

EUROFAMCARE

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

SUMMARY OF MAIN FINDINGS FROM EUROFAMCARE

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

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

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THE EUROFAMCARE STUDY

Summary of main findings and policy implications

This summary and the policy implications that follow are based on the EUROFAMCARE research results from six National Surveys in Germany, Greece, Italy, Poland, Sweden and the UK, from a socio-economic evaluation and from 23 National Background Reports (NABAREs), summarised in a Pan-European Background Report (PEUBARE)¹. The national surveys are based on personal interviews with about 6,000 European family carers providing at least 4 hours of care a week to a dependent older person of at least 65 years. For all interviews a common questionnaire was used.

The Socio-economic Evaluation of Family Care (ECO) examines the direct and indirect costs involved in family care. Issues arising from the survey data are linked to selective findings from the National Background Reports and the Pan-European Background Report. Detailed information can be found on:

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

The policy implications of these findings are developed in the form of recommendations for the type of support family carers need to ensure their continuing contribution to the long term care of dependent older people in Europe.

WHY do family carers provide care?

- ★ Physical illness/disability of the OP is most often declared as the main reason for needing care. Over 46% of cared-for persons were reported to have memory problems, 34% had some behavioural problems, and 28% both. The two latter groups are the OP whom carers find it most difficult to support.
- ★ 31% of the OP are severely dependent regarding most activities of daily living and 34% are moderately dependent. National variations reflect different levels of dependency of OP as reported by FCs in the 6 countries samples.
- ★ "Emotional bonds" (i.e. love and affection) constitute the principle motivation for providing care reported by FCs (57%), followed by a "Sense of duty" (15%) and a "Personal sense of obligation" (13%). Just 3% say they "Had no other alternative" than to care.

¹ For the National Background Reports the countries involved were AT, BE, BU, CH, CZ, DE, DK, EL, ES, FI, FR, HU, IE, IT, LU, MT, NL, NO, PL, PT, SE, SI, UK

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

WHAT are the OP's needs for care and help as reported by FCs?

SURVEY RESULTS	ISSUES ARISING
Domestic needs: e.g. housework	
All countries: 92% ² (High IT 95%, Low EL 86%)	OP with a FC are least likely to get domestic care 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 OP e.g. UK. The wealthier can pay for such a service.
Emotional/psychological/social needs: e.g. companionship, reassurance	
All countries: 89% (High IT 96%, Low SE 85%)	A very important need not classically considered as a responsibility of home care services, even though day care, Alzheimer cafes, and community centres may fulfil this function. Such services are important for both working carers and non-working 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 and better integrated with formal care services.
Mobility needs: e.g. inside or outside the house, transport	
All countries: 82% (High IT 95%, Low EL 72%)	<p>Mobility aids, technical adaptations and the wider introduction of IT based technologies in home, are services that need to be further developed by LAs, NGOs. More information about their availability must be provided. Half of SE respondents got such technical adaptations but few in other countries.</p> <p>Outside the house: environmental modifications and the adoption of new building standards in all built environments need to be actively promoted by services, NGOs and LA planning departments.</p> <p>Special transport services were almost absent in EL and PL, compared with SE where 38% had such access.</p>

² Total percentages concern groups of OP, who are partially or completely reliant on others to meet the various needs.

