all over the world, but tend to be divided between the four sectors of the “welfare diamond”: the family and informal care sector; the state or public sector; the voluntary and non-governmental sector; the care market or private sector. How this welfare diamond is divided in each country depends on factors such as tradition, legal responsibilities, health and social policy, national budgets and national wealth and, demographic trends regarding fertility levels and life expectancy, which affect the availability of informal family carers.

When a person due to old age, illness or disability no longer can manage on his or her own, he or she has to turn to others for help. Traditionally, the family, next of kin and the social network has been the major source of help. In fact, regarding dependent elderly persons, there has been an implicit "intergenerational contract", guaranteeing necessary support on a normative basis. In this sense, changes in care provided within the family and social network indicates a normative change in patterns of relations and exchanges between individuals, what we often term ‘solidarity’.

Some countries have replaced the intergenerational contract, by a “societal contract”. Sweden together with other Nordic countries is a good example of this development. In fact, one of the cornerstones in the post-war Swedish welfare system has been that former family responsibilities should be taken over by the state. Then, in pace with the economic growth, the state should gradually extend and secure service and care for children, disabled and elderly persons.

A central tenet of Swedish national policy is to guarantee older people financial security, adequate housing, social services and health care according to their needs. In return for taxes, people are provided a broad spectrum of welfare benefits that guarantee a minimum standard of living, service and care as well as redistributing income more evenly over a lifetime and between individuals.

At the national level, the Parliament and the Government decide on policy and directives by means of legislation and economic incentives. The framework of this national policy is implemented at a local government level: i.e. local governments are mandated by laws and regulations to provide services and care to their citizens.

At the regional level, the county councils (21) are responsible for the provision of health and medical care. At the local level, the municipalities (290 in all) are legally obliged to meet the social service and institutional care needs of the elderly. Local governments, levy their own taxes and have a very high degree of autonomy vis-à-vis the central government, and decide whether to prioritise the elderly over other groups, or not.

Public policies and programmes providing health care and social services, as well as pensions and other forms of social insurance, are comprehensive. The high percentage of women in the labour market (76 per cent in 2004) necessitates a formal system of care for the elderly, as does the fact that few elderly (about 2-3 per cent) share their homes with their grown up children. A well developed pension system means that nobody has to abstain from service and care, due to economic reasons.

Care of the elderly is almost totally financed by taxes. The user only pays a fraction of the costs (some 4-5 per cent). The largest share of the costs (about 82 – 85 per cent) is covered by local taxes. National taxes cover the remaining costs of elderly care (about 10 percent). The fact that health care and social services for the elderly is primarily funded by local taxes, further confirms the independent role of the local authorities, i.e. their independence of the national government.

2.1.1 Legal status of carers

The national policy is that care of the elderly is a public responsibility in Sweden. The underlying philosophy of the Swedish system is that public support should target the person in need for care. The aim is to promote maximum independence (from others, the family and next of kin), even if you need service and care for your daily living. Then present policy statements in Sweden, emphasises the prime responsibility of the formal system to meet the needs of the elderly. On the other hand, if a family by own choice, prefer to care for a family member, they should be given recognition and support. Then, local governments are recommended to provide support to informal caregivers.

In the Swedish Civil law, no formal expectations on family support exist, excepting *married* persons for their partner, but officially not to include heavy personal care. There are no statutory requirements for children to provide care or economic security for their elderly.

Within the framework of the National Social Insurance, relatives, who take care of an elderly family member in a terminal care situation, can receive payment from the Social Insurance - the Care leave. It is possible for relatives (with gainful employment, i.e. under 67 years of age) to take time off work, with compensation from the social insurance, for up to a total of 60 days per relative. The level of payment is 80% of the income qualifying for sickness benefit.

The Health and Medical Care Act contains no specific rights for the carer of his/her own. If a spouse wants to have information about her husbands' illness, treatment and prognosis, she need informed consent from the sick person to get information about his condition from the physician. If the person cannot speak for himself due to e.g. cognitive impairment, the next step is legal guardian-ship, which come under special regulations.

Swedes have a statutory right to claim service and care whenever needing.

According to the Social Services Act, the municipality has an obligation to provide help if a need 'can not be seen to otherwise'. Elder care provision is based on a single-entry system; elderly people in need for help turn to the municipality where he lives, to claim help. Need determination takes place through a process of need assessment, carried out by a municipal care manager. The single individual could claim services but he/she has no automatic right or entitlement to services. Then, the municipality decides on the service level, eligibility criteria and range of services provided.

Also, the carer could claim help on his/her own, although this is not well-known and consequently seldom used. If the elderly requesting services is dissatisfied with the care manager's decision, the case can be appeal in the administrative court. Although the number of appeals is very low, the right to appeal is considered as an important individual protection.

In practice this is often interpreted, with dubious legality, by many municipalities to the effect that they do not provide for elders who have off-spring or other family living nearby. And, the independent position of the municipalities, enabling them to ”manage elderly care on their own”, means that service responses to carers is very much a question of the attitudes in the single municipality. As local support policies seldom are established, there are no overt rules about the categories of carers that should receive help, or the bases on which providers should respond. As a result, service responses are open to negotiation and the exercise of discretion.

2.1.2 The re-discovery of the family

In the 1990s, Sweden 're-discovered' the important role of the family in supporting older people. There are several explanations for this development. First was the realisation that the success of a policy of home-based community care was largely dependent on extensive family input. Second, as a result of economic recession, there was a growing interest in the informal care sector and its potential to substitute for costly formal service provision. Third, there was increasing research evidence pointing to the crucial role of families, their care burdens and their need for support. Finally, there has been the recent emergence of carer organisations that are now lobbying the public elder care system for increased recognition and support.

The first nation- wide study on informal care of the elderly was carried out in the beginning of the in 1990s. In a descriptive approach, data from a national representative interview study among elderly living at home showed that a majority of those needing help with ADL, received help from the family (Johansson 1991). Another study, ten years later, showed that family care increased in the 1990s: families were estimated to have provided 60 % of all care in 1994, but 70 % in 2000, for elders 75+ (Sundström, Johansson & Hassing, 2002). Comparable pattern has also been found in several local studies (Herlitz, 1997; Herlitz & Dahlberg, 1999). Hellström found in a study among elderly, 75 years and older living at home that among those receiving help with ADL (37%), almost half of all (49 %) received informal care only, one third (30%) received both informal and formal care, and one fifth (21%) relied solely on formal services (Hellström, 2003).

Indeed, Swedish families now help their elderly more than before. It is especially daughters who obey the commandment to honour one's parents: In 1994 29 % of the elderly (75+) were helped by a female family member, in 2000 39 %. Daughters made up 22 % and 33 % respectively of these figures. Help from males was constant at 15 %, mostly a son. Usually, it is one person in the family who supports a frail elderly person: a spouse, a daughter or a son. When a son is the main carer, often no daughter is available (Johansson, Sundström & Hassing, 2003).

Kristensson Ekwall (2004) found in a postal questionnaire, addressing a population sample aged 75 years and older, that 18 per cent of the respondents were caring for another elderly person. Challenging previous understanding, of what is to be a family carer, this study also showed that a majority of the carers were men and that satisfaction was a great part of the carers experience for a majority of carers.

Many studies have focused the experiences of living together with a dependent spouse (Sällström, 1994) and the burden carers of elderly people feel (Grafström, 1994). Most of these studies have target care for persons with cognitive impairment (Grafström, 1994; Sällström 1994; Almberg et al. 1997). Much of the available research has adopted a stress-coping model, and caring has been described in terms of "trying and burden- some", with little or no positive outcome for the carer (Grafström, 1994; Sällström 1994, Johansson & Åhlfeldt, 1996). Then, less attention has been paid to the rewarding aspects, in caring for the next of kind. However, Sällström (1994) also reported on feelings of satisfaction and usefulness among the spouses caring for a demented partner.

Then, in contrast to earlier research, Lundh has carried out a couple of studies, showing that sources of satisfaction are numerous and diverse and that the majority of carers experience some feelings of reward (1999a, 1999b). Building on that, Hellström (2005) has explored the "couple hood" in caring for a demented spouse, its nature, quality of relationships and the potential satisfactions of caring.

Along a similar theme, Söderlund (2004) has studied feelings and experiences by carers of people of dementia. The result reveals carers' coping capacities and resources and the possibilities to manage stress and develop satisfaction in caring.

Another important source of support for both the elderly and their carers is help from different types of voluntary organisations. Recent studies show that many Swedes are involved in voluntary work, including helping elderly, to an extent that is comparable to many other European countries (Lundström and Svedberg, 2003). However, unlike in many other countries, voluntary organisations do not in generally take on the role as hands-on service and care providers in Sweden.

Dahlberg (2004, 2005) has also found further evidences for extensive complementarity at the local level between the voluntary organisations and local authorities in providing support for the elderly and their families.

So far, there is little implementation research in Sweden, but Janson and colleagues (1998), have carried out pioneering work training volunteers and carers together. Then, after training, the volunteers replaced the carers in the homes on a regular basis, resulting in increased life satisfaction among the carers. Another type of intervention has been developed by Magnusson (2005), by providing multimedia caring programmes, video phone facilities for on-line communications with other carers and call centres, staffed with professionals. This type support of was much appreciated by the carers, enabling them to go on caring with a feeling of security, competence and satisfaction in their caring role.

2.1.3 Service and care for the elderly and their families

Sweden has an extensive system for service provision for in elderly. The most important services for making it possible for elderly to go on living in there old home are home help services. It provides help with daily activities, e.g. shopping, cooking, cleaning and laundry. It also includes personal care such as help with bathing, to go to the toilet, getting dressed and in and out of bed.

Besides home help, there is also a comprehensive range of municipal services for the elderly, such as transportation services, foot care, meals on wheels, security alarms, housing adaptations, handicap aids, etc.

Over the past few decades, it has been stated in official policy documents and political decisions at national and local levels that the care of the elderly should be given priority. In the 1960s, a rapid expansion of both institutional and home care took place in both absolute and in relative terms. However, since the end of the 1970s, home care provision has not expanded in relation to the size of the population. Moreover, a shift has taken place, whereby an increasing amount of help is given to the oldest elderly. Another important shift has been from institutional care to home-based care.

Elderly in need of care and their families have two major sources to turn to for help. Fist, and in accordance with national policy, elderly could claim support from the public health care and social services in the municipality. Municipalities also offer supportive services to the family carers, sometimes in combination with help offered to the person cared for. The other opportunity is help provided by friends and neighbours and/or from voluntary organisations. This kind of support could address both the elderly and their family carer.

On top of services provided to the person cared for, family carers can receive different of supportive services. There are two programs for **economic support** provided by the municipalities. Caregivers can receive an *attendance allowance*: this is an untaxed cash payment that goes to the dependent, to be used to pay the family member. The monthly payment is rather modest – at most about SEK 5000/month (~ 550 Euro). Eligibility is usually based on level of dependency/amount of care. Another option is the *carers allowance* which means that the municipality reimburse or salary the family caregiver for her work. Carers allowance provides similar social security protection as for the care personnel in the formal services and this income is taxed.

These programs are a matter for the municipality to decide own (whether to provide this program or not, eligibility criteria, level of payment), i.e. no national/federal regulation exist. In year 2004, about 7500 carers altogether received this kind of economic support, i.e. very few do so and the number has been slowly going down recent years.

The second type of support is **respite care.** In 2004 there were about 9 000 beds available for institutional respite care in Sweden. Another mode of respite care is (adult) day care. There are no data at the national level on how many day care units there are, but survey data point to about 600 units in Sweden in total. Finally, there is also a growing number municipalities offering in-home respite care for carers.

The third possibility to receive support could be labelled **counselling and personal support**. In recent years, support groups have been very popular - usually run by voluntary organisations - and now available in a growing number of municipalities. Counselling services in terms of a one-to-one contact is not provided on a regular basis, but can also be offered.

2.1.4 Recent developments

The ‘Carers’ Issues’ have been the subject of recent legislation. In 1998 there was an amendment to the Social Services Act stating that the local authorities should support families and next of kin when caring for elderly, sick and dependent family members. The law sends a strong message to municipalities to provide services for carers. Subsequently, the ways in which formal services can best support and work in collaboration with family caregivers has received increasing government attention. The need to further develop support systems for family carers is an integral part of the national plan for the care of older people (Ministry of Health and Welfare, 2000).

In order to underpin and sustain the new legislation, and to stimulate service development the Swedish government, between 1999-2001, allocated 300 million crowns to be distributed amongst municipalities in Sweden who provided services such as respite care for family carers (Family Carer 300 Initiative, National Board of Health and Welfare, 2003, 2004).

Table 1: Development of support programmes for carers in Sweden. Percent of the Swedish municipalities providing these

Type of programme	Available in 1999	Available in 2004
In-Home respite care	69	91
Institutional respite	99	99
Day care	80	92
Carers support group	28	72
Carers resource centres	7	32
Carers consultant	5	50
Counselling	47	74

As shown in table 1, it is obvious that the number of support programmes available in the municipalities has increased substantiality. **Respite services** are now available in virtually all of Sweden’s 290 municipalities. Especially in-home respite care has become a very popular support program. And, an increasing number of municipalities are offering in-home respite, free of charge. There are also interesting trends towards more innovative types of services. This involves greater variation and scope of different types of relief services. Here the ultimate goal is to be able to offer carers "24-hours instant relief" or drop-in services. One innovative example is the ”emergency unit”, that has been developed is some municipalities in order to maximise security for the elderly and their carers. Some municipalities also offer this service without (or with minimal) bureaucracy, in order to maximize access to relief for the carers. Respite could be combined with „weekend-breaks“, when carers are offered to stay at spa-hotel, in order to stress-down, take time out, and care for themselves.

Interesting is also that there has been a substantial growth in **counselling** and personal support services provided in the municipalities. This has become a vital part of the core package offered to the carers. This is at the same time a good example of collaboration between formal services and the voluntary organisations, as e.g. support groups are often run by voluntary organisations, as well as befriending and sitting services and help-line services, all over the country.

Another trend is to develop richer opportunities for **information** – using modern IT-technology-, educational and personal counselling **services** (Magnusson, 2005). Training programs, seminars and conferences, addressing both politicians, care personnel, carers and their organisations have been carried out all over the country in recent years. Many local authorities are trying different types of out-reach strategies. To improve the contact and interface with the carer, many municipalities have appointed a "Carer’s Consultant", who functions as a two-way co-ordinator of contacts between the formal services and the carers. Finally, another trend in recent years has been to establish “Carer’s Centres”, which function as meeting-place and home base, both for formal services, carers and voluntary organisations.

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3 Assessment tool

Content

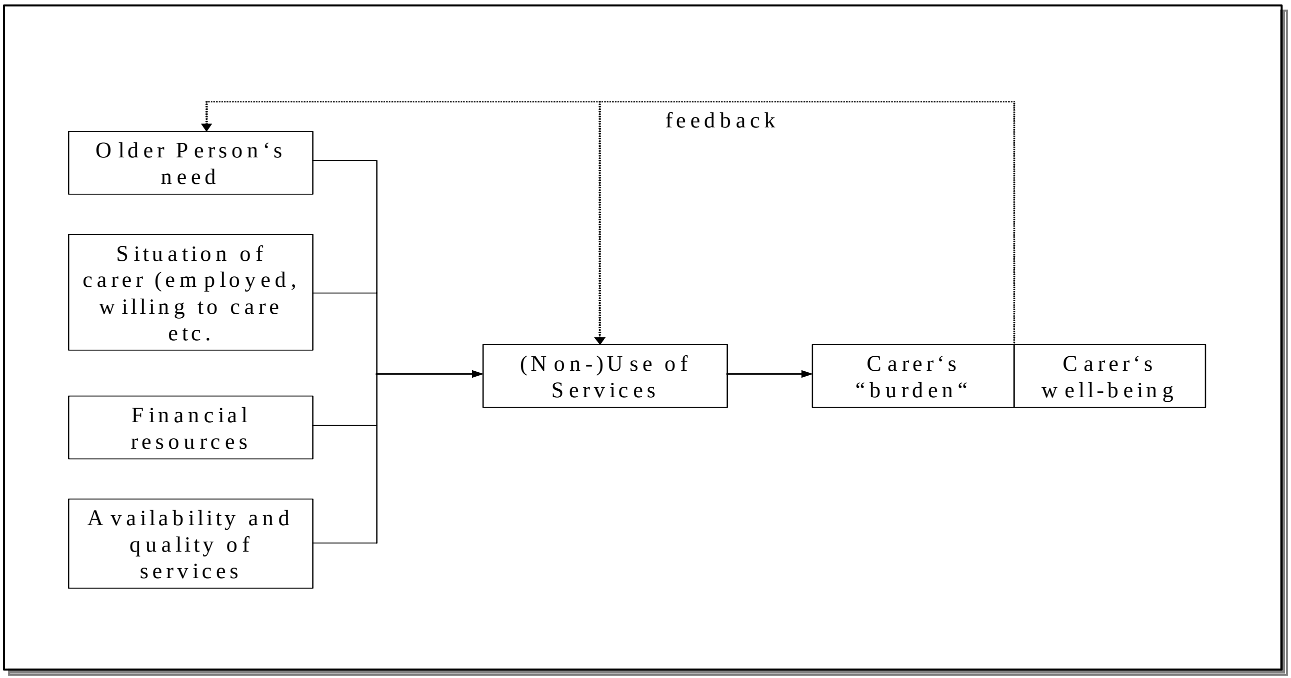
3.1 Introduction

This chapter describes the assessment tools that are used for family carers in the EUROFAMCARE project, it is the same as described in EUROFAMCARE Trans-European Survey Report (TEUSURE) 2005, Chapter 3 (Mc Kee et al., 2005).

