

EUROFAMCARE

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

OVERVIEW SUMMARY of the EUROFAMCARE Trans-European-Survey Report

EUROFAMCARE Research Consortium

© The EUROFAMCARE consortium



This summary report is part of the European Union funded project.

“Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage” - EUROFAMCARE

EUROFAMCARE is an international research project funded within the 5th Framework Programme of the European Community, Key Action 6: The Ageing Population and Disabilities, 6.5: Health and Social Care Services to Older People, Contract N° QLK6-CT-2002-02647 "EUROFAMCARE"

<http://www.uke.uni-hamburg.de/eurofamcare/>

All rights by the authors and the EUROFAMCARE-consortium.

EUROFAMCARE is co-ordinated by the
University Medical Centre Hamburg-Eppendorf,
Institute for Medical Sociology,
Dr. Hanneli Döhner
Martinistr. 52
20246 Hamburg
Germany

doehner@uke.uni-hamburg.de

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

Written and edited by Elizabeth Mestheneos and Judy Triantafillou

Layout by Christopher Kofahl

OVERVIEW SUMMARY of the EUROFAMCARE Trans-European-Survey Report (TEUSURE)¹

This brief summary presents some of the main findings emerging from the survey of 6,000 European family carers of dependent older people carried out in 2004 in the 6 EUROFAMCARE countries involved (Germany, Greece, Italy, Poland, Sweden and the United Kingdom). Family carers were interviewed using a common questionnaire, and their answers are reported here in the form of research questions, survey responses to these questions and their implications for both policy and practice in the support of family carers.

WHY do family carers provide care?

- ★ Physical illness/disability of the OP is most often declared as the main reason for needing care. In 46% of all caring situations the family carers reported that the OP has memory problems. 34% of all cared-for suffer from some behavioural problems and these represent the older people whom carers find most burdensome. Only 10% of OP were independent in carrying out most activities of daily living.
- ★ “Emotional bonds” (i.e. love and affection) constitute the principle motivation for caring for FCs (57%), followed by a “Sense of duty” (15%) and a “Personal sense of obligation” (13%). Just 3% said they “Had no other alternative” than to care as the main reason.

¹ Country abbreviations: Germany - DE, Greece - EL, Italy - IT, Poland - PL, Sweden - SE, United Kingdom - UK

Other abbreviations: Older person/people - OP, Family care/carer - FC, Local authority - LA, Non-governmental organization - NGO, Information technology - IT

WHAT are the older persons' needs for care and help as reported by FCs?

SURVEY RESULTS	ISSUES ARISING
Domestic needs	
All countries: 92% (High IT 95%, Low EL 86%)	OP with a FC are least likely to get such services, either because limited home care services have to focus on isolated OP e.g. EL, or because home care services are having to provide more intensive care for fewer but more dependent older people e.g. UK. The wealthier can pay for such a service.
Emotional/psychological/social needs	
All countries: 89% (High IT 96%, Low SE 85%)	A very high need not classically considered as a responsibility of home care services, even though day care, Alzheimer cafes, and community centres may fulfil this function. These latter are important for carers as a way of providing respite care during the day. The potential role of volunteers in providing emotional and psychological support to the OP and thus respite to the FC needs to be further developed.
Mobility needs	
All countries: 82% (High IT 95%, Low EL 72%)	<p>Inside the house: the need for mobility aids, technical adaptations and eventually the wider introduction of IT based technologies, are services that need to be further developed by LAs, NGOs and the promotion of information about their availability. Half of SE respondents got such technical adaptations but few in other countries.</p> <p>Outside the house: environmental modifications, the adoption of new building standards in all built environments needs to be actively promoted by services, NGOs and LA planning departments.</p> <p>Transport services were almost absent in EL and PL, compared with SE where 38% had such access.</p>
Financial management	
All countries: 80% (High IT 92%, Low UK 67%)	A significant area of need and a major responsibility for FCs, which highlights the problems of protecting OP living alone and/or using services from financial mismanagement and theft. It needs practical organization and legal safeguards regarding the everyday management of the OPs resources. This need may also reflect memory and mobility problems and even low educational levels.

