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Care Provision within Families and its Socio-Economic Impact on Care Providers

Report for the European Commission DG EMPL
Negotiated Procedure VT/2007/114

Social Policy Research Unit, University of York
in collaboration with
Vilans Centre of Expertise for Long-Term Care, Utrecht

Caroline Glendinning, Frits Tjadens, Hilary Arksey,
Marjolein Morée, Nicola Moran, Henk Nies

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Glossary

AGIR	Aging, Health and Retirement in Europe
CC3	those countries that are currently (2009) candidates to join the EU at a later date – Croatia, Former Yugoslav Republic of Macedonia and Turkey
ECHP	European Community Household Panel (discontinued as of 2001)
EPC	Economic Policy Committee of the European Union; committee of high civil servants of all the Member States of the EU
EPSCO	Council of Ministers for Employment, Social Policy, Health and Consumer Affairs of the European Union
EQLS	European Quality of Life Survey
EU	European Union
EU15	the 15 EU Member States up to May 2004 – Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, the Netherlands, Portugal, Spain, Sweden and the UK
EU25	the 15 Member States up to May 2004 plus the ten countries that joined the EU in May 2004
EU27	the 25 EU Member States following the 2004 enlargement, plus the two countries that joined the EU in January 2007, Bulgaria and Romania
FP5	Framework Programme 5
GDP	Gross Domestic Product
NMS12	the ten countries that joined the EU in May 2004 – Cyprus, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia and Slovenia – and the two countries that that joined the EU in January 2007, Bulgaria and Romania
SHARE	Survey of Health, Ageing and Retirement
SPC	Social Protection Committee of the European Union; committee of high civil servants of all the member States of the EU
SQLS	Second European Quality of Life Survey
WHO	World Health Organisation

Chapter 1 Introduction

1.1 Introduction

The European Commission (DG EMPL) invited tenders for a study of care provision within families and the socio-economic impact of family care-giving. The tender was won by a team of researchers from the Social Policy Research Unit, University of York, England and Vilans, the Dutch Expertise Centre on Long-Term Care. Both organisations are founding research members of Eurocarers; Eurocarers is an EU-wide network of organisations representing carers' interests or providing services to carers, together with leading research organisations with particular expertise in carers' policy and practice issues. The mission of Eurocarers is to highlight the situation of carers within EU and member state policy forums (www.eurocarers.org).

1.2 EU policies and their relevance for carers

Informal and family care has recently developed a high profile within EU policy forums. For example, the 2007 spring meeting of European Ministers of Employment and Social Affairs (EPSCO), in their headline messages to the European Council, endorsed support for informal care as a top priority of the EU (EPSCO, 2007). Also during 2007, both Eurocarers and a family carers special interest group of the European Parliament were launched.

These developments reflect the widespread recognition of the increasing pressures on the sustainability and quality of long-term care systems and of the critical role that family care-giving plays in safeguarding that sustainability. European demographic trends are well documented. It is estimated that the number of people aged 65-plus will increase by 77 per cent by 2050; the old age dependency ratio is expected to double during the same period. Population ageing leads to an increasing share of old and very old people in the population, with increases in degenerative and chronic diseases leading to new patterns of morbidity. Although advanced age and chronic disease do not necessarily or automatically lead to a need for care, demographic ageing nevertheless serves as a useful proxy indicator of demand for long-term care (EC, 2008). Moreover, carers themselves are expected to become older (Schultz, 2004); to become more diverse; and to belong to smaller family networks because of declining fertility, increased divorce rates, greater geographical and time distance between family members, and broader socio-economic trends towards individualisation. Additional demands on family members are likely to arise from the development of new medical technologies that enable even people with the most complex health conditions to be cared for at home (Glendinning *et al.*, 2001).

However, the key role of family care in responding to a growing demand for long-term care also has a potential impact on the future economic competitiveness of the EU. At the same time as reducing demands on public long-term health and social care systems, family care may hinder people in their ability to work (and earn a taxable income). This constraint has implications for EU policy ambitions to increase the labour market participation of the working age population, as set out in the Lisbon Strategy. With these dual roles in mind, the following sections set out key relevant developments in EU policies.

1.2.1 The EU Charter of Fundamental Rights

The 2000 Charter (www.europarl.europa.eu/charter/pdf/text_en.pdf) sets out the main shared values of member states concerning the rights of their inhabitants – dignity, freedom, equality, solidarity, citizens’ rights and justice. The Charter is referred to by the Treaty of 2007 and is therefore potentially a legally binding document. Although the Charter does not specifically mention carers, some of its Articles have relevance for carers (see also Kerschen *et al.*, 2005: 51):

- **Article 15** states that ‘everyone has the right to engage in work and to pursue a freely chosen or accepted occupation’. However, pressures on carers may prevent them from pursuing a freely chosen or accepted occupation or seeking employment.
- **Article 21** refers to non-discrimination and has already led to a landmark ruling in the European Court of Justice (see box below).
- **Article 33** refers to the reconciliation of professional life with family responsibilities (albeit relating to the care of children).