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.

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



Adapted from Aneshensel et al. (1995)

Following further development, the constructs were operationalised in the CAT via a series of variable categories: *Elder's demographic and background characteristics; Elder's disability and need; Carer's demographic and background characteristics; Carer's caregiving situation; Carer quality of life (QoL); Financial circumstances; Service use; Characteristics and quality of services*. In addition, some variables in the CAT addressed issues related to the administration of the questionnaire. The CAT also included a project consent form. Finally, each EUROFAMCARE partner was allowed to include a small number of country-specific items in their own version of the CAT. The description of these items can be found in the partners' respective NASUREs.

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

3.2 CAT Items and Instruments

3.2.1 CAT administration

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

3.2.1.1 Mode of recruitment

This item, indicating the manner in which the respondent had been recruited, had eight optional responses: health or social care professional (1); priest/parish/religious organisation (2); door-to-door (3); voluntary organisation (4); advertisement (5); lists (6); other (7); 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 their were any services that the Carer or Elder needed but had not used so far (yes=1, no=0). Again, where the answer to this item was 'yes', the respondent was asked to specify up to the three most important services they had not used, and to indicate for each specified service whether the reason they had not used the service was because it was 'too expensive'; 'too distant'; because of the 'low quality of the service'; because they 'didn't know about it'; because carer/elder was 'not entitled to use it'; or 'other' (specified).

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

3.2.9 Characteristics and quality of services

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

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

3.3 Item transformation

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

3.3.1 Elder's demographic and background characteristics

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

3.3.2 Elder's disability and need

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

A measure of elder's dependency was derived taking into account both cognitive and functional disability. To this end a disability index was first derived, which took into account ADL, IADL, and the additional mobility item (see section 3.2.3.4). These items were first dichotomised as to separate elders with the highest degree of disability (1=not able or not continent, where appropriate) from the less disabled others (0=able with or without help or continent, where appropriate) and then summed to produce the disability index, which had a theoretical range of 0 to 17. The dependency variable was then constructed by combining a dichotomous version of the cognitive status variable above – where elders without cognitive disorder were differentiated from those with cognitive disorder – and a dichotomous version of the overall disability index – where the median (50th percentile) of the distribution was used to distinguish elders with no/slight disability from elders with more severe functional disability. Thus, the elder's dependency variable was made up by the following categories (groups) of elders: ‘cognitively able and no/slight disability’ (0); ‘cognitively able and more severe disability’ (1); ‘cognitively impaired and no/slight disability’ (2) and ‘cognitively impaired and more severe disability’ (3). A three-category ordinal measure of elder’s dependency was also made available for more complicated – rather than merely descriptive – analyses, in which the ‘cognitively able and more severe disability’ category was merged with the ‘cognitively impaired and no/slight disability’ category of the original dependency variable.

Table 1: CAT transformed elder-related variables

Variable name	Categories/Levels	Values
Elder’s marital status		
	Widowed, divorced/separated or single	1
	Married/cohabiting	0
Elder’s usual place of residence		
	At home	1
	Care home/sheltered housing/other places	0
Elder’s cognitive status		
	No cognitive disorder	0
	Behavioural problems without cognitive disorder	1
	Age associated memory impairment	2
	Suspected dementia	3
Elder’s dependency		
	Cognitively able and no/slight disability	0
	Cognitively able and more severe disability	1
	Suspected cognitive disorder and no/slight disability	2
	Suspected cognitive disorder and more severe disability	3

3.3.3 Carer's demographic and background characteristics

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

3.3.4 Carer's caregiving situation

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

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

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

3.3.5 Financial Circumstances

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

3.3.6 Service use

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

Table 2: CAT transformed carer-related variables

Variable name	Categories/Levels	Values
Carer’s marital status		
	Widowed, divorced/separated and single	1
	Married/cohabiting	0
Carer’s relationship to elder		
	Partner	0
	Child	1
	Son/daughter in law	2
	Others	3
Number of children aged 14 or less in carer’s household		
	None	0
	At least one	1
Carer’s highest educational attainment		
	Low	1
	Intermediate	2
	High	3
Carer’s employment status		
	Retired	0
	All other non-working (e.g., housewife/househusband)	1
	Working	2
Proximity of the respondent to Elder		
	Cohabitant	1
	Non-cohabitant	0
Number of nights of caregiving in typical week		
		0-7
Units of caregiving during week-end		
		0-10
Additional costs index		
		0-5
Number of services used by elder		
		0-15
Number of services used by carer		
		0-15

3.4 Scale development

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

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 (α=.78). Thus, responses to the three items were summed to produce a behavioural problems scale with a theoretical range of 0 to 9 (highest frequency of behavioural problems). The strong positive skew obtained on the scale implies that it is not optimally suited to discriminate individual differences at lower levels of behavioural problems in this sample.

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 (α=.78), and finally summed to produce an IADL scale with a theoretical range of 0 to 6 (highest number of activities for which elder needed help). The scale mean and median were quite high (M=4.27, SD=1.74; Median=5.00) indicating that the cared-for elders had, on average, a high degree of impairment on these kind of activities.

The individual items comprising the Barthel Index of ADLs (Mahoney & Barthel, 1965; see section 2.3.4) were then considered. The two Barthel items with four response categories had their two middle categories collapsed, prior to determining the internal consistency of the items, which was high (α=.92). The Index makes use of a weighting system for scale scoring, with each item response score multiplied by 5 prior to summing, producing a theoretical range of0 to 100 (totally independent on activities of daily living). There were a high number of missing values on this scale (N=239, 4%). Mean and median values were moderately high (M=69.70, SD=29.75; Median=80.00), indicating that the majority of elders had a high level of independece on ADL activities.

To have available for analysis a more sensitive measure of functional impairment than ADL and IADL taken alone, the disability index was used (see section 3.3.2). The index had an excellent internal consistency (α=.93). Due to the number of items comprising the scale, there was a high number of missing cases (n=306, 5.2%). The mean and median (M=5.43, SD=5.04; Median=4.00) indicated a relatively low level of functional disability in the sample.

A further indicator of elder dependency was built through summing the items assessing need for help in different domains (see section 2.3.1). Items were recoded into dichotomous variables (partial need for help (1) vs. no need for help (0)). The newly created items had satisfactory internal consistency (α=.69), and were summed to produce a scale of overall need for assistance with a theoretical range of 0 to 8 (highest need for assistance). The scale mean and median were high (M=6.02, SD=1,79; Median=7.00) indicating a substantial need for help.

Table 3: Elder-related scales

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

3.4.2 Carer-related scales

3.4.2.1 Well-being Index

The five items of the World Health Organisation-5 Well-being Index (WHO, 1998) demonstrated high internal consistency (α= .87) and were summed to produce the Well-being Index with a theoretical range of 0 to 25 (highest well-being). The mean and median (M=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 (α= .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 (α=.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 (α=.82), and when summed produced a scale of elder's need's covered by formal support with a theoretical range of 0 to 8 (highest number of needs covered by services or support organizations). The scale mean and median (M=.85, SD=1.60; Median=0.00) clearly indicated that elder's needs covered by services or support organizations were on average very few.

3.4.2.2.4 Elder's needs for which more help is required

The items assessing elder's need for support were here recoded so as to indicate needs for which the carer would like to have more support (1=yes, 0=no/not applicable). Internal consistency for these items was very good (α=.86), and the items were summed to produce a scale of carer perceived need for support with a theoretical range of 0 to 8 (highest number of needs for which carer wanted more support for elder).

Table 4: Carer-related scales

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

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

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

After this preliminary exploratory work, the COPE Index subscales were developed. The Negative Impact items were analysed for their internal consistency, which was satisfactory (α=.83), and were summed to create the Negative Impact subscale with a theoretical range of 7 to 28 (highest impact of caregiving). The items comprising the Positive Value subscale had a low alpha (α=.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 (α=.66) and were therefore summed to give a subscale with a theoretical range of 4 to 16 (highest quality of support).

Table 5: The Cope Index: Items and factor loading

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

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

3.5.1 Background

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

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

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

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

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

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

3.5.3 CAT-FUQ Items and Instruments

3.5.3.1 CAT-FUQ administration

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

3.5.3.2 Items to determine current caregiving status

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

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

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

After these two questions answered only by participants no longer providing more than 4 hours of care, all participants answered Question 4 (and subsequent questions). This question was the single item measure of carer health status drawn from the Short Form-36 (SF-36; Brazier et al., 1992). Following this question, a single item assessed overall carer quality of life for the preceding two weeks, also drawn from the SF-36, and information on carers’ psychological well being was gathered using the World Health Organisation-5 Well-being Index (WHO, 1998) (see Section 3.2.6).

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

Following this item, carers providing 4 hours of care per week or less were directed to the final section of the questionnaire, which offered the opportunity to provide additional comments (see

Section 3.5.3.3.6) before returning the questionnaire to the researcher. Carers providing more than 4 hours of care per week were asked to continue to the main questionnaire.

3.5.3.3 CAT-FUQ Main Questionnaire

3.5.3.3.1 Elder's residence

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

3.5.3.3.2 Elder's disability and need

3.5.3.3.2.1 Mental health problems

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

3.5.3.3.2.2 Behavioural problems

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

3.5.3.3.2.3 Dependency

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

3.5.3.3.3 Carer's demographic and background characteristics

3.5.3.3.3.1 Carer employment status and impact of caregiving on employment

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

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

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

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

3.5.3.3.3.2 Change in circumstances

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

3.5.3.3.4 Carer's caregiving situation

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

3.5.3.3.4.1 Role inflexibility

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

3.5.3.3.4.2 Positive and negative aspects of care

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

3.5.3.3.4.3 Future care role

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

3.5.3.3.5 Caregiving allowances

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

3.5.3.3.6 Service Use

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

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

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

3.5.3.3.7 Additional comments

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

3.6 References

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4 Sampling recruitment and representativeness of the sample

Content

4.1 Aims of chapter 4

The aim of this chapter is to present how the data was collected and describe the sampling strategy in the project. The aim is also to discuss the representativeness of the sample.

4.2 Method and sample

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

- Questionnaires and guidelines for data collection
- How to evaluate the percentage of family carers in the whole population and to develop sampling strategies
- How to train the interviewers
- The criteria of the sample unit (i.e. definition of “family carer of older people”)

To ensure a reasonable level of representativeness and comparability 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.

4.2.1 Sample units

This definition includes any person who:

- perceives themselves to be a career;
- supports an older person 65+ for at least 4 hours a week and/or organises the care provided by others;
- provides care to an older person living at home or in residential care settings (nursing homes, sheltered housing, etc);
- excluded: those who only provide financial support or companionship.

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

4.2.2 Sampling strategy

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

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

4.2.3 Recruitment procedure

Family carers have been recruited through the agreed saturation method, which consists in contacting the universe of caregivers living in the chosen sample communities through all the following potential recruitment channels.

The following recruitment procedures have been used:

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

4.2.4 Number of planned respondents

It was planned to carry out interviews with 1000 respondents in each country.

4.2.5 Type of sampling

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

4.2.6 Sampling parameters

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

- Territorial parameter: a proportionate sampling has been carried out according to the size of the population aged 65+ living at home in the sub-areas identified in each country.
- Urban-rural parameter: each of the sub-samples have been subsequently subdivided according to the metropolitan, urban and rural population distribution.
- Availability of services; the regions and municipalities to be involved in the survey have been chosen according to the criteria of level of supply of support services for elderly people, in order to assure that regions with high, medium and low availability of services were included.

The described strategy for sampling was aimed to try to ensure that the sample would represent a variety of caring situations. To further discuss the representativeness, each country has tried to compare the collected samples to existing descriptions of elderly or carer in existing national data bases or from other studies.

4.2.7 Distribution of the sample based on urban - rural parameter

Table 1 illustrates the distribution of the Swedish sample by locality type and shows that the majority of the people recruited lives in urban and rural areas. The results must be considered in relation to the urban/rural characteristics within each country as presented further down in the text.

Table 1: Distribution of sample by locality type

Locality type	**n**	**%**
Metropolitan	34	3.7
Urban	561	61.9
Rural	312	34.4
Total	907	100

4.2.8 Recruitment modes

Each country used the instructions from the step for NASURE and used different ways of recruitment modes to achieve the agreed number of participants. Sweden, experienced major problems in the recruitment of participants and therefore the strategy included contracting subcontractors to speed up the inclusion. This changed the initially agreed sampling strategy and details on this are presented further down in the text. The major mode used was personal contacts and contacts by telephone using a random sample of the inhabitants in Östergötland. Few were recruited by advertisement (Table 2).

Table 2: The distribution of different recruitment modes

Recruitment mode	n	%
Health or social care professional	143	15.6
Religious organisations	3	0.3
Door to door	3	0.3
Voluntary organisations	43	4.7
Advertisement	59	6.4
Lists (of inhabitants in a region etc.)	480	52.3
Personal contacts, neighbours, friends, relatives of interviewers	179	19.5
Other	8	0.9
Total	918	100

4.2.9 Sampling strategy in Sweden

Method and sample sampling procedure was chosen and guided by the agreed procedures in the step for NASURE.

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

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

4.2.9.1 Sample distribution in the different regions

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

The chosen areas were South West, Eastern and North of Sweden. In each region we calculated the expected number of family caregivers based on the above reports also including the expected number form urban and rural areas. The calculated numbers are presented in table 3.

Table 3: The expected number of carer based on the population in each region

Region	Inhabitants ≥40 years (50% of inhab.)	Family carers (10% of ≥40 years)	Calculated interviews (with 75% response frequency)		
			Number of interviews	% of inhab. ≥40	% of the study
Eastern					
Linköping	Ca 75 000	7 500	350	4.6	35
Urban			*250*		*25*
Rural			*100*		*10*
Norrköping	Ca 75 000	7 500	350	4.6	35
Urban			*250*		*25*
Rural			*100*		*10*
South West					
Varberg	Ca 15 000	1 500	200	13.3	20
Urban			*100*		*10*
Rural			*100*		*10*
North					
Nordanstig	Ca 7 500	750	100	13.3	10
Rural			*100*		*10*
Total			1000		100
Urban					*60*
Rural					*40*

4.2.9.2 Recruitment procedure

Following recruitment procedure was used:

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

4.2.9.3 Recruitment of family carers survey

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

The distribution of the planned and accomplished cases in the different regions is presented below in table 4.

Table 4: Distribution of planned and accomplished cases in the different regions

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

4.2.9.4 Recruitment channels

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

- Advertisement in newspapers
- Flyer at places where target group was supposed to be found
- Contacts with voluntary or religious organisations
- Door to door
- Contacts with Health and social care .Primary care centres, geriatric elderly centres etc
- Snow ball through further contacts by any of the previous methods
- Personal contacts of interviewers.

At each site a coordinator was used and a between 5 – 20 interviewers per site were recruited and introduced by training to do the interviews.

4.2.9.5 Introducing a subcontractor

After 5 months the recruitment results was very low and therefore it was decided to use an authorised telemarketing service to achieve a higher number of responders.

Of the 3500 questionnaire sent out to people of 40 year of age or older 1400 responded out of these only 70 fulfilled the criteria for inclusion in the study and accepted to participate. The advertisements in papers and flyers did not speed up the recruitment. It was therefore decided that a subcontractor was needed to achieve the number of interviews planned. A telemarketing company was contacted and it was agreed that 425 telephone interviews should be done. The method used was based on the same assumption as in the first step by sending out a questionnaire to identify family caregivers. The consultant used public register and contacted those over 45 years by phone and asked for participation.

4.2.10 Sample distribution according to metropolitan and rural differences

The Swedish sample was based on the three geographically different areas .North represent only rural area , Eastern represented urban and rural areas and South west, urban rural and metropolitan The postal code was used for stratification urban/rural areas. The distribution based on urban rural differences is presented in table 5. The sample is dominated by urban areas and very few in metropolitan areas.

Table 5: Distribution in urban, rural and metropolitan areas in the different regions

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

4.2.11 Representativeness in the Swedish sample

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

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

Different studies that are focusing carer of older people was used to analyse if the Swedish EFC sample is comparable to the data collected in those studies. However these studies have slightly different definition of help and support and also the targeted group could be different. This might explain some of the occurred differences.

The comparisons show some of the characteristics of the older people and the family carers and a sub sample of those of 55 years and older their frequency of caregiving (table 6 and 7). The question used to identify carers in the Surveys of Living Conditions in Sweden (ULF) by Statistics Sweden was “Do you on a regular basis help someone old, sick or handicapped that lives in your household or somewhere?”.

According to table 6 the characteristics of the samples are in many aspects similar. Though there are also some differences. One exception concerns the cognitive status at the older person where the EFC data has a higher frequency of persons with dementia at lower age and lower frequency at higher age. This probably reflects that the EFC study focuses on family carers while the reference data is the epidemiology based on the Swedish population. The EFC sample is characterised by a high frequency of daily caregiving and of married especially married female carers, which might be explained by the high number of couples living together in the EFC study.