Organising and managing care and support	
All countries: 79% (High IT 94%, Low UK 71%)	Care managers for services can undertake the role of FCs for OP in this area, but there is limited evidence as to how cost-effective they are. The effectiveness of integrated care services and teams needs to be evaluated. An additional issue is that care services have to consider 24 hour and all year round coverage.
Health care needs	
All countries: 79% (High EL 88%, Low UK 66%)	This reflects the needs for support FCs have to supply in utilising health care services, including making appointments and accompanying their OP, ensuring correct medication, preventive and rehabilitative practices, diet etc. This need overlaps with the management of care and with personal care. Some new technologies may aid in this, but needs assessments rarely take into account this need of management.
Physical/personal care needs	
All countries: 66% (High IT 78%, Low PL 46%) (% differences reflect different levels of dependency as reported by FCs of OP in the 6 coun- try samples)	The most dependent OP require daily hands-on care to deal with their personal care needs on a 24-hour, year round basis. Services have to be very well organised to be able to provide the intensity of care required at home in such cases. This is one area where training for FCs and professionals is vital, although many FCs are not very sensitised for the need of training. It is a sensitive area from the perspective of the FC, the OP and the professionals, where conflicts and barriers between service providers are most likely to arise and integrated service provision hard to achieve.
Financial support	
All countries: 36% (High EL 53%, Low SE 13%)	While only a third of FCs report such OPs needs, country variations e.g. the higher figures for EL and IT, reflect low incomes of OP and have implications for the reported high costs of using services.

HOW are needs matched to care provision? WHO provides WHAT types of support?

SURVEY RESULTS	ISSUES ARISING
Recognition	
<ul style="list-style-type: none"> ★ Family carers and health and social services (probably older people too) find it difficult to recognize that family care is occurring unless there is a real incentive for FCs to register (e.g. money, services, rights), or incentives (e.g. training and resources) for services to reach out to FCs and OP. FC is both part of private life and yet may need public support. ★ FC is dynamic but the research shows it is a long term commitment: the average duration of family care in the moment of the interview was reported as 60 months (variation from 47 months in DE to 70 months in PL). ★ 27% of FCs had stopped caring after one year, two thirds because the OP had died i.e. 17% death rate for resurveyed FC's OP. 	<p>Early intervention targeting FCs e.g. recognition and information (local and national media programmes, newspapers etc), health protection, training in care techniques etc.</p> <p>Training of services and care workers to recognise FCs</p> <p>Political will and resources to provide more help to FCs</p> <p>Levels of dependency and length of time caring can act as signals to service providers</p> <p>Information needed on effectiveness of bereavement counselling services</p>
Who are the family carers and the cared for?	
<ul style="list-style-type: none"> ★ Women are predominantly both the main carers (76%) and the main older person cared for (68%). ★ 50% of FCs are children of the cared-for OP, though the SE sample had a high proportion of spouse carers. ★ In the UK the proportion of carers drawn from the extended family and neighbours (30%) was much higher than in other countries. ★ 37% of OP being cared for were married (56% in SE). ★ FCs average (mean) age was 55 years and 53% of OP being cared for were 80+ years old. 	<p>Older women needing care in some countries constitute some of the poorest people in their population.</p> <p>Current low birth rates have implications for the future supply of FCs.</p> <p>Unknown effects of increases in divorce or non marriage on willingness to care.</p> <p>Demographic ageing means that FCs will also be older.</p> <p>The ageing of the EU migrant population will require culturally specific services; already occurring in the UK and being debated in SE.</p>

- ★ 96% of older people were of national origins; only in UK were 20% of older people of non-ethnic British origins.
- ★ 69% of the OPs needing care lived with someone else, with a tendency for those living alone to be the less dependent. 56% of FCs live in the same household or in the same building as the cared-for person. 10% of the carers in the European sample lived further away and needed at least 10 minutes by car, bus or train to get to the cared-for person.
- ★ A year later, 1 in 10 FCs had moved to the OPs home or the OP moved to theirs (19% EL, marginal in SE and UK).