Financial management: e.g. paying bills for the cared for from the OP's own money	
All countries: 80% (High IT 92%, Low UK 67%)	This is a significant area of need and a major responsibility for FCs, and highlights the problems of protecting vulnerable 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 OP's resources. This need may also reflect memory and mobility problems or low educational levels amongst the existing generation of OP needing care.
Organising and managing care and support: e.g. contacting services	
All countries: 79% (High IT 94%, Low UK 71%)	Meeting OP's complex needs calls for good coordination and management to effectively cover 24 hour and year round responsibilities. The cost effectiveness of integrated care services and teams needs to be evaluated, including care managers. Continuity of care by providers is a critical issue.
Health care needs: e.g. assistance with medication, medical treatment, rehabilitation, therapy etc.	
All countries: 79% (High EL 88%, Low UK 66%)	This reflects the need OP have for support from FCs when utilising health care services, e.g. making appointments, accompanying, collecting prescriptions and ensuring correct medication, preventive and rehabilitative practices, diet etc. This need overlaps with the management of care and with personal care, but formal assessment rarely takes such tasks into account; new technologies may aid in this area (a <i>Good Practices Report</i> for examples is planned to be published on the EUROFAMCARE-website).
Physical/personal care needs: e.g. washing, dressing, eating or going to the toilet	
All countries: 66% (High IT 78%, Low PL 46%)	The most dependent OP require daily hands-on care to address their personal care needs on a 24-hour, year round basis and services need excellent organisation to be able to provide the intensity of care required at home in such cases in cooperation with the family carer.
Financial support: e.g. supporting OP by providing them with money	
All countries: 36% (High EL 53%, Low SE 13%)	While only a third of FCs support OP in this way, 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, though this varies substantially between countries.

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

SURVEY RESULTS	ISSUES ARISING AND POLICY IMPLICATIONS	RECOMMENDATIONS DERIVED FROM PEUBARE, TEUSURE and ECO RESULTS
Who are the family carers and the cared for?		
<p>Women were predominantly both the main carers (76%) and the main older person cared for (68%).</p> <p>FCs average (mean) age was 55 years and 53% of OP being cared for were 80+ years of age.</p> <p>Nearly 50% of FCs were children of the cared-for OP, though the SE sample had a high proportion of spouse carers. In the UK the extended family and neighbours (30%) acting as family carers was much higher than other countries.</p> <p>Only 37% of OP being cared for were still married (56% in SE).</p> <p>FCs spent a mean 45,6 hours per week providing care for the dependent OP.</p> <p>Most FCs cared for only one OP (81% EL, 93% DE).</p>	<p>Older women needing care in some countries constitute some of the poorest people in their population.</p> <p>Demographic ageing means that FCs will also be older and caring for more people over 80 years.</p> <p>Current low birth rates have implications for the future supply of FCs and this will be critical by 2030.</p> <p>Unknown effects of increases in divorce or non marriage on willingness to care.</p> <p>There is a wide spread in each country due to the research protocol for sample selection specifying a lower limit for care provision of only 4 hours per week, but many FCs reporting 24 hour care for the very dependent.</p>	<p>Ensuring that FCs are adequately covered by social insurance (accidents, health, pensions etc.) during the time spent caring should be a minimum EU standard contributing to the reduction of long term poverty amongst those who undertake family care, especially women.</p> <p>The promotion of the EU Carers' "Charter" aims to protect FCs of dependent people of all ages. The current discussion at EU level for the adoption of compulsory social insurance for family carers providing assessed levels of care above, e.g. 18 hours per week, is a positive development.</p> <p>National and EU standardised comprehensive needs assessment procedures for OP should be developed and include a separate assessment of the current and future role and needs of the FC.</p>

Over 1/3 of all carers also cared for at least one younger person (60% EL, 9% SE).

96% of OP were of national origins; only in UK were 20% of OP of non-ethnic British origins.

2/3 of the OP needing care lived with someone else; those living alone tend to be the less dependent. Over half of FCs live in the same household or in the same building as the cared-for person. Every fourth carer 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 OP's home or the OP moved to theirs (19% EL, marginal in SE and UK).

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%).

The overwhelming majority of FCs (over 80%) felt caring was worthwhile and that they coped well even under difficult circumstances.

A third of all FCs can be classified as the 'sandwich' generation, caring for both older and younger family members.

The ageing of the EU migrant population will require culturally specific services; already occurring in the UK and being debated in SE.

Mobility and the growth of single person households as income rises, leads to new issues of how to provide services for OP and support FCs.

This may indicate the positive role of good service support for FCs reflecting active public policies to support FCs.

The positive value attached to family caregiving is probably the most critical element in ensuring good quality care of the dependent OP.