Table 6: Characteristics of elder and family carers - comparison between the Swedish EFC sample and selected data from reference studies

Characteristics		Reference %	EFC sample %
Elder			
Living	lives in their own home	92[1]	83
	lives in institutional living and sheltered housing	20[1]	17
Married	married of those who needs help	48[1]	56
Gender	women of those who needs help	65[2]	58
Cognitive status	those who have dementia aged 70-74	5[3]	20
	those who have dementia aged 90-94	40[3]	9
Carer			
Caring for elder >75	male carers who cares for elder aged >75	81[2]	68
	female carers who cares for elder aged >75	88[2]	79
Married	men	81[2]	83
	women	53[2]	84
Employed	age 45-54	90[2]	85
	age 55-64	70[2]	68
Carers aged ≥75	men	60[4]	44
	women	40[4]	56
	married	82[4]	93
	married men	90[4]	97
	married women	73[4]	90
	widow	17[4]	7
	widower	4[4]	3
Health of carers aged ≥75	excellent or very good	20[4]	25
	good	36[4]	32
	fairly good	36[4]	39
	bad	8[4]	5

[1] Busch-Zetterberg (1996), [2] Sweden statistics (2002), [3] SUB The Swedish Council of Technology Assessment in Health Care (2006), [4] Kristensson Ekwall et al (2004)

The frequency of caregiving the EFC data is compared with data from the Surveys of Living Conditions in Sweden (ULF) by Statistics Sweden, concerning those 55 years of age and older (table 7). In both studies about half of the carers are children of the cared-for. The EFC sample has a higher proportion of caregivers who provide care on a daily bases. There are also more men who are caregivers in the EFC sample and they also provide care more often. However as explained above the carers in the ULF concerns those who help someone old, sick or handicapped on a regular basis while the EFC includes carers who provide care at least 4 hours per week to persons aged 65 years and older. The slightly different inclusion criteria of carers might explain the differences concerning frequencies.

Table 7: The frequency of caregiving - Comparison between the ULF study and the EFC study

		% of men and women respectively		% of total	
	Frequency	**ULF[1]**	**EFC**	**ULF[1]**	**EFC**
Men aged ≥55	Daily	25.9	73.0	11.9	20.7
	Several times a week	25.3	14.2	11.6	4.0
	Few times a week	48.8	12.8	22.3	3.6
	Total men	(n 191 536) 100.0	(n 211) 100.0	(n 191 536) 45.7	(n 211) 28.4
Women aged ≥55	Daily	28.8	66.9	15.6	47.9
	Several times a week	28.4	24.4	15.4	17.5
	Few times a week	42.8	8.6	23.2	6.2
	Total women	(n 227 149) 100.0	(n 532) 100.0	(n 227 149) 54.3	(n 532) 71.6
Total				(n 418 685) 100.0	(n 743) 100.0

[1] Statistics Sweden (2002)

4.3 Final comment

The initial strategy to collect participants by sending a postal request did not give enough numbers in relation to the timeframe for the project and this led to changing the strategy by involving a subcontractor. The subcontractor did a collection by using phone numbers in the chosen areas and therefore a random procedure was used but on the other hand the saturation in each area cannot be guaranteed. This weakens the sampling method but the analysis of the collected material showed that it seems to be reasonable representative according to basic characteristics even if the geographical distribution is a bit skewed. The strength of the sample is that it gives the picture of the plurality of the caring situation from the carers perspective .

Even if the sampling gave some difficulties the sample is useful for description and comparison of different caring situations and a more in depth analysis allows for further comparisons between areas with different models for service distribution.

4.4 References

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

Content

5.1 Aims of chapter 5

The main aim of this chapter is to describe the profiles of the people involved in the caring situation; the main family carer (FC) and the family member who is in need of care and support (OP). This chapter tries to answer basic questions like; who is the main family carer and who is the cared-for person? i.e. present basic characteristics of both groups.

The data in the chapter is presented in a simple and descriptive way and it contain among other thing, socio-demographic characteristics and financial situation of both carers and cared-for people. The chapter also describe working situation and heath status of the carers as well as level of impairment of the cared-for people.

5.2 Profile of older cared-for people (OP)

5.2.1 Socio-demographic characteristics of the cared-for people

The cared-for people are 65 years or older due to the age criteria to enter this survey. The average age in the Swedish sample is over 81 years and the average age of the cared-for females are a few years higher then the cared-for males. More then two-thirds of the females are 80 years or older while only half of the males reached this category (Table 1). The oldest female in the sample is 106 years old and the oldest male is 101 years old.

Table 1: Age and gender of cared-for people

Gender of OP	Percentage	
Male	42.3	
Female	57.7	
Mean age of OP	**Male**	**Female**
81.3	79.1	82.9
Age of OP (grouped)	**Percentage**	
65-79	39.6	
80+	60.4	
Age of OP (grouped)	**Male**	**Female**
65-79	49.9	32.0
80+	50.1	68.0

More then half of the cared-for people in the Swedish sample are married or living together. Another large group consists of widowed people (Table 2).

Table 2: Marital status of cared-for people

Marital status of OP	Percentage
Married / cohabiting	55.9
Widowed	38.7
Single	2.8
Divorced / separated	2.6

Almost every older cared-for person in the sample are Swedish citizens, only less then one percent represent a different nationality. The ethnic origin follows a similar pattern, approximately 96 percent have Swedish origin and as much as 98 percent is of Scandinavian descent.

5.2.2 Place of living and household structure

Most of the Swedish people, over 96 percent, lives in urban or rural areas. Almost two-thirds of these older cared-for people lives in urban areas and one-third lives in rural areas.

Over 80 percent of the older cared-for people still lives at home. At home means their own home, where the elder either lives alone or with their partner or some other person. At home can also mean there children's home. These living arrangements has to be distinguished from professional offers such as care home or sheltered housing. Almost 16 percent of the older cared-for people lives in such professional care arrangements (Table 3).

Cared-for people living at home shows a mean Barthel Index of 74.9 compared to 63.9 for people living in sheltered housing and 41.0 for people living in a care home. Not very surprisingly this shows that people living in sheltered housing or care home are more physically disabled than those living at home. The mean IADL for these groups follows the same pattern. The group of older cared-for people that lives alone shows a high mean value on both Barthel Index and IADL, 78.3 and 6.1, which means that they are quite physically able. The same values for the group who lives together with someone are 65.7 and 3.7.

Nearly 40 percent of the older cared-for people lives alone and approximately half of the cared-for lives with their partner. The Swedish sample also shows that a very small part of the cared-for lives with there children or other relatives and an even smaller part lives with a paid carer (Table 3).

People who lives with their main carer or in a care home are excluded from the variable; *number of people in OP's household, OP included.* This group represent nearly 45 percent of the Swedish sample. Over 80 percent of the cared-for people in this group lives alone (Table 3).

Table 3: Place of living, living-situation and household composition

Place of living for OP	Percentage
At home	83.0
Care home	10.0
Sheltered housing	5.7
Other place	1.3
OP lives alone or with others	**Percentage**
Alone	39.0
With others	61.0
Household structure*	**Percentage**
With partner	49.3
With children	3.4
Other relatives	0.9
Paid carer	0.7
Other care arrangements	14.3
Number of people in OP's household, OP included**	**Percentage**
1	83.8
2	15.3
3	0.8
4 or more	0.3

*multiple answer possible, % of whole sample

**Cared-for persons who lives with main carer or in a care home are excluded

5.2.3 Cared-for persons' financial situation

Everyone in the Swedish sample receive pension or some other financial support from the state. A few people also receive some kind of allowance due to the caring situation. Approximately seven percent receive such allowances and the amount of these very from 84.7 to 423.6€[2] per month. The average amount of these allowances are 165.3€ per month.

Figure 1 describe the monthly household income of the cared-for persons that don't live together with their main carer. It should be mentioned that the total income per household is affected by the number of income-holders that lives there.

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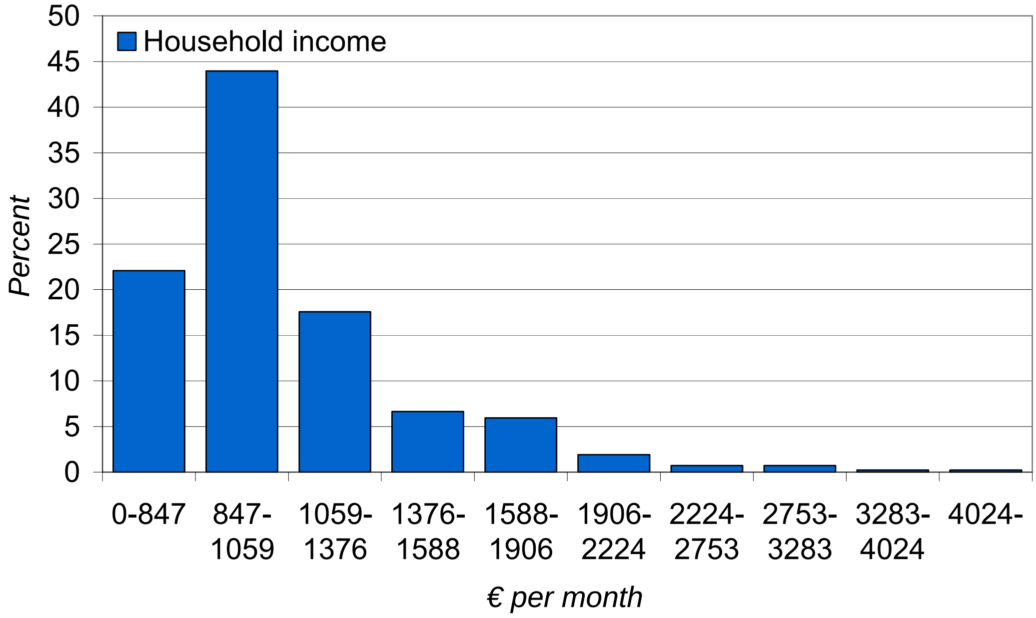
[2] Exchange rate 1€ = 9.44359 SEK (2005.12.14)

Figure 1: Cared-for persons' household income per month divided by interval



5.2.4 Cared-for persons' health situation and need for support

The Swedish sample shows that the main reasons why people need care and support are; physical illness/disability, age-related decline and memory problems or cognitive impairment. These three reasons represent more than 80 percent of the answers on this question. Only every tenth person mentioned mobility problems as the main reason for caring (Table 4).

Table 4: Main reason why cared-for person needs care and support

Reason	Percentage
Physical illness/disabilities	38.8
Age-related decline, old age	23.9
Memory problems or cognitive impairment	19.0
Mobility problems	9.7
Sensory problems	3.9
Psychological/psychiatric illness/problems	2.2
Non self-caring	0.7
Safety/feeling of insecurity	0.5
Social reasons, loneliness, need for company	0.4
Other reason	0.9

The questions about memory and behavioural problems reveals the carers' perception of the cared-for persons' problems. Approximately half of the Swedish sample state that they suffer from memory problems. Over 40 percent of these people haven't yet got their problems diagnosed. About one-fourth of the cared-for people show signs of behavioural problems (Table 5).

As table 5 also shows, the sample consists of a quite large group of people, approximately 45 percent, that doesn't suffer from neither memory nor behavioural problems. The second largest group, almost one-third of the cared-for people, only suffer from memory problems.

Table 5: Memory and behavioural problems among the cared-for people

<table>
<tr><th colspan="2">Memory or Behavioural problems</th><th colspan="2">Percentage</th></tr>
<tr><td colspan="2" rowspan="4">Memory problems</td><td>Total</td><td>51.2</td></tr>
<tr><td>Undiagnosed memory problems</td><td>43.3</td></tr>
<tr><td>Dementia</td><td>36.1</td></tr>
<tr><td>Other diagnosis/explanation</td><td>20.6</td></tr>
<tr><td colspan="2">Behavioural problems</td><td>Total</td><td>26.3</td></tr>
<tr><th>Memory problems</th><th>Behavioural problems</th><th colspan="2">Percentage</th></tr>
<tr><td>No</td><td>No</td><td colspan="2">45.2</td></tr>
<tr><td>No</td><td>Yes</td><td colspan="2">3.4</td></tr>
<tr><td>Yes</td><td>No</td><td colspan="2">28.5</td></tr>
<tr><td>Yes</td><td>Yes</td><td colspan="2">22.9</td></tr>
</table>

Dependency level is a measurement of how the carer evaluate the cared-for persons' functional status. More than 70 percent of the cared-for people in the Swedish sample are moderately or severely dependent and only just over 3 percent claims to be independent. As expected, dependency level and Barthel Index are strongly correlated. The higher level of dependency the worse score on Barthel Index (Table 6).

Table 6: Cared-for persons' level of dependency

Dependency level[3]	Percentage	Mean Barthel Index
Independent	3.3	94.1
Slightly dependent	23.4	89.5
Moderately dependent	38.8	79.6
Severely dependent	34.6	46.0

The need where the largest part, over 90 percent, of the cared-for people partially or completely rely on others to handle is *domestic needs*. Other needs where over 80 percent of the cared-for people rely partially or completely on others to handle are; *Organising and managing care/support, financial management and emotional/psychological/social needs.* The domain where a predominately part of the cared-for don't need help is *financial support*. This means that the mainly part doesn't consider money as an obstructive object to whether they get help or not (Table 7).

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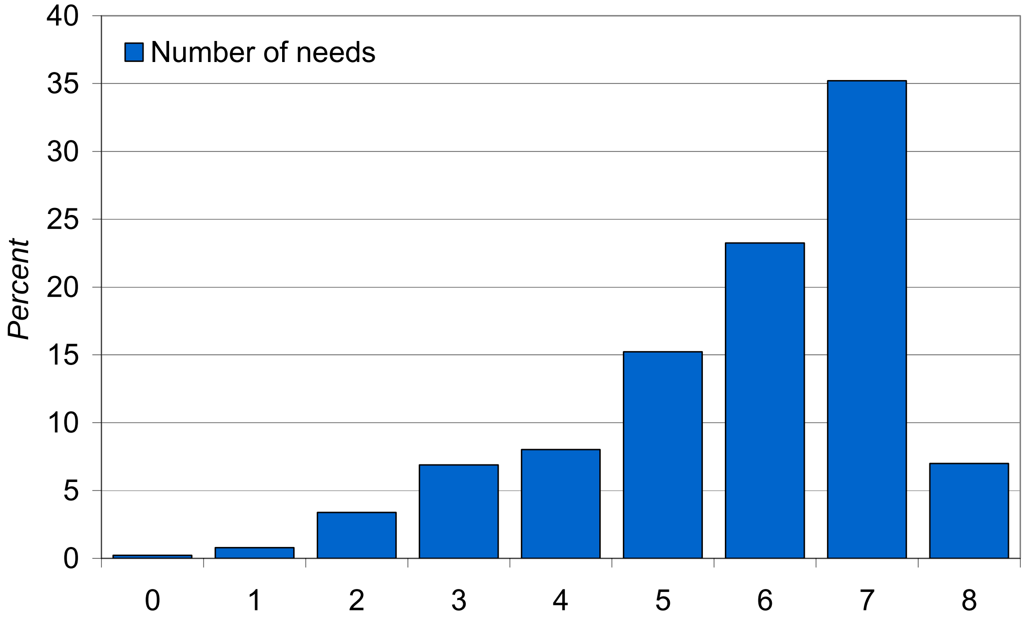
[3] The possible answers and the related description of the level of dependency that carers could choose where:
Independent: Able to carry out most activities of daily living, but may need some help occasionally.
Slightly dependent: Able to carry out most activities of daily living, but requires help with some instrumental activities (e.g. shopping, cooking, housework, etc).
Moderately dependent: Able to carry out some basic activities of daily living (e.g. bathing, feeding, dressing), but unable without help to carry out most instrumental activities of daily living (e.g. shopping, cooking, housework, etc).
Severely dependent: Unable to carry out most activities of daily living, without help (e.g. feeding themselves or going to the toilet).

Table 7: Cared-for person rely completely or partially on others to meet their needs

Needs	Completely	Partially	No help needed
Domestic needs	53.9	39.0	7.1
Organising and managing care/support	65.3	22.1	12.6
Financial management	70.0	15.1	14.9
Emotional/psychological/social	30.1	54.5	15.4
Health needs	50.1	26.6	23.3
Mobility needs	22.3	51.0	26.7
Physical/personal needs	25.6	43.0	31.4
Financial support	6.3	6.6	87.1

When the different needs are summarized we get an understanding on how much help the cared-for people need. More than 80 percent of the cared-for needs help in five or more domains and only one percent needs help in one or less domains (Figure 2).

Figure 2: Total number of needs for which the cared-for person rely partially or completely on others to handle.



5.3 Profile of family carers (FC)

5.3.1 Socio-demographic characteristics of family carers

The mean age of the main carer is 65.4 years in the Swedish sample. There is significant difference between males and females mean age. The mean age of the male carers are four years higher then the females. If we divide the age variable into two groups, with 65 years as a cut point, we can se that the sample is quite evenly spread over these groups. Approximately 55 percent of the carers are 65 years or older (Table 8).

More than 70 percent of the main carers are females (Table 8). The oldest female carer is 85 years old and the oldest male carer is 96 years old.

Table 8: Age and gender of family carers

Gender of FC	Percentage	
Male	28.0	
Female	72.0	
Mean age of FC	**Male**	**Female**
65.4	68.3	64.3
Age of FC (grouped)	**Percentage**	
≤64	44.8	
65+	55.2	
Age of FC (grouped)	**Male**	**Female**
≤64	34.0	48.9
65+	66.0	51.1

The carers nationality and ethnic origin are quite similar to the cared-for persons. Over 99 percent of the carer are Swedish citizens and only four percent are of different ethnic origin.