Mobility and the growth of single person households as income rises, leads to new issues of how to provide services and support FCs. Evidence needed on the effectiveness of and preferences for “sheltered accommodation” combined with family care arrangements in maintaining OPs autonomy.

Employment and working carers

- ★ Employed carers (41%) were less than non-working carers (59%). Carers are more likely to be employed in the public sector (42%); private sector (37%) and 17% self employed.
- ★ 15% of the employed carers had reduced their working hours as a result of caring for elder relatives, and most had experienced a decline in their income as a result.
- ★ Non-working carers were mainly retired (60%, 35% in EL, 91% in SE) and 26% said they were housewives/ househusbands (54% in EL, 1% in SE).
- ★ For 89% of FCs a year later there was no change in their employment situation.

Women in most countries are disproportionately employed in the public sector, which tends to be more accommodating about care responsibilities, as illustrated by child-care rights. Self-employment possibly also allows some flexibility.

Non-working carers are both retirees and housewives/-husbands. Increasing female participation in the formal labour force will reduce the numbers of younger carers who have never been in the labour market and thus create increasing pressures on the reconciliation of work with caring for both men and women.

Services

- ★ Less than one third of FCs had used a support service in the previous 6 months. Very few services are specifically intended for FCs in PL, IT, EL. Only SE, DE and UK have systematic and regularly used respite, socio-psychological and information services for FCs. In IT, EL and

One third of OP cared for are very dependent and their FCs need appropriate relief.

Expensive acute hospital admissions are sometimes used if there are no alternative forms

PL one result is substitution, with FCs using generic services instead e.g. information, advice and socio-psychological support from the GP, while the hospital is used as a substitute for missing rehabilitation and respite care.

- ★ The more frail and dependent the OP the more they use services, but also the greater the negative impact on carers (largest negative effect in EL and SE, lowest in PL).
- ★ 94% of cared for OP used at least one care service in the previous 6 months (mean 3.5 services), highest in SE, IT, DE, lowest in EL.
- ★ Users and non-users of care services saw as a main barrier to use the bureaucratic complex procedures to get access to them (13%, from 28% in IT and 19% in DE, to 4-7% only in PL, UK and SE) and their high financial costs (13%, from 29% in PL and 18% in EL, to 4-8% in the other countries), albeit less than 10% of FCs spend more than 20 € per month for specific support services, since these are often free, but inadequate provision means the alternative is the use of private care.
- ★ Lack of information on available support (except for SE), low quality (except for PL), inadequate coverage (especially in PL and EL) and the refusal of OP to accept existing services (especially in UK, SE and, to a lesser extent, DE) represent other major barriers, preventing wider service use.
- ★ In all countries services have problems in distribution, especially in rural areas (particularly in PL and EL), and covering hours when FCs may be working. Respite care and the actual provision of practical relief is important but less readily available.
- ★ Access to services takes place mainly through health professionals except for SE where it is social services. But in IT, EL and PL family, friends and neighbours remain the main sources of information. NGOs can be important (esp. in UK & DE).

of respite and rehabilitation support. "Unnecessary/ inappropriate" hospital (re-)admission may also reflect inadequate 24hr. supervision, management and evaluation of OPs needs.

There is a high need for simplifying access procedures to services in some countries. Payment for services is less of a problem when OPs pension/ income is adequate to cover this (SE), but sometimes it might be reasonable to consider the income of both the OP and the FC when reviewing the costs of services.

Inadequate OPs pensions can only be fairly compensated for by free-to-user services (UK), otherwise FCs bear the costs, either by giving their own care services or paying others.

Local Authorities can systematically assess and evaluate their services both for OP and FCs in terms of accessibility, availability and coverage.

Public information campaigns could target FCs and promote services at national and local level, and thus aim to cover the many currently unmet needs of both FCs and OP.

Lack of flexibility and inadequate coverage of services were reported by FCs as barriers to use of existing services. How can the optimum balance between formal and informal support networks and services be promoted and achieved?