Services need to be flexible to fit different needs and different groups e.g. the special needs of spouse carers.

Policy and planning must develop services to cover the needs of ageing migrants.

The development and promotion of appropriate new technologies to aid FCs in maintaining the autonomy and safety of the OP is needed at EU and national levels.

Existing information needs to be evaluated on the cost-benefit to FCs and OP of different types of care arrangements i.e. in the home, day centres, or in special separate facilities e.g. "sheltered accommodation", new style residential homes.

FCs need support from integrated formal care services both to aid in the provision of good care to OP as well as for the protection of the FCs own health and wellbeing.

The development of good and accessible information systems for FCs in all countries is critical.

<p>Determinants of negative impact of caring on FCs are related to the health of the OP (especially behavioural problems), the intensity of caring tasks (high dependency), the carers' support networks (poor quality of support) and the availability of formal support (EL worst).</p>	<p>Indicates the need for early interventions to identify, inform, train and protect FCs from the potential negative impact of some aspects of caring e.g. by information provision, support in maintaining and creating social networks</p>	<p>The role of NGOs and self help groups of FCs emerged as important in this area.</p>
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Commitment to care

<p>Family care is a dynamic but long term commitment: the average length of time of care giving was reported as 60 months at the time of the interview (47 months in DE to 70 months in PL).</p> <p>69% of FCs were willing to increase the level of care in the next year and almost 59% would never consider their cared-for OP's placement in a care home, 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 OP's health worsened, and 17% even if it stayed the same.</p> <p>Those FCs who considered OP's placement in a residential home were more likely to be caring for those with behavioural problems.</p>	<p>FCs and health and social services (probably OP 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.</p> <p>Levels of dependency and length of time caring can act as signals to service providers.</p> <p>The SE tradition of well funded and extensive welfare state services with high quality residential institutions creates 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>NGOs need to campaign for recognition of the role of FCs by policy makers on all levels and of the need to recognize the real costs in time and money of: providing essential care and support to dependent OP and accessing and using services.</p> <p>National Action Plans for Health and social support, should include the recognition of FCs and the provision of information (through local and national media programmes, newspapers, websites) on health protection, training in care techniques, support groups etc.</p> <p>Policy makers have to ensure that service providers have the remit and resources to support FCs.</p>
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<p>One year later 5% of the sample resurveyed reported the OP as being in a nursing home (12% in SE, 0.3% in EL). Amongst FCs no longer providing care where the OP was still alive, in 45% of the cases the OP had gone into residential care and were characterised by severe ADL and cognitive decline and urban residence.</p> <p>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>	<p>Indicates the critical role of serious dependency caused by cognitive and associated behaviour problems. Demographic projections and health studies suggest increasing levels of cognitive decline due to ageing populations, and some improvements in serious ADL.</p>	<p>Staff, at all levels, should be trained to recognise both the contribution and needs of FCs.</p> <p>Information needed on effectiveness of bereavement counselling services.</p>
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Financial Implications of care

<p>FCs had less than average disposable income as a result of caring. This is the result of co-payment for services (high in DE and EL) and a reduction in employment (less hours or withdrawal), high in EL, DE and UK.</p> <p>Only 4% of all FCs received care allowances and 37% of the OP, 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).</p> <p>Particularly in countries with significant care allowances (DE, IT, UK) equivalent net income is less than for the general population.</p>	<p>Highlights the cost implications of FCs of caring.</p> <p>Highlights the cross-national inequalities in financial support for FCs and dependent OP.</p> <p>The issue of real costs and funding of services (payments and co-payments) is critical for FCs.</p> <p>Linking obligatory training to payments for care, as in FI, helps to ensure both quality in care provision and adequate incomes for FCs.</p> <p>Highlights a possible selection effect: if care allowances are granted, care-giving becomes particularly interesting for low income families.</p>	<p>FCs need to be adequately covered by social insurance (accidents, health, pensions etc.) during the time spent caring should be a minimum EU standard contributing to the reduction of long term poverty amongst those who undertake family care (see earlier recommendation).</p>
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Employment and working carers

Employed carers (41%) represent a significant proportion of all FCs. Carers were more likely to be employed in the public sector (42%), private sector (37%) and 17% self employed.