Just over 50 percent of the carers belongs to a religious denomination, where almost everyone is protestants. Only 1.7 percent belongs to another denomination.

Approximately 52 percent of all carers consider themselves to be religious, 46 percent state that they are “quite religious” and only six percent state that they are “very religious”. This means that almost 48 percent of the carers are non-religious.

5.3.2 Educational and employment characteristics

The level of education were divided into three groups; *low-, intermediate- and high level.* About two-thirds of the carers have at least an intermediate level of education of which approximately 37 percent have a high level of education. Barely five percent of the carers are currently in some kind of education.

Approximately one-third of the carers in the sample are, at the time of the interview, employed. Almost 90 percent them are working in the private or public sector, the rest are either self employed or working in a non-specified sector (Table 9).

Table 9: Family carers’ employment situation and sector of work

Employment situation	Percentage
Non-working	66.1
Employed	33.9
Sector of work	**Percentage**
Private sector employee	25.6
Public sector employee	61.4
Self employed	10.2
Other	2.7

About 14 percent of the employed carers have been forced to reduce their working hours due to the caring situation. The average number of reduced working hours for these employees are 14.3 hours and the average reduction on their income has been approximately 260€ per month.

There is just a small part of the non-working carers who cannot work at all or had to give up their work (Table 10).

Table 10: Work restrictions due to caring, for the non-working and all family carers

Non-working carers	Percentage
I cannot work at all	1.5
I had to give up work	2.1
All carers	**Percentage**
I can/could not develop my professional career or studies	6.0
I can/could work only occasionally	2.3
Other restrictions	3.3

As table 11 shows, almost every non-working carer is retired. Only just over 5 percent are seeking work or intend to return to work after a long term sick leave (Table 11).

Table 11: Status of non-working family carers

Status	Percentage
Retired	92.9
Unemployed and seeking work	3.7
On long term sick leave, but intend to return	1.8
Housewife/househusband	1.2
Other	0.5

5.3.3 Carers’ family situation

Close to 85 percent of the family carers are either married or cohabiting. The remaining 15 percent of the carers are single, divorced or widowed (Table 12).

Table 12: Marital status of family carers

Marital status	Percentage
Married/cohabiting	83.6
Single	8.0
Divorced/separated	5.1
Widowed	3.3

Approximately 87 percent of the family carers have children and close to one-fifth of these have one child and about 48 percent have two children. The remaining part of the family carers who have children have from three up to eight children. As much as 74 percent of the cared-for who has children also have grandchildren.

The number of people living in the carers household vary from living alone up to eight people, main carer included. Nearly 17 percent lives alone and the largest group, close to 72 percent, lives together with one person. The average number of people living in carers household, carer included, is two.

Approximately nine out of ten family carers are either married to the cared-for person or their child. Almost half of the carers are the cared-for persons' spouse or partner and just over 40 percent are the cared-for persons' son or daughter. Other less common relationships between the carer and the cared-for are for example daughter/son-in-law or sibling (Table 13).

Table 13: Relationship between family carers and cared-for person

FC's relationship to OP	Percentage
Spouse/partner	48.1
Child	40.5
Daughter/son-in-law	4.5
Sibling	1.8
Other relation	5.1

Nearly half of the family carers in the sample lives in the same household as the cared-for person. Only just over four percent of the family carers lives as much as a 30 minutes drive from their cared-for person, which means that close to 96 percent lives within a 30 minute drive or closer (Table 14).

Table 14: Distance between family carers and cared-for persons' place of living

Distance	Percentage
In the same household	45.6
In different household but in the same building	2.1
Within walking distance	21.5
Within 10 minutes drive or bus/train journey	14.4
Within 30 minutes drive or bus/train journey	12.3
Within 1 hour drive or bus/train journey	3.0
Over 1 hour drive or bus/train journey	1.1

The average time the current care situation been going on is about 64 months (median=48 and std. deviation=62.3). The duration of the caring time vary from one month to 44 years. Approximately 70 percent of the family carers have been the main carer for more than two years.

Family carers were asked to state the main reason or factor that influenced their decision to take care of someone. The most common reason for caring is the *emotional bond* between the carer and the cared-for person, more than 70 percent mention this as the most contributing factor. The second and third reason are; *a sense of duty and a personal sense of obligation* (Table 15).

Table 15: Principal reason for caring

Reason	Percentage
Emotional bonds	72.0
A sense of duty	8.3
A personal sense of obligation	6.9
Caring makes me feel good	4.9
OP would not wish for anyone else to care for them	1.8
I found caring by chance	1.6
There was no alternative	1.1
Religious beliefs	0.2
The cost of professional care would be too high	0.1
Other	3.1

COPE Index is a screening instrument that tries to detect the family carers' needs, in other words it tries to describe the caring situation. Table 16 shows 15 questions, that were asked to the carers, and the answer frequency of each question.

The answer of each question were ranked from *Always = 4* to *Never = 1*. Some of the COPE Index questions can then be summed to give an indication on how well the carer is coping with the caring relationship. COPE Index has three sub-sections; *Negative Impact*, *Positive Value* and *Quality of support*. A high score on the *Negative Impact scale* means that the carer has a hard time coping with the caring situation and a high score on the *Positive Value scale* means that the carer cope very well with the caring relationship (Figure 3 and 4)

Table 16: COPE Index – How the family carers perceive their caring situation

Question	Always	Often	Some-times	Never
Do you feel you cope well as carer?	46.0	45.4	7.8	0.8
Do you find caring too demanding?	2.7	9.9	57.9	29.5
Does caring cause difficulties in your relationship with friends?	5.5	11.2	26.5	56.9
Does caring have a negative effect on your physical health?	4.7	10.5	35.1	49.7
Does caring cause difficulties in your relationship with your family?	1.7	4.1	20.8	73.3
Does caring cause financial difficulties?	1.6	2.0	7.6	88.8
Do you feel trapped in your role as a carer?	27.1	17.1	33.5	22.4
Do you feel well supported by your friends and/or neighbours?	31.2	19.8	17.5	31.6
Do you find caring worthwhile?	56.4	31.3	11.0	1.3
Do you feel well supported by your family?	63.2	15.9	9.2	11.7
Do you have a good relationship with the person you care for?	78.2	15.7	5.1	1.0
Do you feel well supported by health and social services?	42.5	23.7	15.7	18.2
Do you feel that anyone appreciate you as a carer?	56.5	23.0	13.4	7.0
Does caring have a negative effect on your emotional wellbeing?	6.4	12.5	41.5	39.6
Overall, do you feel well supported in your role of caring?	42.9	31.1	19.1	6.9

Figure 3: Negative Impact scale

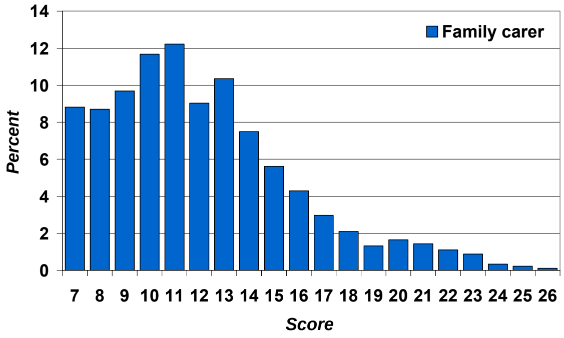
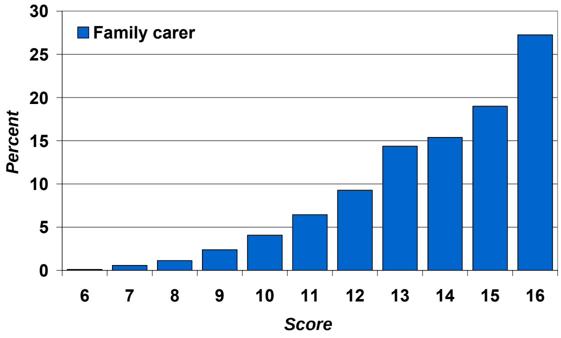


Figure 4: Positive Value scale

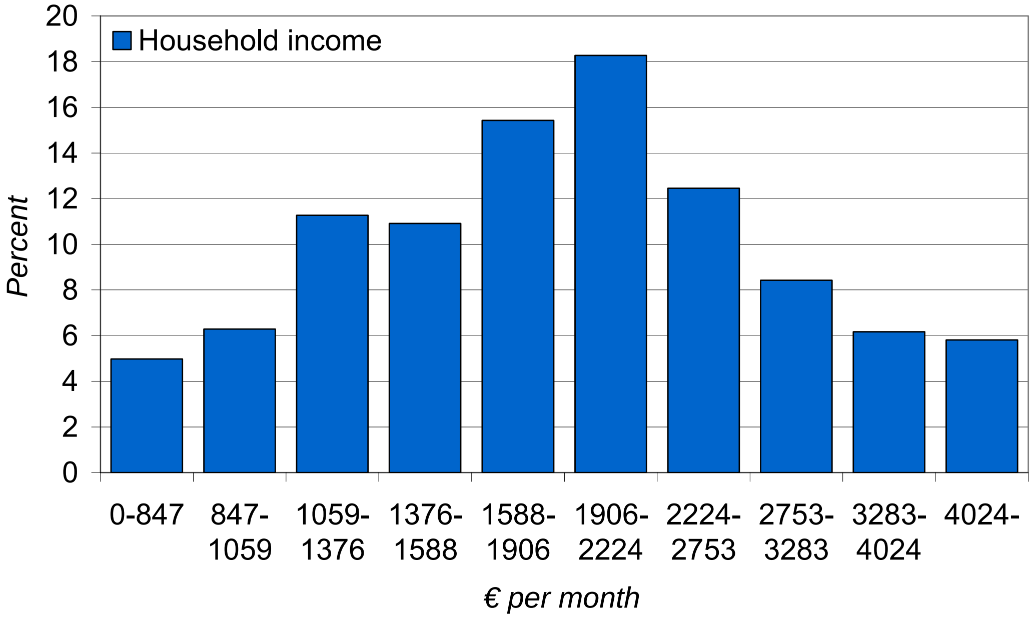


5.3.4 Carers' financial situation

A small part, just under two percent, of the family carers receive some kind of allowance due to their caring situation. This allowance vary from 105.9 to 1482.5€ per month and the average amount is 592.4€ per month.

The family carers were asked to estimate their total household income per month (Figure 5). The monthly household income is cause affected in the same way as for the cared-for persons, i.e. by the number of income-holders per household.

Figure 5: Family carers' household income per month divided by interval



As table 17 shows, the two most common areas where the cares experience financial change are; *travel costs and medicines.* Approximately 47 percent of the carers have not experienced any additional cost due to the caring situation.

Table 17: Additional cost due to the caring situation

Types of costs*	Percentage
Travel costs	34.6
Medicines	27.4
Special food	5.9
Adaptation of home environment/furniture	5.2
Other	9.0

*multiple answer possible

5.3.5 Family carers' health status and quality of life in relation to number of care-hours and age

Over 63 percent of the family carers estimate their health status to be *"good"* or better. The two most common answers are *"good"* and *"fair"*. As table 18 shows, the older the carer is, the worse they estimate their health, except for the group that estimated their health status to be *"poor"*. The average number of care-hours follows a similar pattern (Table 18).

Almost nine out of ten family carers estimate their quality of life to be *"neither good nor poor"* or better. The most common answer is *"good"*, which close to half of the carers gave. Both average age and average number of care-hours follows the same pattern as mentioned in health status (Table 18).

The average number of care-hours in the Swedish sample is 37.6 hours (median=12 and std. deviation=49.5).

Table 18: Heath status and quality of life of family carers

Health status	Percentage	Mean age	Average number of care-hours
Excellent	10.7	60.2	21.7
Very good	18.4	64.0	34.3
Good	34.3	66.2	37.4
Fair	31.3	67.4	44.1
Poor	5.3	64.9	45.2
Quality of life	**Percentage**	**Mean age**	**Average number of care-hours**
Very good	16.6	61.4	23.8
Good	48.3	65.3	30.5
Neither good nor poor	26.7	67.6	56.3
Poor	7.7	67.4	48.8
Very poor	0.8	64.3	18.6

5.3.6 Family carers' opinion on future care

Over 50 percent of the family carers are willing to continue to provide care even if they have to increase their effort. Almost everyone are prepared to continue to provide care, although some carers feel that they need more help and support to be able to continue (Table 19).

Table 19: Willingness to continue to take care

Answer	Percentage
Yes, and I would even consider increasing the care if necessary	51.6
Yes, and I would consider increasing the care for a limited time	10.0
Yes, I am prepared to continue to provide care, if the situation remains the same	29.2
Yes, I am prepared to continue to provide care, but only if I have some more support	8.1
No, I am not prepared to continue to provide care, no matter what extra support I receive	1.1

Most family carers do not want to place their cared-for in a care home. More than 83 percent of the carers are against this, assumed that the cared-for persons' conditions stays the same. About 16 percent of the carers are prepared to place the cared-for in a care home (Table 20).

Table 20: Consider to place the cared-for person in a care home

Answer	Percentage
No, not under any circumstances	13.2
Yes, but only if OP's condition gets worse	70.2
Yes, even if OP's condition remains the same as now	16.5

5.4 Final comments

The following is a summary of the sample characteristics. It consists mainly of two large subgroups - those who are caring for their spouse and those who cares for a parent.

Over 80 percent of the older cared-for people still lives at home. More then half of the cared-for people in the Swedish sample are married or living together. Another large group consists of widowed people. Nearly 40 percent of the older cared-for people lives alone and approximately half of the cared-for lives with their partner.

Everyone in the Swedish sample receive pension or some other financial support from the state. A few people also receive some kind of allowance due to the caring situation.

The main reasons why people need care and support are; physical illness/disability, age-related decline and memory problems or cognitive impairment. Approximately half of the Swedish sample state that they suffer from memory problems according to the carers' perception. Over 40 percent of these people haven't yet got their problems diagnosed. About one-fourth of the cared-for people show signs of behavioural problems. About 45 percent doesn't suffer from neither memory nor behavioural problems, almost one-third of the cared-for people, suffer only of memory problems.

More than 70 percent of the cared-for people in the Swedish sample are moderately or severely dependent. over 90 percent, of the cared-for people partially or completely rely on others to handle is domestic needs. Over 80 percent of the cared-for people rely partially or completely on others to handle are; organising and managing care/support, financial management and emotional/psychological/social needs.

The mean age of the main carer is 65.4 years in the Swedish sample. There is significant difference between males and females mean age. The mean age of the male carers are four years higher then the females. Approximately 55 percent of the carers are 65 years or older. More than 70 percent of the main carers are females.

About two-thirds of the carers have at least an intermediate level of education of which approximately 37 percent have a high level of education.

Approximately one-third of the carers in the sample are employed. Almost 90 percent them are working in the private or public sector. About 14 percent of the employed carers have been forced to reduce their working hours due to the caring situation. There is just a small part of the non-working carers who cannot work at all or had to give up their work.

Eighty-five percent of the family carers are either married or cohabiting and 87 percent of the family carers have children and close to one-fifth of these have one child and about 48 percent have two children. The average number of people living in carers household, carer included, is two.

Almost half of the carers are the cared-for persons’ spouse or partner and just over 40 percent are the cared-for persons’ son or daughter. Ninety-six percent lives within a 30 minute drive or closer

Approximately 70 percent of the family carers have been the main carer for more than two years. The average number of care-hours in the Swedish sample is 38 hours (median=12 and std. deviation=ca 50 hours) so there is a large variation in the sample.

A small part, just under two percent, of the family carers receive some kind of allowance due to their caring situation.

Over 63 percent of the family carers estimate their health status to be “good” or better and about the same consider that their quality of life is "good" or better. The less hour of caregiving and the younger family carer the better health and quality of life. However the pattern is broken by those who consider they have poor health and very poor quality of life. About ten percent that caring have often have negative impact on their lives and most of the family carers consider that caring have positive value.

6 Different care situations

Content

6.1 Aim of chapter 6

The aim of this chapter is to show different family care situations in Sweden. It is based on chapter 6 in EUROFAMCARE Trans-European Survey Report (TEUSURE) 2005[4], where a common cluster analysis on data from all the six country are presented.

6.2 Method

The use of clusters allow – independent of the marginal distribution – the comparison of the care situation in the six countries. It is to be noted that the distribution of the individual clusters in the countries does not necessarily represent the statistical distributions in these countries due to different recruiting strategies and representatives.

6.2.1 Procedure

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

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

As for the elder-related variables: elder’s <u>age</u> and <u>gender</u>, elder/carer <u>cohabitation</u> status and weather the elder had a need for <u>financial support</u>. Measures of elder’s functional disability were elder’s <u>cognitive status</u> and <u>IADL</u> abilities.

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

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[4] Mnich E, Balducci C, McKee K, Mestheneos L, Öberg B, Wojszel B, EUROFAMCARE consortium. 2005. Typology of caregiving situations In: EUROFAMCARE The Trans-European Survey Report (TEUSURE) 2005. http://www.uke.uni-hamburg.de/extern/eurofamcare/

Table 1: Variables for the cluster analysis

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

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

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

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

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

6.2.2 Description of clusters

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

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

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

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

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

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

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

The possibility that there was someone else who could take over the caregiving in case of sickness of the family carer are reported by caregivers in cluster 5 and 6. In all other clusters the majority (from 57% to 73%) does not have such possibility.