Most important types of support	
<ul style="list-style-type: none"> ★ Information and advice about the disease/condition of the OP and on how to access services agreed as critical by FCs and service providers. Services to provide FCs with time to have a care break, undertake activities they enjoy, spend time with their families and combine work with caring were what they desired. 	<p>The important role of NGOs in providing information, advocacy and services, an issue not directly addressed in the survey, needs to be clarified.</p>
Commitment to care	
<ul style="list-style-type: none"> ★ 69% of FCs were willing to increase the level of care in the next year and almost 59% would never consider their cared-for OPs placement in a care home, irrespective of circumstances, especially in PL and EL, while in SE 70% of carers would consider the placement of the cared-for OP in a care home if the health of the OP worsened, and 17% even if it stayed the same, compared to the European averages of 37% (if worse) and 4% (the same). ★ One year later 5% of the sample resurveyed reported the OP as being in a nursing home (12% in SE, 0.1% in EL). Amongst FCs no longer providing care where the OP was still alive, in one third of the cases the OP had gone into residential care and were characterised by severe ADL and cognitive decline and urban residence. 	<p>The SE tradition of well funded and extensive welfare state services with high quality residential institutions create open attitudes to the cared-for persons' placement in such centres. OP move to these homes with spouses and almost every second Swedish carer is a spouse/partner of the cared-for person. The quality and cost of residential homes influences decisions to care and PL and EL attitudes are influenced by these factors.</p> <p>Confirms the critical role of serious dependency caused by decline in ADL and cognitive problems. Demographic projections and health studies suggest more cognitive decline and improvements in serious ADL.</p>
Quality of Life	
<ul style="list-style-type: none"> ★ The highest level of quality of life is found among the UK and the SE carers (67% and 65% respectively), and the lowest in the Mediterranean countries (EL 50% and IT 51%). ★ Determinants of negative impact of caring on FCs dependent on health of OP, intensity of caring tasks, the carers' support networks and the types of services used. 	<p>Provides some evidence for the positive role of good service support for FCs.</p> <p>Indicates the need for a wider variety of service support as well as flexible, comprehensive and integrated care services.</p>

Financial Support

★ Only 4% of all FCs received care allowances and 37% of the older people, though large cross national variations in coverage (60% in DE, 2% in EL) and in amounts paid, low in PL compared to IT, UK and DE).

Highlights cross-national inequalities in financial support for family caregivers and dependent older people and underlines the need for EU policy and guidelines on minimum standards in this area.

POLICY IMPLICATIONS OF TEUSURE

NATIONAL AND EU POLICY

- ★ Using the Open Method of Coordination, formulate EU guidelines and recommendations on the best and most viable forms of financially supporting dependent OP and FCs for implementation at national levels.
- ★ Achieve an increase in female participation in the labour market (the Lisbon Targets), by promoting service support for family care and redefining family care as work. Psychological research suggests that such an approach would reduce the intrinsic value of caring, i.e., remove much of the positive value currently found in caring and thereby perhaps increase the likelihood of the breakdown of family care.
- ★ Promote and adopt EU standards in training for employment in care services as a step in improving quality in services.
- ★ Create new jobs in the care sector by ensuring that services are planned to be flexible and more extensive, to cover the practical support of family carers, including working carers, on a 24/12 basis.
- ★ Optimise existing care resources for dependent older people by supporting family carers, specifically by providing financial and service support.
- ★ Target support for the most burdened family carers i.e. those caring for OP with memory and behaviour problems, by providing practical and flexible respite, day care and information services.
- ★ Invest in "family carers support centres" since they can make savings within the national health and social care systems.
- ★ Promote and adopt national standardised evaluation and monitoring procedures for all services and use these as a basis for future funding.

- ★ Acknowledge and develop measures to regularise the current use of and reliance on migrant care workers, legally and illegally employed in many European countries, and include them in the formal labour market.
- ★ Review the real costs in time and money of accessing and using health and social services to make them more accessible and useful to family carers.