15% of working 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.

Of all FC who gave care for an OP at home 6% reduced working hours and 5% stopped working.

Non-working carers were mainly retired, (35% in EL, 91% in SE) and over 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. 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.

The reconciliation of work and family life to include specified periods of time devoted to the care of children, dependent adults and dependent OP, needs to be covered by pension and insurance credits.

To achieve an increase in female participation in the labour market (the Lisbon Targets), service support for family care will be essential.

The development of viable policies for the promotion of flexible working-hour arrangements and insurance credits for FCs need to be investigated by Ministries of Labour.

Ensuring that services are planned to be flexible and more extensive, to cover the practical support of FCs, including working carers, on a 24/12 basis will create new jobs in the care sector.

Most important types of support

Social networks including kin, friends neighbours and volunteers were associated with lower levels of carer stress and burden.

Information and advice about the disease/condition of the OP and on how to access services were identified as critical by FCs and service providers.

The promotion of social inclusion and social participation appears to be a key policy and FCs are an important target group. (National Plans for Social Inclusion and actions at LA level).

The important role of NGOs in providing information, advocacy and services, an issue not directly addressed in the survey, needs to be clarified.

NGOs and staff in health and social care at local, national and EU levels can play an active role in providing information to FCs.

Volunteers: LAs should consider partial funding for organised, trained volunteer groups who can help with

<p>Services to provide FCs with time to have a break, undertake activities they enjoy, spend time with their families and combine work with caring were what FCs desired and demonstrating differences in perceptions of most useful services between service providers and FCs.</p>	<p>How can the optimum (or at least a better) balance between formal and informal support networks and services be promoted and achieved?</p>	<p>respite care, lighter tasks and the social support of FCs. They may also consider promoting active social participation of FCs and OP through "family carers support centres" which could make savings within the national health and social care systems.</p>
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Services for Family Carers and Older People

<p>Less than one third of FCs had used a support service in the previous 6 months. Less than 10% are specifically intended for FCs especially in PL, IT, EL. Only SE, DE and UK have systematic and regularly used respite, socio-psychological and information services for FCs. In IT, EL and PL one result is substitution, with FCs using generic services instead e.g. information, advice and socio-psychological support from the GP, while the hospital is used as a substitute for missing rehabilitation and respite care.</p> <p>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.</p> <p>The more frail and dependent the OP the more they use services.</p>	<p>Current services for OP and FC do not offer what FCs need. A lack of flexibility and inadequate coverage of services were also reported by FCs as barriers to use of existing services.</p> <p>One third of OP cared for are very dependent and their FCs need appropriate relief.</p> <p>Expensive and unnecessary/inappropriate acute hospital admissions are sometimes used by FCs as a substitute for respite and rehabilitation services.</p> <p>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 FCs in society.</p> <p>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</p>	<p>Policy makers need to optimise existing care resources for dependent OP and FCs by providing appropriate service support.</p> <p>In countries with limited resources, initially target support for the most burdened FCs i.e. those caring for OP with memory and behaviour problems and/or without an informal support network, by providing practical and flexible respite, day care and information services.</p> <p>Promote and adopt national standardised evaluation and monitoring procedures for all services including their coverage, quality and accessibility and use these as a basis for future funding.</p> <p>NGOs should advocate for more flexible and extensive services, including both home based and residential respite and emergency care.</p>
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<p>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 considered important by FCs but less readily available.</p> <p>The greatest help in accessing services is 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).</p>	<p>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, though issues remain as to what incentives can be used to provide integrated services.</p> <p>Most countries have difficulties in extending services into rural areas at a reasonable cost. Hungary has managed under difficult economic circumstances to develop networks of support using neighbours, friends and volunteers.</p>	<p>Readily accessible and flexible respite care is an essential service that needs to be given priority by national governments for implementation at the local level.</p> <p>Collaboration between public, private and voluntary resources may improve coverage.</p>
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Barriers to Service Use