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

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

6.3 Findings

The distribution of clusters in the Swedish sample shows that cluster 3 (wives, high burden) is the most frequent care situation.

Table 3: Distribution of Swedish family carers in the clusters

Cluster	The six-country sample		The Swedish sample	
	n	%	n	%
1	964	17.9	65	8.2
2	937	17.4	121	15.3
3	838	15.6	243	30.7
4	436	8.1	127	16.0
5	943	17.5	113	14.3
6	1266	23.5	123	15.5
Total used cases	5384	100	792	100

6.3.1 Care situations and motivations for caring and view on future care

Five different dimensions of motivation for family caregiving have been identified on a European level using a factor analysis to explore the underlying dimensions of the originally 10 reasons that were inquired (Table 4).

Table 4: Factor analysis of motives for caregiving by the family carers

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

To give care due to strong emotional ties is the most frequent reason for family caregiving in the Swedish sample. Only in the care situation that characterise cluster 2 no alternative was a more dominant reason. In cluster 3 and 4 characterised by the husband and wife situation also financial advantages was a contributing reason for caregiving. A sense of duty or religious beliefs are no main reasons in Sweden (Table 5).

Table 5: Care situation and motives for caregiving

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

About two third are willing even increase caring in cluster 4 (husbands) and cluster 6 (low subjective and objective burden). Two third in cluster 1 and 2 (high subjective and objective burden) say they are not prepared to do so, one eight of them can do so for a limited time. Approximately three fifth in cluster 1 and 2 and three quarter in cluster 3-6 (the husband and wives and those who perceive low burden) are willing to let the older person live in a care home only if the situation get worse (Table 6).

Table 6: Family carers view on future care

Response alternative	Cluster					
	1 %	2 %	3 %	4 %	5 %	6 %
In the next year, are you willing to continue to provide care to ELDER?*						
Yes and I would even increase	35	37	49	69	58	63
Yes I would increase for a limited time	17	13	10	4	13	9
Would you be prepared to consider ELDER's placement in a care home?**						
Yes but only when the situation gets worse	63	57	72	70	69	79

* The complete response alternatives 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

6.4 Final comments

One of the aim in the EUROFAMCARE project is to show different care situations and the cluster analysis makes this possible. The distribution of clusters in the Swedish sample shows that cluster 3 (wives, high burden) is the most frequent care situation. It is to be noted that the distribution of the individual clusters in the countries does not necessarily represent the statistical distributions in these countries due to different recruiting strategies and representatives. The use of clusters allow – independent of the marginal distribution – the comparison of the care situation in the six countries.

The most frequent motive for family caring in Swedish sample is emotional ties as love and affection and caring makes the family carer to feel good. A large majority also consider that the state/society/public authority society should have main responsibility, and that family contribute, (this question was posed in the follow-up study). This might contribute to a situation in which people support their older people mostly by their free will.

Many of the family carers also consider it possible to let the older person live in a care home if they got worse, but only then, might reflect that they have strong emotional ties but also that they consider care home as a possible alternative.

7 Need of support and service use

Content

7.1 Aims of chapter 7

The aims of this chapter is to present an overview of what service family carers and cared for older people need, use and how this fit with their needs. It shows their experience in using services as well as the greatest help and the greatest barriers in accessing services. Their preferences of different type of services and quality characteristics is also presented as well as why necessary services are not used or why the carer or older person stopped using some services. There is some information about the costs of services.

7.2 Methodology used to collect, analyse and present the data

Each national-team developed a national list of services in addition to the common questionnaire, for detailed information, see chapter 3 and annex. In Sweden, the list included 53 services of which 48 were services that could be used by older people but also in some cases by family carer of which 21 services covered health care, 19 social care, 7 services describing different type of living and 5 services exclusively designed for family carers. Family carers were explicitly asked to list only those services which where relevant to them in their role as caregivers. Services used by family carers are described separately from those used by older people.

The interviewees were asked about the older person's needs, who provided the support and if they would like more support for her/ him. They were also asked what services the older person respectively the family carer used in the last 6 month preceding the interview. For each used service they were asked if it met the older person's respectively their own needs, if and how much they paid for the service and how often they used it.

Other questions concerned if the older person and/ or they received any allowances due to the caring situation, their experiences, greatest help/ difficulties, in accessing services, reasons for stop using/ not using needed services, reasons for not accessing services. Family carers were also asked about their preferences concerning different types of support and quality characteristics of services and if they received these.

7.3 Main findings

7.3.1 Older peoples' needs and support

A large majority of the older persons needs completely or partially support concerning the *domestic* domain, that is to a large extent provided by the family carer and almost one third also get support from formal services. About one fifth of the family carers would like more support for the older person with this domain (Table 1).

Financial management and *organisational management* are the most salient domains for which older people need completely support, these are also some of the needs that family carers support most, whereas older people get minor support of this kind from formal services. Not many family carers ask for more support for the older person with these domain.

Another central domain concerns *emotional, social and psychological* needs, about half of the older persons relay partially on others to meet this need and one quarter rely completely on others. This is the most provided support by the family carers and other informal carers, more than one quarter receive also support from formal services. Still almost half of the family carers consider that the older person needs more support for this domain and by that it is the largest domain for which family carers ask for more support.

Almost three quarter of the older people needs support with *mobility and transport*, most of these are supported by family carers and other informal carers, almost one third get support also from formal services. One quarter ask for more support for the older person with this domain, that is the second largest domain for which family carers ask for more support.

Three quarter of older people needs *health care* support, which is provided by the family carers to a large extent but also more than one third get support from formal services. Almost one fifth consider that the older person needs more health care support.

The most common formal service is *personal care*, however three quarter of those who have this need is supported by the family carer whereas two fifth by formal services. One fifth of family carers ask for more support with personal care for the older person.

Table 1: Older persons' need domains and received support

Need domain	OP partially rely on others to meet this need (%)	OP rely completely on others to meet this need (%)	Who provide support to the domain?				FC would like more support for OP with this domain (%)
			Nobody (%)	Carer (%)	Other informal carers (%)	Formal services (%)	
Health care	26.6	50.1	0.6	72.3	12.8	36.4	18.1
Personal care	43.0	25.6	1.4	75.5	15.0	40.0	20.9
Mobility and transport	51.0	22.3	3.0	91.2	19.1	28.4	25.2
Emotional, social, psychological	54.5	30.1	1.6	94.8	27.8	26.8	44.6
Domestic	39.0	53.9	0.8	86.6	17.3	28.9	21.3
Financial management	15.1	70.0	0.5	91.0	11.8	4.8	3.9
Financial support	6.6	6.3	5.3	91.2	8.8	0.9	17.6
Organizational management	22.1	65.3	1.4	92.3	10.6	12.4	12.0

7.3.2 Allowances

Hundred percent of all people 65+ years of age in Sweden receive a pension from the state. It differs between individuals due to their previous income, though everyone get a minimum pension. Just a few persons receive allowances and they are generally small (Table 2 and 3).

Table 2: Allowances for the older persons and the family carers

	OP		FC	
	%	n	%	n
Home care allowance	0	0	0.7	6
Family caregiver allowance	6.8	63	0	0
Family caregiver employment	0	0	1.1	10
Palliative family caregiver allowance	0	0	0	0

Table 3: Total amount benefits from allowances due to the caring situation (except pension)

	OP n=67 (valid)	FC n=6 (valid)
	€/month	€/month
Mean	165.3	592.4
Median	127.1	423.6
Std. Deviation	84.2	448.1
Minimum	84.7	105.9
Maximum	423.6	1482.5

7.3.3 Service use, service's ability to meet needs and payment

There is a large variety of services most for older people but there are also some specially designed for family carers and health care services are used by both groups.

7.3.3.1 Family carers'

One quarter of the family carers used at least one service during the last six month due to their caring role, and they do not use a large amount of services. The most commonly used services that are used by between sixty and ten family carers are:

- *generic services*: general practitioner; specialised physician; physiotherapist; district nurse

- *special services for family carers*: consultant, care attendant/sitter, relatives support group, free ‘keep-fit-activities’ (Table 4).

The family carers consider these services meets their needs to a large extent. They also pay for most generic services though half of them do not pay for district nurse support. Few paid for special services for family carers. Physiotherapist and care attendant/ sitter are the most frequently used services when it is used.

Table 4: Descriptive analysis of services used by FC (Percentages, frequencies, meets needs, payment).

Code	Description of services used by FC	Use		Frequency in valid %				Mostly meets needs	Do you pay for this service?
		% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	Valid % of users	Valid % of users answering yes
		%	n	%	%	%	%	%	%
	No service used	**77.7**	**716**						
	At least one service used	**22.3**	**205**						
	HEALTH CARE SERVICES								
1	General practitioner	5.9	54	-	-	7.0	93.0	90.7	98.1
10	Specialized physician	2.0	18	-	-	6.3	93.8	88.9	94.4
4	Physiotherapist	1.1	10	-	60.0	-	40.0	100.0	100.0
2	District nurse	1.3	12	-	11.1	11.1	77.8	100.0	50.0
6	Welfare officer	0.9	8	-	-	66.7	33.3	87.5	87.5
11	Chiropodist/ podiatrist	0.9	8	-	-	12.5	87.5	100.0	100.0
13	Visit at hospital consulting	0.5	5	-	-	-	100.0	80.0	100.0
14	Visit for visually impaired	0.4	4	-	-	25.0	75.0	100.0	100.0
5	Occupational therapist	0.2	2	-	-	-	100.0	100.0	100.0
7	Psychologist	0.2	2	-	100.0	-	-	100.0	100.0
12	Technical aides	0.2	2	-	-	-	100.0	100.0	100.0
21	Rehabilitation in a residential setting outside the home	0.2	2	-	50.0	50.0	-	100.0	100.0
3	Community nurse	0.1	1	-	-	-	-	100.0	0.0
17	General hospital	0.1	1	-	-	-	-	100.0	100.0
19	Care at home (LAH)	0.1	1	-	-	-	100.0	100.0	100.0
36	Transport services	1.0	9	-	50.0	50.0	-	100.0	88.9

Table 4: Descriptive analysis of services used by FC (Percentages, frequencies, meets needs, payment).

Code	Description of services used by FC	Use		Frequency in valid %				Mostly meets needs	Do you pay for this service?
		% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	Valid % of users	Valid % of users answering yes
		%	n	%	%	%	%	%	%
	SOCIAL SERVICES								
44	Social worker	0.4	4	-	-	-	100.0	75.0	25.0
35	Telealarm system	0.3	3	50.0	-	-	50.0	100.0	66.7
39	Cleaning services	0.3	3	-	-	100.0	-	100.0	100.0
47	Help lines provided by charities	0.2	2	-	-	100.0	-	100.0	0.0
30	Social service: personal care, food	0.1	1	-	-	-	-	100.0	100.0
42	Counselling agency	0.1	1	-	-	-	-	100.0	0.0
48	Diaconal work	0.1	1	-	-	-	100.0	-	-
	SERVICES ESPECIALLY FOR CAREGIVERS								
49	Consultant	6.5	60	-	5.7	5.7	88.6	100.0	5.2
50	Care attendant/sitter	6.1	56	2.3	47.7	15.9	34.1	98.1	5.7
52	Relatives support group	5.2	48	-	21.7	52.2	26.1	97.8	4.4
51	Free ‘keep-fit-activities’	2.5	23	-	21.1	21.1	57.9	95.5	0.0
53	Training courses in caring	0.5	5	-	-	100.0	-	100.0	0.0

7.3.3.2 Older peoples' service

Almost everyone of the older people had used at least one service the last six month. Concerning health care services had half of the older persons visited a general practitioner, about two fifth used technical aids, one third used district nurse and just as many chiropodist / podiatrist. One quarter visited a specialised physician. Community nurse, consulting for visually impaired, occupational therapist or physiotherapist gave support to one tenth each. Hospital care was also used by every tenth person (Table 5).

The most used social services were transport services used by almost two fifth and tele-alarm system used by more than one third.

Public social services 29-31 that concern different combinations of personal care, food, cleaning, laundry, shopping, are used by one quarter of the older people. Day care is used by every tenth person.

A large majority lived at their own home. About one tenth was living at a long term residential care setting, and every twentieth person used sheltered housing. Respite home was used by every seventh to eighth person.

The interviewees consider that the older person's needs are met by the used services to a very high degree, mostly over 90%.

The most frequently used health care services of the above were: district nurse; community nurse; occupational therapist and it was less common that the older person paid for these services. Physiotherapist was also one of the most frequently used health care services and more than half of the older people paid for this service. Technical aides were used daily by most of the older persons and it was few who paid for these.

The most frequently used social services of the above were: the public social services concerning personal care, food, cleaning, laundry, shopping. The tele-alarm system was used daily by three quarter and almost two third used transport services weekly or monthly. A large majority of the older persons who used day care visited it at least once a week. Most older people paid for the social services.

Table 5: Descriptive analysis of services used by OP (Percentages, frequencies, meets needs, payment).

Code	Description of services used by the OP	Use		Frequency in valid %				Mostly meets needs	Do you pay for this service?
		% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	Valid % of users	Valid % of users answering yes
		%	n	%	%	%	%	%	%
	No service used	**3.9**	**36**						
	At least one service used	**96.1**	**885**						
	HEALTH CARE SERVICES								
1	General practitioner	50.9	469	0.8	1.0	10.9	87.3	88.3	92.7
12	Technical aids	37.1	342	86.6	1.8	1.3	10.3	99.1	5.4
2	District nurse	33.2	306	10.7	19.8	26.1	43.5	98.6	29.7
11	Chiropodist / podiatrist	32.8	302	0.4	0.4	12.1	87.1	97.3	95.7
10	Specialised physician	24.6	226	0.5	3.1	8.3	88.0	91.8	90.1
17	General hospital	12.5	115	10.2	4.5	6.8	78.4	92.6	98.3
3	Community nurse	10.6	98	9.0	20.5	30.8	39.7	94.7	17.9
14	Consulting for visually impaired	9.9	91	-	-	10.3	89.7	86.7	80.0
5	Occupational therapist	9.6	88	5.0	11.7	11.7	71.7	96.5	22.4
4	Physiotherapist	9.0	83	1.5	64.7	16.2	17.6	81.5	68.7
13	Visit at hospital consulting	8.6	79	5.2	5.2	6.9	82.8	94.7	89.9
15	Consulting for hearing impaired	7.1	65	-	2.0	7.8	90.2	92.2	67.7
21	Rehabilitation in a residential setting outside the home	2.1	19	-	93.3	6.7	-	78.9	66.7
8	Geriatrician	2.0	18	-	6.3	-	93.8	94.4	100.0
19	Care at home (LAH)	1.7	16	16.7	41.7	8.3	33.3	93.8	31.3

Table 5: Descriptive analysis of services used by OP (Percentages, frequencies, meets needs, payment).

Code	Description of services used by the OP	Use		Frequency in valid %				Mostly meets needs	Do you pay for this service?
		% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	Valid % of users	Valid % of users answering yes
		%	n	%	%	%	%	%	%
6	Welfare officer	1.2	11	-	-	33.3	66.7	81.8	54.5
16	Day hospital	1.2	11	18.2	36.4	9.1	36.4	100.0	100.0
7	Psychologist	0.9	8	-	-	57.1	42.9	83.3	42.9
9	Psychiatrist	0.9	8	-	-	28.6	71.4	42.9	75.0
20	Rehabilitation at home	0.5	5	-	100.0	-	-	100.0	25.0
18	Hospice (in patient)	0.1	1	-	-	-	100.0	100.0	100.0
	HOME AND LIVING SUPPORT								
25	Long term residential care	9.2	85	96.3	-	2.5	1.3	94.0	98.8
22	Respite care home / hospital: ‘Short stay care’	6.7	62	20.0	8.0	28.0	44.0	93.3	96.8
23	Respite care home / hospital: ‘Intermittent care’	6.1	56	2.0	14.0	72.0	12.0	91.1	96.4
26	Sheltered housing	4.9	45	100.0	-	-	-	95.5	97.7
28	Adaptation of physical environment	3.8	35	11.8	-	-	88.2	100.0	5.9
27	Residential living	0.7	6	100.0	-	-	-	100.0	100.0
24	Respite care home / hospital: ‘Safety bed’	0.3	3	-	-	33.3	66.7	100.0	66.7
	SOCIAL SERVICES								
36	Transport services	38.0	350	4.9	33.5	27.4	34.2	95.1	98.8
35	Telealarm system	31.3	288	72.4	3.1	5.6	18.9	94.5	73.2
30	Public social service: personal care, food	10.7	99	83.9	14.0	2.2	-	97.8	94.8

Table 5: Descriptive analysis of services used by OP (Percentages, frequencies, meets needs, payment).