SERVICE PROVIDERS

- ★ Improve service provision for older people and family carers in terms of coverage, quality and accessibility by granting appropriate funding or rationalising existing resources to this purpose.
- ★ Develop more imaginative and proactive approaches to informing FCs of existing services e.g. through use of local and national media to increase knowledge about services, improve their social acceptability. This will also act to promote the image of family carers in society.
- ★ Adopt quality standards in training for employment in care services as an integral part of all local services.
- ★ Adopt standardised evaluation and monitoring procedures for needs and services supporting family carers and older people.
- ★ Consider how best to integrate service provision, based on comprehensive needs assessment, to cover the diverse and changing needs of FCs for help and support (medical, social, psychological, financial). This will require the development of specially trained, interdisciplinary teams (public or NGO) to co-ordinate existing services and develop new networks of services at local levels. Appropriate incentives shall be introduced to improve current levels of integration of existing services and inter-disciplinary care work.
- ★ Provide migrant care workers with opportunities for training and registration, to avoid the possible exploitation of both care workers and cared for and to improve the quality of delivered care.

FAMILY CARERS ORGANIZATIONS

- ★ NGOs need to campaign for a recognition of the real costs in time and money of:
 - providing essential care and support to dependent older people
 - accessing and using services
- ★ NGOs need to advocate for more flexible and extensive services, including both home based and residential respite and emergency care.
- ★ Family carers need more information and NGOs can help provide this.

The Members of the EUROFAMCARE Group

- ★ Germany, Hamburg: University Medical Center Hamburg-Eppendorf, Department of Medical Sociology, Social Gerontology, University of Hamburg (Co-ordination centre) – Hanneli Döhner (Co-ordinator), Christopher Kofahl, Susanne Kohler, Daniel Lüdecke, Eva Mnich, Nadine Lange, Kay Seidl, Martha Meyer
- ★ Germany, Bremen: Centre for Social Policy Research – Heinz Rothgang, Roland Becker, Andreas Timm, Kathrin Knorr, Ortrud Olessmann
- ★ Greece: SEXTANT Research Group, Department of Health Services Management, National School for Public Health (NSPH), Athens – Elizabeth Mestheneos, Judy Triantafillou, Costis Prouskas, Katerina Mestheneos, Sofia Kontouka, Anastasis Loukissis, Vickey Goltsi
- ★ Italy: INRCA Dipartimento Ricerche Gerontologiche, Ancona – Giovanni Lamura, Cristian Balducci, Maria Gabriella Melchiorre, Sabrina Quattrini, Liana Spazzafumo, Francesca Polverini, Andrea Principi, Marie Victoria Gianelli
- ★ Poland: Department of Geriatrics, The Medical University of Bialystok; Institute of Social Economy, Warsaw School of Economics and Institute of Philosophy and Sociology, University of Gdansk – Barbara Bien, Beata Wojszel, Brunon Synak, Piotr Czekanowski, Piotr Bledowski, Wojciech Pedich, Mikolaj Rybaczuk, Bozena Sielawa, Bartosz Uljasz
- ★ Sweden: Department of Health and Society, Linköping University – Birgitta Öberg, Barbro Krevers, Sven Lennarth Johansson, Thomas Davidson
- ★ United Kingdom: The University of Sheffield, Sheffield Institute for Studies on Ageing (SiSA) and the School of Nursing & Midwifery – Mike Nolan, Kevin McKee K, Jayne Brown, Louise Barber
- ★ AGE - The European Older People's Platform, Brussels, Belgium – Anne-Sophie Parent, Catherine Daurèle, Jyostna Patel, Karine Pflüger, Edward Thorpe

The Members of the International Advisory Board

- ★ Robert Anderson, European Foundation for Improvement of Living and Working Conditions, Dublin
- ★ Janet Askham, King's College London, Institute of Gerontology, Age Concern, London
- ★ Stephane Jacobzone, OECD, Social Policy Division, Paris
- ★ Kai Leichsenring, European Centre for Social Welfare Policy and Research, Vienna
- ★ Jozef Pacolet, Catholic University of Leuven, Higher Institute of Labour Studies Social and Economic Policy, Leuven
- ★ Marja Pijl, The Netherlands Platform Older People and Europe (NPOE)
- ★ Joseph Troisi, University of Malta, Institute of Gerontology
- ★ Lis Wagner, WHO - European Office, Copenhagen