<p>Users and non-users of care services saw main barriers to use as:</p> <ul style="list-style-type: none"> the bureaucratic (i.e. complex) procedures to get access to them (mean 13%, from 28% in IT and 19% in DE, to 4-7% only in PL, UK and SE). their high financial costs (mean 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 euros per month for specific support services, since these are often free, but inadequate provision means the alternative is the use of private care. 	<p>The real costs in time and money of accessing and using health and social services need to be evaluated to make them more accessible and useful to FCs.</p> <p>There is a high need for simplifying access procedures to services in some countries.</p> <p>Payment for services is less of a problem when OP's 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.</p> <p>Inadequate OP's pensions and/or care allowances can only be fairly compensated for by free-to-user services (UK), otherwise FCs bear the costs, either by</p>	<p>ISO standards for all types of care services need to be implemented and encouraged in all European countries as a way of promoting quality evaluation.</p> <p>Develop methods e.g. through EU projects, of effective, efficient and easily implemented evaluation of services by service providers that includes FC and OP.</p> <p>NGOs need to advocate for the minimum but universal provision of care services.</p>
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<p>Other major barriers, preventing wider service use include:</p> <ul style="list-style-type: none"> • lack of information on available support (except for SE), • low quality (except for PL), • inadequate coverage (especially PL and EL), • the refusal of the OP to accept existing services (especially in UK, SE and, to a lesser extent DE). 	<p>giving their own care services or paying others.</p>	
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Formal Care Work – Labour Supply

<p>Migrant care workers were used for support in 10% of Italian and 7% of Greek households caring for an OP.</p>	<p>In 17 of the 23 countries in PEUBARE migrant workers are important in the care and support of OP in health and social services.</p>	<p>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.</p>
<p>The most important characteristics in care workers for FCs and service providers was that they treat the OP with respect and were skilled.</p>	<p>Develop measures to regularise the current use of and reliance on migrant care workers, legally and illegally employed in many European countries.</p>	<p>Adopt quality standards in training for employment in care services as an integral part of all local services.</p>

The evidence from a number of the 23 countries suggests that poor recruitment and retention in care work can be successfully overcome. Improving the training and status of the work as well as conditions of employment are key elements to success. The recruitment of men as care workers may aid in the improvement of the status and wages of care work as would scholarships for those in residential and other caring services; and well-funded chairs in gerontological nursing and geriatric medicine.

Develop EU recognised training standards and programmes for care workers, and in conjunction with national training schemes, run advertising campaigns by national governments to promote a better image of care work.

FC should always be invited to participate in the training of formal care personnel.

NGOs, ADVOCACY, INFORMATION, LEGAL ADVICE

Information was a key need of FCs – both on the disease of the OP and service availability.

Links with successful disease-specific groups (Alzheimer, Parkinson's, diabetes, etc.), as well as NGOs and advocacy groups to develop common interests and issues promotes effective collaboration and outcomes. The newly founded NGO EUROCARERS (European Association Working for Carers) may consider making web and other links to existing NGOs and disease specific groups to promote general knowledge and common policy issues.

One further issue is whether policy for the support of FCs of OP should be included with that of FCs of dependent people of all ages. Unified policies have the advantage of avoiding age discrimination, though the younger disabled may feel that public resources for 'their' FCs may be 'diluted' by the increasing needs of dependent OP.

The Alzheimer Associations throughout Europe provide very good examples of cooperation between professionals and FC.

Local, national and EU support for FCs advocacy groups is a way of promoting partnership between all sectors involved in family care. National and local governments should support FCs to get organized.

The vulnerability of many dependent OP and also FCs to exploitation and abuse needs to be addressed through adequate public legislation, that several countries have already put in place.

Public authorities and policymakers should work closely with the media (e.g. public television and radio stations) to develop programmes aimed at FCs at home (skills training, counselling advice, chat shows, information).

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