Code	Description of services used by the OP	Use		Frequency in valid %				Mostly meets needs	Do you pay for this service?
		% on total sample	absolute value	Daily	At least once a week	At least once a month	Less frequently	Valid % of users	Valid % of users answering yes
		%	n	%	%	%	%	%	%
43	Day care	10.1	93	6.7	88.8	4.5	-	95.4	77.4
31	Public social service: personal care, food, cleaning, laundry, shopping	9.7	89	83.5	7.1	7.1	2.4	90.8	92.1
29	Public social service: cleaning, laundry, shopping	5.8	53	53.2	12.8	31.9	2.1	86.0	92.3
33	Meals on wheels	5.6	52	76.6	19.1	2.1	2.1	94.1	98.1
39	Cleaning services	5.5	51	2.1	25.0	68.8	4.2	84.8	82.4
37	Personal care	5.3	49	66.7	17.8	8.9	6.7	95.6	83.7
44	Social worker	3.3	30	-	5.0	10.0	85.0	96.4	0.0
32	Night care	2.0	18	100.0	-	-	-	100.0	73.3
41	Social visits	1.4	13	10.0	40.0	20.0	30.0	91.7	25.0
47	Help lines provided by charities	1.0	9					100.0	22.2
45	Home help / privately paid home help	0.9	8	-	37.5	50.0	12.5	100.0	100.0
48	Diaconal work	0.9	8	-	50.0	-	50.0	100.0	0.0
40	Laundry services	0.8	7	-	16.7	83.3	-	100.0	71.4
34	Telemedicine (for monitoring purposes)	0.2	2	100.0	-	-	-	100.0	50.0
38	Shopping services	0.2	2	-	100.0	-	-	100.0	50.0
42	Counselling agency	0.2	2	-	-	-	100.0	100.0	0.0
46	Cohabitant home helper	0.1	1	100.0	-	-	-	100.0	0.0

7.3.4 Experiences in accessing services

The social services and health care staff are the greatest help in accessing services, though the family carer and her/ his personal network contribute as well (Table 6).

Table 6: Frequency of the greatest help in accessing services/support
multiple answers possible, (percent, n=absolute value) N = 769 (valid)

	Total frequency	
	%	n
Social services	48.2	371
Health care professionals	32.8	302
Family carer's experience and knowledge	8.8	68
No one, nothing	8.5	65
Family, friends and neighbours	7.7	59
Other reasons (combined)	12.4	95

Almost half of the family carers have not experienced difficulties in accessing services. Those who have mention a large variety of reasons as lack of information, administrative problems, few services and poor quality. Almost two fifth mention other reasons (Table 7).

Table 7: Frequency of the greatest difficulties in accessing services/support
multiple answers possible, (percent, n=absolute value) N = 507 (valid)

	Total frequency	
	%	n
No one, nothing	43.8	222
Lack of information concerning existence/access to service	7.5	38
Bureaucratic/complicated procedures	7.5	38
Few available services (with no other specification)	7.5	38
Poor quality of services	5.7	29
Other reasons (combined)	38.3	194

7.3.4.1 Reasons for stop using needed services

Every eighth interviewee said that they had stopped using a service they still needed. The main reason was low quality and that concerned for all some social services. Other common reasons were not available or entitled to use it, that concerned physiotherapist. Some also consider some social services to be too expensive. Though there were a relatively large proportion that had other reasons as well (Table 8 and 9).

Table 8: Frequency of services that OP or FC still need but stopped using

	%	n
Yes	13.7	126
No	86.3	795
Total	100.0	921

Table 9: Service that OP or FC stopped using and reasons for that,
multiple answers possible, (percent, n=absolute value) N = 117 (valid)

Code	Service	Stopped using		Expen-sive	Distant	Low quality	No longer available	No longer entitled	Other reason
		%	n	n	n	n	n	n	n
4	Physiotherapist	12.8	15	-	1	-	4	4	7
36	Transport services	11.1	13	-	-	6	-	1	6
29	Social service: cleaning, laundry, shopping	10.3	12	3	-	5	1	1	2
43	Day care	10.3	12	1	1	1	2	1	7
33	Meals on wheels	8.5	10	3	-	6	-	-	4
	Other services (combined)	56.4	66	7	1	19	8	6	29

7.3.4.2 Reasons for not using some needed services

Almost a quarter of the interviewees said that they had not started to use a service although it was needed by themselves or the older person. Most of them were different types of social services as transport services, services that concerned personal care, food, cleaning, laundry, shopping, tele-alarm system. Some did not use day care, sheltered housing as well due to lack of information or they were not entitled to use it. The reasons for not using physiotherapist or chiropodist were also that they were not entitled to or they found it too expensive. The main reason for not using services was that they didn't know about it before. Another reason was low quality and that concerned above all some of the social services. One fifth that did not used tele-alarm thought it was too expensive. Though the majority had other reasons for not using services (Table 10 and 11).

Table 10: Frequency of services not yet used although OP or FC need them

	%	N
Yes	23.7	218
No	76.3	701
Total	100.0	919

Table 11: Services never used by OP or FC and reasons for that
multiple answers possible, (percent, n=absolute value) N = 210 (valid)

Code	Service	Never used		Expen-sive	Distant	Low quality	Don't know about it	Not entitled	Other reason
		%	n	n	n	n	n	n	n
36	Transport services	14.3	30	-	-	-	1	4	24
31	Social service: personal care, food, cleaning, laundry, shopping	12.9	27	-	-	4	-	1	22
35	Telealarm system for older people and their relatives	12.4	26	5	-	1	1	-	21
26	Sheltering housing	6.7	14	-	-	-	1	3	10
41	Social visits	6.7	14	-	-	-	3	-	9
43	Day care	6.7	14	-	1	-	4	1	7
4	Physiotherapist	5.7	12	2	-	-	-	2	8
11	Chiropodist / Podiatrist	5.7	12	1	-	-	1	4	6
39	Cleaning services	5.2	11	3	-	1	2	-	5
29	Social service: cleaning, laundry, shopping	4.8	10	2	-	1	1	-	7
	Other services (combined)	51.0	107	6	1	8	23	3	81

7.3.4.3 Reasons for not using formal services

Almost two third of those who did not use any services said that they didn't need it. Besides that the main reason for one quarter was that they found it difficult to use service due to social or attitudinal reasons. Financial reasons and lack of trust in service providers were minor reported reasons (Table 12).

Table 12: Reasons for not using services?
multiple answers possible (%, n=absolute value) N = 260 (valid)

	Total frequency	
	%	n
Not needed/necessary	61.9	161
Social/attitudinal reasons by elderly or carer	26.9	70
Financial reasons, high costs	6.9	18
Lack of trust to service workers or service providers	4.6	12
Other reasons (combined)	15.4	40

7.3.5 The importance and supply of different types of support

To get information about the older person's disease and information about available support were the highest ranked types of service as about four fifth to three quarter valued this as very important. About three quarter got information about the older person's disease but only half of the interviewees thought that they got information about available support (Table 13).

The question about support that made it possibility to combine care giving with paid employment was answered by 34% while it didn't concern all family carers. Though of those three quarter considered it to be very important support and two third reported that they received such support.

Opportunities to talk over problems was another very important type of support and this was also met for two third. More than half of the family carers considered it to be very important to have service that provided opportunities for them to have a holiday or take a break, less that half of all interviewees considered this to be met.

Support that gave them opportunities to undertake enjoyable activities for the older person as well as for themselves were also high valued. Three firth of the older person and half of the family carers had not this support. The same pattern appeared concerning opportunities to spend more time with the family and help to make the older person's environment more suitable for caring.

About one third considered that it was very important to have support that gave them help with planning future care, opportunities to attend a carer support group, help to deal with family disagreements (though the latter concerned just about one quarter of all interviewees). These types of support were received by one fifth of the family carers.

Some of the support that were least asked for were money to help provide things need to give good care and training to help family carers develop caring skills. These types of services were also least provided, however there were more family carers that considered this to be very important than those who received such support.

Table 13: The importance of different types of support to family carers and if these are provided by the support they receive

Type of support		Very important	Quite important	Not important		Received
	N	%	%	%	N	%
Information about older person's disease	916	85.0	12.8	2.2	903	70.8
Information about available support	915	72.8	21.2	6.0	908	50.0
Possibility to combine care giving with paid employment	313	72.5	11.2	16.3	300	67.0
Opportunities to talk over problems as a carer	916	66.3	20.3	13.4	891	68.0
Opportunities to have a holiday or take a break	908	56.8	20.8	22.4	884	46.6
Opportunities for the older person’s to undertake activities they enjoy	913	54.8	22.5	22.8	891	39.6
Opportunities to enjoy activities outside of caring	906	53.1	24.6	22.3	885	50.6
Opportunities to spend more time with the family	576	52.3	28.8	18.9	554	50.0
Help to make the older person's environment more suitable for caring	898	45.2	17.5	37.3	829	41.3
Help with planning future care	905	35.2	26.6	38.1	865	21.8
Opportunities to attend a carer support group	911	34.7	20.4	44.9	870	19.9
Help to deal with family disagreements	206	33.0	27.7	39.3	187	23.5
Training to help family carers develop caring skills	905	24.3	22.3	53.4	877	14.8
More money to help provide things need to give good care	902	17.5	19.3	63.2	828	8.5

7.3.6 The importance and supply of different quality characteristic

Almost all family carers consider that care workers ought to treat the older person with dignity and respect and that help shall improve the quality of life of the older person, these are the highest valued quality characteristics.

Another very important characteristic is that help is available at the time they need it most, three quarter of the family carers perceived that they received this.

This is closely followed by the high valued characteristics that care workers have the skills and training they require; that help arrives at the time it is promised; and that care workers treat carers with dignity and respect. A large majority reported that they the service they use meet these characteristics. Thought one fifth of the family carers perceived that the care workers don't have the skills and training they require. Almost three quarter considered it very important that a service improve their quality of life provide, one fifth did not perceived that they had such support that provided that.

Almost two third perceived that the help is provided by the same care worker each time, that was less than those who considered this to be very important, which was about three quarter.

There were some less important characteristics even though somewhat more than half of the family carers put the highest value to that help provided is not too expensive; that help focuses on the carer’s needs as well as those of the older person. One quarter reported that they did not received this and one third thought that their service was too expensive.

Nearly half said that it is very important that the help provided fits in with carers own routines, a quarter considered that the service they used did not provide this.

Table 14: The importance of quality characteristics of a service to family carers and if these are provided by their support

Type of characteristic		Very important	Quite important	Not important		Received
	N	%	%	%	N	%
Care workers treat older person with dignity and respect	915	97.9	2.1	0.0	731	91.8
The help provided improves the quality of life of the older person	909	93.9	5.8	0.2	688	83.4
Help is available at the time they need it most	911	91.7	7.9	0.4	656	76.7
Carers views and opinions are listened to	910	91.2	8.6	0.2	720	88.3
Care workers have the skills and training they require	912	88.3	11.2	0.5	699	81.3
Help arrives at the time it is promised	902	86.3	13.0	0.8	630	84.8
Care workers treat carers with dignity and respect	910	84.2	14.6	1.2	725	93.0
Help is provided by the same care worker each time	909	73.8	22.3	3.9	696	61.6
The help provided improves the carers' quality of life	900	71.9	24.3	3.8	654	81.7
The help provided is not too expensive	896	59.9	28.3	11.7	610	63.8
Help focuses on the carer's needs as well as those of the older person	888	57.5	33.4	9.0	626	77.0
The help provided fits in with carers own routines	894	46.5	35.0	18.5	553	75.4

7.4 Final comments

In this study the family carers provide the most support. Personal care is the most shared need domain that formal services also provide. Older persons' needs of financial and organisational management are mainly handled by family carers. Emotional, social and psychological needs are the domain that family carers support most and that is also a domain that they want more support for the older person.

Allowances are received just by a few persons and either not a highly requested type of support. This is not a great issue in Sweden since all Swedish inhabitants 65+ receive a pension and a high percentage of the women are in the labour market.

Family carers use a small amount of services due to their caring situation. Six percent use health care services and the most frequently used service specially designed to family carers are consultant, care attendant and relatives support group though each are use just by 5-6%.

The most used health care services for older people are GP, technical aids, district nurse, chiropodist/ podiatrist. these are used by 30-50% during the last six month. The most used social services are transport services and tele-alarm system, used by 30-40%. Some type of public social service that includes 2-5 of following services: personal care, food, cleaning, laundry, shopping are used by approximately 25% of the older people. Day care is used by 10%.

Social services and health care professionals are the greatest help to access service. Though about 50% consider that more information about available support is needed. They also consider that information about older person's disease is the most important type of support, one third need more information about this.

The greatest difficulties that are specified in accessing services are besides lack of information, bureaucratic difficulties; few available services and poor quality. The dominate reason for those who did not use services were they did not needed any service, other reasons were social attitude by elder or carer; less frequent reasons were financial reasons and lack of trust in the service.

Family carers consider that used service mostly meet high values quality characteristics as that the older person shall be treated with dignity and respect by the care workers and that the help provided improves the quality of life of the older person. However one quarter perceive that the help is available at the time they need it most.

8 Service providers view on service for family caregivers and older people

Content

8.1 Aim of chapter 8

The aim of this chapter is to describe the service provider survey study.

8.2 Introduction

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

The legislation concerning service support for older people and family caregivers is an important framework for formal provided services (chapter 2). This has consequences for what kind of service they offer for family caregivers and older people. The most provided services for older people and their families is medical health care and social care services.

Private business are often contracted by the public social or health sector and therefore they have to follow the same legislation as well as the professionals are governed by the same legislation no matter if they are employed in the private or public sector. Voluntary and religious organisations have no such legislation or official responsibility.

8.3 Purpose of the service providers survey study

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

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

8.4 Method and sample

8.4.1 Data collection

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

The SPQ contained five sections:

A. Basic background information about the respondents and their organisation

B. Semi-structured questions about services for family carers

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

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

E. An overview of provided services, access, usage, cost, satisfaction, need of improvement and gaps between needs and access/provision.

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

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

The identified potential respondents were contacted by telephone, the project explained and their agreement to take part in an interview established in principal. This was then followed by mailing or posting a written explanation of the project and a copy of the interview schedule.

Once the respondent had the opportunity to consider this material a telephone interview was carried out at a date and time of their choosing.

Interviews were carefully noted during the interview and transcribed directly afterwards.

8.4.2 Method of Analysis

Content analysis was used on the semi-structured questions and with the open answers in section B and C. The analysis was guided by a common guide with following main categories:

- Goals and benefit
- Coverage
- Usage and access
- Costs
- Quality
- Attitude towards family carers
- Future development

In the analysis guide each of the main categories was followed by questions to be used as support for synthesizing the interview content.

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

8.4.3 Sampling strategy

The geographical sampling for the service provider interviews followed that of the original sampling areas for the interviews with family caregivers, Southeast (SE), Southwest (SW), and North (N) of Sweden. The respondents for the service provider interviews were collected in four municipalities: Linköping (SE), Norrköping (SE), Varberg (SW), Nordanstig (N), representing urban and rural areas.

A theoretical sampling procedure was applied to include all relevant types of services offered to family carers and older people. The sampling framework allowed for interviews to be conducted with management representatives of different types of service providers in each area: public social and health service organisations, religious organisations, voluntary organisation and private/commercial organisations. The aim was to interview at least 5 service providers per area.

8.4.4 The sample

Totally 25 service providers were interviewed. The service providers in Linköping, Norrköping and Varberg were mainly working in urban areas even if it also exists rural areas in these municipalities, Nordanstig however is only a rural area (Table 1).

The majority were head or manager for a service organisation, and most respondents were working in public social care organisations, one third was working with in public health care, just a few were service providers from the other sectors.

Two fifth were working in large (over 50) organisations and about the same in medium sized organisations (11-50 employees).

One fifth of the respondents' organisation did not provided special service intended directly to family carers. Also one fifth provided nearly 100% of their service only to family carers. Most of the organisations provided services for older people but many also considered that those services had an impact on the family carers' situation.

Table 1: Description of the sample

	South east		South west	North	Total
	Linköping **n=7**	**Norrköping** **n=6**	**Varberg** **n=7**	**Nordanstig** **n=5**	**n=25**
Type of area	mostly urban	mostly urban	mostly urban	rural	
Respondents' role					
Head	1	2	1	2	**6**
Manager	4	3	1	1	**9**
Practitioner	1	1	2	2	**6**
Other	1	0	3	0	**4**
Type of organisation					
Public social care	5	3	3	4	**15**
Public health care	2	2	2	1	**7**
Religious denomination	0	0	1	0	**1**
Voluntary organisation	0	0	1	0	**1**
Private business	0	1	0	0	**1**
Other	0	0	0	0	**0**
Number of employed people					
Small (10 or less people)	2	0	2	2	**6**
Medium (11-50)	4	1	3	1	**9**
Large (more than 50)	1	5	2	2	**10**
Portion of the services intended for family carers					
No service	3	2	2	0	**5**
Less than 50%	3	3	2	3	**11**
More than 50%	0	0	2	1	**3**
100% or nearly 100%	1	1	3	1	**5**
Portion of the services intended for older people					
Less than 50%	1	0	0	1	**2**
More than 50%	6	4	3	3	**16**
100% or nearly 100%	0	2	3	1	**6**

8.5 Main findings

8.5.1 Goals and benefits

The goals and benefits are to support and relieve relatives based on their physical, psychological and social needs so they can handle their situation, to empower the carer and maintain them in the caring situation, to maintain or increase their quality of life. And to make it possible for the cared for older person to remain at home as long as possible and maintain their quality of life.

8.5.2 Service and coverage

Most of the provided services concern counselling, individual or in groups, such as advice and support including crisis support. The providers give relatives and family caregivers information and education about disease and care and involve them in care planning. Some also give support concerning care and medication via telephone service. Service providers also manage “relative groups” for which they offer lectures and social activities. Some provide relieving support in terms of access to a care attendant for some hours a month.

Table 2 shows the frequency of provided types of service for family carers that respondents were asked about. The religious organisation did not consider that they provide any of the types of service that were asked about. The private business provided service for older people.

Table 2: Number of provided defined service provided for family carers

Type of service	**Public social care n=15**	**Public health care n=7**	**Religious denomination n=1**	**Voluntary organisation n=1**	**Private business n=1**	**Total n=25**
Training courses	3	4	0	0	0	7
Telephone service	5	4	0	0	0	9
Internet service	6	3	0	0	0	9
Carer support groups	12	3	0	1	0	16
Counselling services	10	4	0	0	0	14
Home service provision	8	1	0	1	0	10
Temporary home service	5	0	0	0	0	5
Assessment of carers needs	11	4	0	0	0	15
Monetary provision	2	1	0	0	0	3
Crisis management	7	4	0	0	0	11
Integrated planning provision	9	4	0	0	0	13
Service provision for ethnic groups	1	1	0	0	0	2
Total	79	33	0	2	0	114

Most service for older people concern residential and institutional care. Also medical service and rehabilitation are frequently provided. Domestic home service as minor repairs, window cleaning and gardening etc is not provided at all though some service providers mentioned that that type of service was requested by family carers and older people.

Table 3 shows the frequency of provided types of service for older people that the service providers were asked about. The religious organisation considered that they had other types of service.

Table 3: Number of defined services provided for older people

Type of service	Public social care n=15	Public health care n=7	Religious denomination n=1	Voluntary organisation n=1	Private business n=1	Total n=25
House keeping services	9	0	0	0	0	9
Cleaning provision	9	0	0	0	0	9
Meals on wheels provision	9	0	0	0	0	9
Transport services	4	1	0	0	0	5
Domestic care provision	0	0	0	0	0	0
Social home visits	6	1	0	0	0	7
Safety monitoring system	9	0	0	0	0	9
Medical service provision	5	6	0	0	0	11
Rehabilitation provision	8	6	0	0	0	14
Partly inpatient care	10	1	0	0	0	11
Residential care provision	10	4	0	0	1	15
Total	79	19	0	0	1	99

Concerning assessment of needs most service providers find out family carer's needs in dialogue where it is important to regard how individuals react upon stress and demands. Service providers generally don't use predefined assessments for this even if there are exceptions. For example by using questionnaires, interviews both individual and in groups to find out what support relatives want, and also reading publications about family carers needs for developing their service.

Regarding family carers' unfulfilled needs service providers thought that services ought to be more equally distributed; now it can be different in different geographical areas, municipalities and county councils. The providers perceive that family carers want something in exchange and being noticed in some way. Different types of services were also mentioned as further need of supportive dialogues and lectures for relatives.

There were more uncovered gaps in the services for family carers than for older people (Table 4).

Table 4: Service and coverage of defined services for family carers and older people

	Services for family carers		Service for older people	
	n	(%)	n	(%)
Number provided services*	114	(100)	99	(100)
Uncovered gaps in the services*	16	(14.0)	7	(7.1)

*Defined services provided by the respondents' organisation (Table 2 and 3)

The service providers view on how important different types of support are to family caregivers is showed in Table They have also reported if these supports are provided by their organisation. All service providers considered that the opportunity to talk over problems as well as information about available support are two the most important support and they also provided this. Equal important is to give opportunities for the family carer to enjoy activities outside caring, three fifth provided this. Least important do they find to support family carers with more money so they can provide good care. This is also provided by less providers.

Table 5: The importance of different types of support to family carers and if these are provided by the service providers (N=25)

Type of support	Very impor-tant	Quite impor-tant	Not impor-tant	Provided	
				yes	no
Opportunities to talk over problems as a FC	25	0	0	24	1
Information about available support	24	1	0	24	1
Opportunities for FC to enjoy activities outside of caring	24	1	0	15	9
Help to make the OP's environment suitable for caring	23	2	0	17	8
Opportunities for the OP’s to undertake enjoyable activities	23	1	0	15	10
Opportunities to have a holiday or take a break	23	1	0	13	12
Information about OP's disease	20	5	0	15	10
Opportunities to attend a carer support group	19	6	0	21	4
Help with planning future care	15	8	2	19	5
Possibility to combine care giving with paid employment	15	6	0	8	12
Help to deal with family disagreements	13	8	1	17	5
Training to help develop caring skills	12	12	1	17	8
Opportunities to spend more time with the family	10	10	0	5	12
More money to help provide good care	7	9	9	6	18

OP= older person, FC= family carer

8.5.3 Usage, access and costs

According to the service providers it probably exists an unknown number of family caregivers that needs support. There is still a need for to make service and support better known. Service providers don’t consider that there are any waiting lists to their services in general though sometimes there can be pressure on services.

Information about support for relatives and family caregivers is a crucial step to reach people. Service providers try to distribute information via folders, telephone service, Internet website etc. Personal contacts e.g. via health care or social care staffs is the best way to guide and help relatives, also friends and neighbours, to identify themselves as family caregivers and encourage them to ask for support.

There are many family caregivers that contact the service providers on their own initiative or after being encourage by care staff or other people. Though there are also many that hesitate. Service providers comment that they educate their staff how to meet and treat older people and their relatives to make the staff aware of the importance of their own attitudes and behaviour. They reflect that this is an important issue for access and usage. There is also cultural aspects on access e.g. persons who don't speak the national language need support in their own language. It depends on where the person lives if this is met or not.

The costs of services are no problem for the access or usage according to service providers. Some support to family caregivers are free but health care service and service to older people costs. Though the costs for the individual are restricted to a certain level and above that level they are subsidized (Table 6).

The service providers reported that half of their services are not fully utilised and there are also some problems with access (Table 6). They considered on the same time that there are uncovered gaps in their services (Table 4).

Table 6: Usage, access, costs aspects of services

	Services for family carers		Service for older people	
	n	%	n	%
Number of provided services*	114	100	99	100
The service is fully utilised	59	51.8	58	58.6
Problems with accessing service	23	20.2	10	10.1
Problems with costs	0	0.0	0	0.0

*Defined services provided by the respondents' organisation (Table 3 and 4)

8.5.4 Quality

Structured follow-up of service quality is variously used. It can be done on an aggregated level at the municipality or county council but not generally for a single service or unit. Single services that are evaluated depend on individual service providers´ initiative and interest by using questionnaires and group meetings for evaluation. However there are rare examples where such follow-up make any difference for the provided services. Others consider that family caregivers often give positive feedback spontaneously and directly to the service provider. The support to the older person is often evaluated continuously in dialogue with relatives.

Service providers have the impression that family caregivers are satisfied with the support family carers receive even if it is a small amount of service. There are family caregivers who perceive that a support group are important for their surviving and happiness e.g. after taking part of support group activities or individual or family counselling. They got help to handle and sometimes to change their situation.

However not everyone is satisfied, e.g. relatives that want more practical pedagogical support. There are relatives who want longer follow-up period for the older person after being ill. And they wish the care staff to give more time to the older person. Other types of services that are requested concerns household and gardening e.g. window cleaning, changing curtains and grass cutting.

Improvements that service providers consider are needed are more flexible support that meet individual needs e.g. home visits for immediate psychosocial support in a stressing situation. And to make support more equally distributed between geographical areas. Furthermore to develop care processes that are agreed e.g. between different service providers in the municipality, at hospital and primary care in the county council. And to make the documentation more accessible to service providers involved. It is now parted by secretes legislation between service providers in the county council and the municipality.

The service providers reported that family carers are more satisfied with the services that support themselves than those that support the older person. Though the service providers considered that service for family carers is more needed to be improved (Table 7).

Table 7: Quality aspects of services provided for family carers and older people

	Services for family carers		Service for older people	
	n	%	n	%
Number of provided services*	114	100	99	100
Problems with carer satisfaction	0	0.0	14	14.1
Service in need for improvement	66	57.9	17	17.2

*Defined services provided by the respondents' organisation (Table 3 and 4)

All service providers view that care worker shall treat the older person and family carers with dignity and respect as the most important quality characteristics as well as that help is available at the time needed. They considered that their services met these characteristics. There are just three characteristics that they reported as less provided: the provided help fits in with family carer's routines; that help is provided by the same care worker each time; and that the provided help is not too expensive. These characteristics were not so high valued either (Table 8).

Table 8: Service providers view on the importance for family carers of different service quality characteristics and if these are provided by the service providers (n=25)

Type of characteristics	Very important	Quite important	Not important	Provided	
				yes	no
Care workers treat OP with dignity and respect	25	0	0	24	0
Care workers treat FC with dignity and respect	25	0	0	24	0
Help is available at the time they need it most	25	0	0	21	1
FC's views and opinions are listened to	24	1	0	25	0
The help provided improves the OP's quality of life	23	2	0	22	1
Care workers have the skills and training they require	23	0	0	24	0
Help arrives at the time it is promised	20	4	0	21	1
The help provided improves the FC's quality of life	19	6	0	22	0
Help focuses on the FC's needs as well as those of the OP	15	10	0	23	0
The help provided fits in with FC's own routines	13	11	0	17	1
Help is provided by the same care worker each time	10	10	4	18	3
The help provided is not too expensive	9	12	2	21	0

OP= older person, FC= family carer

8.5.5 Attitude towards family carers

Service providers consider that relatives and family caregivers are very important and that it is important to listen and ask good questions to the family carers so their needs will be displayed.

However the main view is that relatives are partners by the meaning of being a resource and providers involve them in dialogue, as they are a part of the older person’s context. The older person is the main "costumer" and he/she decides whom to participate in the planning of their care and what service they want. It varies if relatives are present or not, to a certain amount this depends on the type of service and support. Relatives are considered to be a resource for exchanging information and advice especially if the older person has communication impairments and they are mostly the main carer at home. It is important to solve problems and work together with the family members. It also means that it can be several interests in a family that can be conflicting. It is important to recognise whose interest the service providers are shielding.

Some recognise that there is a greater awareness now on a political level about the importance to identify family caregivers´ needs and support them.

8.5.6 Future development

Service providers consider that the demographical development with increasing number of older people in relation to younger will probably lead to a decreasing economy. The challenge is to really provide sufficient support for family caregivers that they need, also to different ethnic groups and relatives to younger disabled people. The service needs to adapt to changes in the society.

There are no special main strategies presented for meeting future challenges. Providers try to give more individual support to relatives and to conduct an increasing number of support groups for relatives. Though several different need for development is mentioned as to make a project for developing the collaboration and common care processes between county council and municipality, and to achieve equal care between different geographical areas, and to improve the information strategy e.g. by IT technology, websites etc. Many people have access to computers and Internet.

8.6 Final comments

As this mainly is a qualitative study the aim was to get as broad information as possible from those who have experiences from service support for family caregivers and older people and their relatives. However there are very few representatives from voluntary and religious organisations, which also reflect that there are less activities from these compared with municipalities and county councils. The same apply to private organisations and most of them are working on contracts from the municipality and have almost the same conditions as the purchasing organisation. With these limitations the study can be regarded to be trustworthy.

Questions that focus on quantitative aspects can just be seen as a pilot study and not representative for Sweden as a whole since it is a small sample. These are however interesting as a background information to the qualitative data.

There is a challenge to achieve flexible and individual service that fits different family carers' and older peoples' needs. There are some important issues:

One of the most crucial points is to develop a view among service providers and decision makers that emphasise that relatives have rights and needs in their own. If such view was more established it would probably lead to other actions. For this the national legislations are important as well as education, the latter is pointed out by the service providers themselves. Health care providers (most of them employed by the county councils) and social care providers (in the municipalities) are ruled by different laws. Compared to the county councils the municipalities have more special services and activities for family carers exclusively.

Even though service providers try to distribute information in a variety of ways there is still difficulties in reaching family carers. It seems as if personal contacts e.g. via health care or social care staffs is the best way to help individuals to identify themselves as family caregivers as well as to inform them about available services and to encourage them to ask for support.

The interviews also show a need for a more systematic and reliable approach on all levels concerning assessment of family carers needs and also evaluation of the effect and quality of services. That would give more reliable facts for decision making and development of services for family carers and older people.

There is also a need for more equal distribution of services, Sweden is a large country and many old people is also living in rural areas.

9 The one-year follow-up study

Content

9.1 Aims of chapter 9

The main aim of this chapter is to present a preliminary report of the changes in the main family carers and the cared-for persons caring situation after approximately one year. The chapter intend to show both subjective and objective changes.

9.2 Method

Eight hundred-fifty two questionnaires were sent out to those who had accepted to participate in the one year-follow-up. Of those 575 answered who answered were 371 is still caring consequently 204 had stopped by various reasons i.e. 107 of the cared for older people had died.

The distribution on some chosen demographical characteristics in the Swedish follow-up sample are similar to those in the first survey. Therefore the Swedish follow-up sample can be seen as a representative sample of the first one. Further information is available in the Trans-European report, chapter 9.

All significance-tests in this chapter are made with either paired T-test or the non-parametric Mann-Whitney U test. A significance level of five percent ($\alpha=0.05$) is used.

The interval between the first (T1) and the second (T2) study were 419.9 ± 30.6 days. In the text of this chapter the time interval sometimes is mentioned as a year.

9.3 Main findings

9.3.1 Socio-demographical changes in the caring situation

9.3.1.1 Mortality- and institutionalisation-rates in the cared-for population

The mortality rate is close to 19 percent in the whole sample. A comparison between the male and female population shows that the males mortality rate is a few percentage points higher. This is further supported by the mean age of death in the sample, women seems to be a few years older when they die (Table 1). However, the difference is not significant.

Table 1 also shows where the cared-for person past away. Over 84 percent past away in a nursing home or in the hospital and the rest of the cared-for people died at home.

A comparison of the mortality rate between those who had more severe IADL dependency and those who had low or moderate dependency is made. About one-fifth of the cared-for persons who suffered from a higher level of IADL dependency past away during the year. The corresponding rate for those who just had a low or moderate dependency is nearly 15 percent (Table 1).

Table 1: Mortality rate of the cared-for persons

Mortality rate	Percentage	
In whole sample	**18.6**	
Male (N = 239)	20.9*	
Female (N = 336)	17.0*	
Mean age of those who died	**Male**	**Female**
82.7	81.2	83.9
Place where cared-for person died	**Percentage**	
At home	15.9	
In a nursing home	45.8	
In hospital	38.3	
IADL dependency	**Percentage**	
Low or moderate (N = 163)	14.7*	
More severe (N = 404)	20.3*	

*Percentages are calculated within each category in the follow-up sample, e.g. 50 of the 239 cared-for males (20.9 percent), whose main carer participated in the follow-up, died within the year

Institutionalisation in this context does not necessarily means that the cared-for person has been transferred to a nursing home, here it means that the main care-responsibility for the cared-for person has transferred from the family carer to the nursing home. In some cases the cared-for person already lived in a nursing home. This is expressed as *institutionalised* or *transferred to an institution* in further text.

Approximately twelve percent of the cared-for persons in the sample were institutionalised during the time between the to studies. A comparison between the male and female population in the sample shows that the females institutionalisation rate is almost three percentage points higher.

Table 2 also shows that the mean age of the institutionalised cared-for females is 1.6 years higher, but the difference is not significant.

When the cared-for persons' IADL dependency is taken under consideration, we can see that a larger part of those who had a more severe IADL dependency were institutionalised compared to those who had a low or moderate IADL dependency. The *negative impact* on the caring situation at the time of the first study follows the same pattern. More of those who felt a higher negative impact on the caring situation transferred their relatives to an institution (Table 2).

Table 2: Institutionalisation rate of the cared-for persons

Institutionalisation rate	Percentage	
In whole sample	**11.7**	
Male (N = 239)	10.0*	
Female (N = 336)	12.8*	
Mean age of those who were put in an institution	**Male**	**Female**
83.4	82.4	84.0
IADL dependency		
Low or moderate (N = 163)	4.3*	
More severe (N = 404)	14.6*	
Negative Impact of care (T1)	**Percentage**	
Lower impact (N = 223)	9.0*	
Higher impact (N = 345)	13.3*	

*Percentages are calculated within each category in the follow-up sample, e.g. 24 of the 239 cared-for males (10.0 percent), whose main carer participated in the follow-up, were put in an institution within the year

9.3.1.2 Reasons of giving up the care

More than one-third of the family carers that participated in the follow-up survey are for different reasons no longer the main carer. The cared-for person past away in approximately 53 percent of these cases. The most common reason, besides the cared-for persons death, is institutionalisation, i.e. the cared-for person is transferred to a nursing home (Table 3).

Table 3: Reasons why the main carer no longer provide care and support to the cared-for person

	Percentage
Stopped caring	35.5
Of those who stopped caring:	**Percentage**
Cared-for person died	52.5
Other reasons	47.5
Other reasons of those who stopped caring:*	**Percentage**
Transferred to nursing home	32.8
Professional carer provide care now	7.4
Other family member provide care now	3.4
Other person provide care now	1.5
Other reason	15.2

*multiple answer possible

9.3.1.3 Changes in the cared-for persons' living arrangements after one year

The living arrangements for those who still provide care and their cared-for person are in most cases unchanged. Only just under one percent, of those who lived in the same building, have now moved to a different building. Just over three percent, of those who lived in different buildings, have now moved to the same building (Table 4).

One out of ten cared-for persons who lived at home have at some point during the year moved to a different place. At the same time has one-eight of those who lived in other place moved in the opposite direction (Table 4). Other place consists mostly of care home or sheltered housing.

Table 4: Living arrangements, comparison between T1 and T2

Cohabitation		**T2**		
		Same building	Other place	Total n (%)
T1	Same building	99.5 %	0.5 %	179 (100)
	Other place	3.4 %	96.6 %	190 (100)
	Total n (%)	174 (47.2)	195 (52.8)	369 (100)
Place of living		**T2**		
		At home	Other place	Total n (%)
T1	At home	90.0 %	10.0 %	301 (100)
	Other place	12.5 %	87.5 %	56 (100)
	Total n (%)	278 (77.9)	79 (22.1)	357 (100)

Table 4 also shows that nearly 78 percent of the cared-for people lives in their own home and just over 47 percent lives in the same building as their main carer at the time of the follow-up.

9.3.1.4 Change in the intensity of the caring situation

Table 5 shows that the average number of hours of care per week has increased with nearly five hours when a comparison between T1 and T2 is made. However, the difference is not significant. Close to 45 percent of the carers have increased their number of hours of care per week.

If we separate the cared-for people according to their level of IADL dependency at the time of the first study, we see that there is a difference in the average number of hours of care per week. Main carers of those people who suffer from more severe IADL dependency had to increase their care-hours, while carers who take care of someone with low or moderate IADL dependency could decrease their care-hours (Table 5).

Table 5: Number of hours of care per week, comparison between T1 and T2

Difference	**Hours**	**[SD]**
Mean difference in hours of care per week	4.5	[45.9]
Distribution of carers	**Percentage**	
Less or the same hours of care per week	56.0	
More hours of care per week	44.0	
Difference in hours of care per week, divided by level of IADL dependency at T1	**Hours**	**[SD]**
Low or moderate IADL dependency at T1	-2.1	[35.5]
More severe IADL dependency at T1	8.7	[49.4]

9.3.1.5 Changes in the family carers' occupational status, restrictions and professional career

Approximately one-third of the main carers are employed at the time of the follow-up, which is just a minor decrease compared to the first study. About 7 percent of the carers had a change in their occupational status during the year.

Table 6 shows the row percentage within each category, e.g. 4.3 percent of the non-working carers in T1 started to work during the year.

Table 6: Occupational status of the family carers, comparison between T1 and T2

Employment		**T2**		
		Employed	Non-working	Total n (%)
T1	Employed	87.2 %	12.8 %	117 (100)
	Non-working	4.3 %	95.7 %	233 (100)
	Total n (%)	112 (32.0)	238 (68.0)	350 (100)

Table 7 shows the row percentage within each category. We can see that some carers had a change of opinion regarding the restrictions of work. Nevertheless, the proportion of carers that feels that the caring situation has prevented them from developing a career or work full time is quite similar at both points in time.

Approximately nine out of ten carers perceive their working restrictions in the same way as earlier.

Table 7: Restrictions of the family carers' working life or career, comparison between T1 and T2

Have the caring situation prevented you from developing a professional career or studies?				
Answer		**T2**		
		Yes	No	Total n (%)
T1	Yes	40.7 %	59.3 %	27 (100)
	No	6.9 %	93.1 %	289 (100)
	Total n (%)	31 (9.8)	285 (90.2)	316 (100)
Can/could you work only occasionally, due to the caring situation?				
Answer		**T2**		
		Yes	No	Total n (%)
T1	Yes	18.2 %	81.8 %	11 (100)
	No	5.1 %	94.9 %	256 (100)
	Total n (%)	15 (5.6)	252 (94.4)	267 (100)

Table 8 shows a tendency that the carers now have a harder time finding someone that could replace them in their caring role for a shorter period of time. Almost one-third of the carer lack the possibility to take a break from the caring situation, the corresponding share at the time of the first study were about 23 percent.

It is notable that 13 percent of those who easily could find a stand-in in the first study, now have no-one to turn to when it comes to taking a break (Table 8).

Table 8: Break from the caring situation, comparison between T1 and T2

Break from caring?		T2			
		Yes, I could find someone quite easily	Yes, I could find someone, but with some difficulty	No, there is no one	Total n (%)
T1	Yes, I could find someone quite easily	41.6 %	45.3 %	13.1 %	137 (100)
	Yes, I could find someone, but with some difficulty	18.9 %	45.7 %	35.4 %	127 (100)
	No, there is no one	6.2 %	37.0 %	56.8 %	81 (100)
	Total n (%)	86 (24.9)	150 (43.5)	109 (31.6)	345 (100)

9.3.2 Changes in the level of the cared-for persons' psycho-physical disability

9.3.2.1 Physical disability after a year

IADL dependency is measured with six questions, which each has three possible answers; *unable (0), with some help (1)* and *without help (2)*. All six questions are then summed to a total IADL dependency score, which reaches from zero to twelve. Lower average scores means worse level of dependency, i.e. the cared-for persons are less able to take care of themselves.

When a comparison of the IADL dependency between T1 and T2 is made, we can see that the mean difference is significant and the cared-for persons' level of IADL dependency has gotten worse at the time of the follow-up (Table 9). The cared-for persons are now more dependent of their family carers to take care of daily activities.

Table 9: Level of IADL dependency, comparison between T1 and T2

		Mean		N		Std. deviation		
IADL	T1	5.21		346		3.37		
	T2	3.97		346		3.39		
		Paired differences				t	df	Sig. (2-tailed)
		Mean	Std. deviation	95% CI of the diff.				
	T1-T2	1.23	2.44	0.98	1.49	9.41	345	0.000

Barthel Index is another instrument to measure the dependency level of the cared-for person. Total Barthel Index score reaches from zero to 100. Barthel Index works in the same way as IADL, lower average scores means worse level of dependency.

Table 10 show that mean difference between T1 and T2 is statistically significant. Barthel Index follows the same pattern as IADL, the cared-for persons' level of dependency, regarding Barthel Index, has gotten worse at the time of the follow-up.

Table 10: Total score of Barthel Index, comparison between T1 and T2

		Mean		N		Std. deviation		
Barthel Index	**T1**	73.96		332		23.92		
	T2	62.74		332		28.34		
		Paired differences				**T**	**df**	**Sig. (2-tailed)**
		Mean	**Std. deviation**	**95% CI of the diff.**				
	T1-T2	11.11	18.98	9.07	13.16	10.67	331	0.000

9.3.2.2 Mental disability after a year

Table 11 shows a comparison between T1 and T2 of the cared-for persons' estimated and diagnosed memory problems. Almost 15 percent of the cared-for people who did not show any signs of memory problems in the first study, now show these signs. A positive change between the two point in time is the fact that a larger part of cared-for people now have had their memory problems diagnosed (Table 11).

Table 11: Memory problems, comparison between T1 and T2

Estimated memory problems		**T2**		
		Yes	No	Total n (%)
T1	Yes	80.0 %	20.0 %	175 (100)
	No	14.7 %	85.3 %	190 (100)
	Total n (%)	168 (46.0)	197 (54.0)	365 (100)
Diagnosed memory problems		**T2**		
		Yes	No	Total n (%)
T1	Yes	90.6	9.4	85 (100)
	No	38.9	61.1	54 (100)
	Total n (%)	98 (70.5)	41(29.5)	139 (100)

The cared-for persons' behavioural problems are measured with three questions. The answers of each question reaches from *most of the time (3)* to *never (0)*. A mean value in calculated for both T1 and T2. Table 12 shows a comparison of these mean value. The mean difference is significantly smaller in T2, which means that carers have estimated the cared-for persons behavioural problems to be worse than before.

Table 12: Behavioural problems, comparison between T1 and T2

		Mean		N		Std. deviation		
Behavioural problems	**T1**	5.21		346		3.37		
	T2	3.97		346		3.39		
		Paired differences				**t**	**df**	**Sig. (2-tailed)**
		Mean	**Std. deviation**	**95% CI of the diff.**				
	T1-T2	1.23	2.44	0.98	1.49	9.41	345	0.000

9.3.3 Changes in the carers' subjective situation

9.3.3.1 Changes in the carers' quality of life

The question about *quality of life* gives main carers an opportunity to estimate their life quality in the last two weeks. The scale of the question reaches from *very good (1)* to *very poor (5)*. Higher scores therefore means worse *quality of life*.

The mean value of these statements are calculated for T1 and T2. A comparison between these different points in time are made. The result shows that the difference between T1 and T2 I significant, i.e. the carers feels that their *quality of life* is worse at the time of the follow-up than in the first study (Table 13).

Table 13: Quality of life, comparison between T1 and T2

<table>
<tr><th colspan="2"></th><th colspan="2">Mean</th><th colspan="2">N</th><th colspan="3">Std. deviation</th></tr>
<tr><th rowspan="5">QoL</th><th>T1</th><td colspan="2">2.24</td><td colspan="2">561</td><td colspan="3">0.86</td></tr>
<tr><th>T2</th><td colspan="2">2.54</td><td colspan="2">561</td><td colspan="3">0.92</td></tr>
<tr><th rowspan="2"></th><th colspan="4">Paired differences</th><th rowspan="2">t</th><th rowspan="2">df</th><th rowspan="2">Sig. (2-tailed)</th></tr>
<tr><th>Mean</th><th>Std. deviation</th><th colspan="2">95% CI of the diff.</th></tr>
<tr><th>T1-T2</th><td>-0.30</td><td>0.94</td><td>-0.38</td><td>-0.23</td><td>-7.65</td><td>560</td><td>0.000</td></tr>
</table>

Almost 40 percent of the carers now feels that their *quality of life* is worse compared to the first study. The rest of the carers feels that their *quality of life* is the same or better.

The main carers were also asked to estimate their general *health status*. They could answer on a scale that reaches from *excellent (1)* to *poor (5)*, therefore higher scores means worse self-estimated *health status*.

The mean difference between T1 and T2 appears to be significant even in this matter. The self-estimated *health status* is slightly worse at the time of the follow-up (Table 14). However, it is worth mentioning that the level of both *quality of life* and *health status* is fairly good.

Table 14: Health status, comparison between T1 and T2

<table>
<tr><th colspan="2"></th><th colspan="2">Mean</th><th colspan="2">N</th><th colspan="3">Std. deviation</th></tr>
<tr><th rowspan="5">Health</th><th>T1</th><td colspan="2">2.99</td><td colspan="2">568</td><td colspan="3">1.07</td></tr>
<tr><th>T2</th><td colspan="2">3.23</td><td colspan="2">568</td><td colspan="3">0.96</td></tr>
<tr><th rowspan="2"></th><th colspan="4">Paired differences</th><th rowspan="2">t</th><th rowspan="2">df</th><th rowspan="2">Sig. (2-tailed)</th></tr>
<tr><th>Mean</th><th>Std. deviation</th><th colspan="2">95% CI of the diff.</th></tr>
<tr><th>T1-T2</th><td>-0.25</td><td>0.89</td><td>-0.32</td><td>-0.17</td><td>-6.54</td><td>567</td><td>0.000</td></tr>
</table>

Approximately one-third of the carers state that their *health status* has gotten worse during the time between the two studies. The rest of the carers experience a similar or better health status.

9.3.3.2 Changes in positive value and negative impact of care

COPE Index is a screening instrument that tries to detect the family carers' needs, in other words it tries to describe the caring situation. Table 16 in chapter 5 shows 15 questions, that were asked to the carers, and the answer frequency of each question.

The answer of each question are ranked from *Always (4)* to *Never (1)*. Some of the COPE Index questions can then be summed to give an indication on how well the carer is coping with the caring relationship. COPE Index has three sub-sections; *Negative Impact*, *Positive Value* and *Quality of support*. A **high score** on the *Negative Impact scale* means that the carer has a hard time coping with the caring situation and a **high score** on the *Positive Value scale* means that the carer cope very well with the caring relationship.

Table 15 shows that the mean difference between T1 and T2 is significant for both the *positive value scale* and the *negative impact scale*. However, the differences between the two points in time are not very big for either of the two scales. But the result points in the same direction as earlier results, i.e. the main carers tend to estimate their caring situation slightly worse at the time of the follow-up.

Table 15: COPE - Positive value and Negative impact, comparison between T1 and T2

<table>
<tr><th colspan="8">POSITIVE VALUE SCALE</th></tr>
<tr><th></th><th colspan="2">Mean</th><th colspan="2">N</th><th colspan="3">Std. deviation</th></tr>
<tr><td>T1</td><td colspan="2">14.05</td><td colspan="2">318</td><td colspan="3">1.91</td></tr>
<tr><td>T2</td><td colspan="2">12.53</td><td colspan="2">318</td><td colspan="3">2.28</td></tr>
<tr><td rowspan="3">T1-T2</td><th colspan="4">Paired differences</th><th rowspan="2">t</th><th rowspan="2">df</th><th rowspan="2">Sig. (2-tailed)</th></tr>
<tr><th>Mean</th><th>Std. deviation</th><th colspan="2">95% CI of the diff.</th></tr>
<tr><td>1.52</td><td>1.99</td><td>1.30</td><td>1.74</td><td>13.57</td><td>317</td><td>0.000</td></tr>
<tr><th colspan="8">NEGATIVE IMPACT SCALE</th></tr>
<tr><th></th><th colspan="2">Mean</th><th colspan="2">N</th><th colspan="3">Std. deviation</th></tr>
<tr><td>T1</td><td colspan="2">12.03</td><td colspan="2">284</td><td colspan="3">3.83</td></tr>
<tr><td>T2</td><td colspan="2">13.12</td><td colspan="2">284</td><td colspan="3">4.04</td></tr>
<tr><td rowspan="3">T1-T2</td><th colspan="4">Paired differences</th><th rowspan="2">t</th><th rowspan="2">df</th><th rowspan="2">Sig. (2-tailed)</th></tr>
<tr><th>Mean</th><th>Std. deviation</th><th colspan="2">95% CI of the diff.</th></tr>
<tr><td>-1,09</td><td>3.21</td><td>-1.46</td><td>-0.71</td><td>-5.71</td><td>283</td><td>0.000</td></tr>
</table>

The *positive value scale* shows that more than two-thirds of the main carers now appears to have a harder time coping with the caring situation. The *negative impact scale* shows the same tendency, that a large part of the carers now feels that it is harder to cope with the caring situation.

Table 16: Positive value scale and Negative impact scale, differences between T1 and T2

COPE	Condition	Percentage
Positive value scale	Worse	67.9
	Better or no change	32.1
Negative impact scale	Worse	55.6
	Better or no change	44.4

The carers are also asked, in the last question of the COPE Index instrument, to estimate their overall feeling on support in their role as a carer. The difference between T1 and T2 is significant for this question. Almost 49 percent of the carers now feels that they have less support in their role as a carer then before. The rest of the group state that they have better or similar support.

9.3.3.3 Changes in willingness of continue the care in the future

The answer on the question about future care is ranked on a scale of five. Higher value means less willingness to continue to provide care.

The mean difference between T1 and T2 is -0.58, which is significant. This indicates that the carers now are less willing or at least need more support to continue to provide care. Table 17 shows how the main carers answers have changed over time.

Table 17: Opinions about future care, comparison between T1 and T2

Are you willing to continue to provide care?	Percentage	
	T1	T2
Yes, I would even consider to increase the care if necessary	53.7	27.9
Yes, I would consider to increase the care for a limited time	10.2	11.6
Yes, I am prepared to continue to provide care, but only if the situation remains the same	27.1	46.1
Yes, I am prepared to continue to provide care, but only if I have more support	8.6	11.9
No, I am not prepared to continue to provide care, no matter what extra support I receive	0.3	2.5

9.4 Final comments

The changes of the situation for family carers who still cares for an older person are small after one year. However the small changes who appear are significant in a deteriorated direction. In summary the situation is as follow:

Nine-teen percent of the older people have died and twelve percent has moved to institutional care. Both groups consist mostly of those with more severe dependency level.

More than one-third of the family carers that participated in the follow-up survey are for different reasons no longer the main carer. The cared-for person past away in approximately 53 percent of these cases.

The average number of hours of care per week has increased with nearly five hours. Nearly 45 percent of the carers have increased their number of hours of care per week. Family carers of those people who suffer from more severe IADL dependency had to increase their care-hours, while carers who take care of someone with low or moderate IADL dependency could decrease their care-hours.

Approximately one-third of the family carers are employed at the time of the follow-up, which is just a minor decrease compared to the first study. Ninety percent perceive their working restrictions in the same way as they did one year ago.

Almost one-third of the carer lack the possibility to take a break from the caring situation, the corresponding share at the time of the first study were about 23 percent. It is notable that 13 percent of those who easily could find a stand-in in the first study, now have no-one to turn to when it comes to taking a break.

The cared-for persons' level of IADL dependency has significantly got worse at the time of the follow-up. The family carers have also estimated the cared-for persons behavioural problems to be significantly worse. Furthermore almost 15 percent of the cared-for people who did not show any signs of memory problems in the first study, now show these signs. A positive change between the two point in time is the fact that a larger part of cared-for people now have had their memory problems diagnosed.

The result shows that the carers feels that their quality of life is significantly worse at the time of the follow-up than in the first study and the self-estimated health status is slightly worse. However, it is worth mentioning that the level of both quality of life and health status is fairly good. Approximately one-third of the carers report that their health status has gotten worse during the time between the two studies. The rest of the carers experience a similar or better health status.

The differences concerning their perception of positive values and negative impact of caring between the two points in time are not very large. However the result points in the same direction as earlier results, i.e. the family carers tend to estimate their caring situation slightly worse at the time of the follow-up. The positive value dimension shows that more than two-thirds of the main carers now appears to have a harder time coping with the caring situation. The negative impact dimension shows the same tendency, that a large part of the carers now feels that it is harder to cope with the caring situation. Almost 49 percent of the carers now feels that they have less support in their role as a carer then before. The rest of the group state that they have better or similar support.