European Court of Justice – discrimination against carers

In 2008, the European Court of Justice delivered one of the first verdicts concerning carers (ECJ C303/06, 17 July 2008; *Coleman v Attridge Law and Steve Law*). The case concerned England’s interpretation of EU law, but has much wider relevance; Greece, Ireland, the Netherlands, Italy, Sweden and Lithuania all sent representatives to be heard in the judicial process.

The case concerned workplace discrimination, in alleged contravention of Council Directive 2000/78/EC (SEC[2008]524) that established a general framework for equal treatment in employment and occupation. Sharon Coleman, a legal secretary who was the main carer for her disabled child, resigned from her job citing constructive unfair dismissal and claiming that she had been treated differently from other parent workers because of her additional caring responsibilities.

The Court considered whether the Directive covered only direct discrimination against a disabled person or also covered indirect discrimination against a carer. It concluded that (art. 38 of the Verdict):

it does not follow from those provisions of Directive 2000/78 that the principle of equal treatment which it is designed to safeguard is limited to people who themselves have a disability within the meaning of the directive. On the contrary, the purpose of the directive, as regards employment and occupation, is to combat all forms of discrimination on grounds of disability.

This verdict confirms that EU regulations can have a direct impact on carers and reflects the growing interest at EU level in carers' rights.

1.2.2 The Lisbon Strategy and the Open Method of Co-ordination

The Lisbon Strategy – the EU's ambition of becoming the world's leading knowledge economy – requires co-ordination between EU-wide economic policies and those of member states. Pressures for co-ordination extend to areas where the EU has no legal remit, such as the public expenditure of member states, including expenditure on health and long-term care. These pressures have led to the formal development since 2004 of the Open Method of Coordination (OMC) in the field of health care and long-term care, as part of the OMC on social protection and social inclusion, which enables member states to share experiences and identify best transferrable practices.

The main goals of the OMC cover the accessibility, financial sustainability and quality of health and long-term care systems. These concepts have different meanings in different member states, but their achievement depends, in part, on the work of family carers in supplementing public spending on long-term health and social care. Even in EU member states with traditions of high public expenditure such as Sweden, the sustainability of long-term care is increasingly dependent on the contribution of family carers. This key role – and the linked importance of supporting family care – will only increase in future.

1.2.3 The 2007 EPSCO Council statement

As noted above, the EPSCO Council of spring 2007 requested leaders of member states to put support for carers at the top of their respective policy agendas. The EPSCO Council referred to a Commission Staff document summarising the main messages from the National Reports (CEC 2007) relating to support for family carers:

- thirteen member states mentioned providing direct financial support for carers
- thirteen member states mentioned providing practical support such as information, training, counselling or respite care
- five member states had provisions to reconcile work and family life by offering different forms of care leave from work.

The background document to the EPSCO message did not spell out the coverage, take-up or effectiveness of these measures – a limitation that to some extent reflects the restricted scope and format of the National Reports. Moreover, the National Reports on which the EPSCO synthesis was based may reflect sectional, country-specific political interests that determine which policies are presented (or not) at EU level (Büchs, 2008; Tjadens, 2008). Nevertheless, despite these limitations, in at least half the member states carer support was stated to be a political issue.

Subsequent work by European Commission staff on the National Reports of the OMC Process (EC, 2008) identified the following potential range of measures for supporting family carers:

- information, training, counselling and respite care
- direct financial support for carers, tax credits and exemptions
- measures to reconcile care and paid employment, mainly through entitlements to leave from work
- recognising time spent caring in the eligibility criteria for pensions and other social insurance benefits.

Examples of such measures are included in Chapter 6 of this report.

1.2.4 Other relevant EU policy documents

Recently, four documents have summarised the relevance and impact of EU-policy domains on long-term care and carers (Tjadens and Schippers, 2006; Pflüger and Patel, 2005; ESN, 2007; Tjadens *et al.*, 2008). All emphasise the multiple policy domains that can affect family carers. Table 1.1 below illustrates these policy domains.

Table 1.1 Some EU policy debates and issues with relevance for carers

<i>EU-policy debates</i>	<i>Impact on carers</i>
The European employment strategy, including employability, working time, duration of working life, social inclusion, equal opportunity and gender-equality issues	Reconciling work with caring responsibilities for people other than children. Working for longer hours and/or extending the duration of working lives leads to increased pressures to reconcile work with care.
Pension debate	As care responsibilities are currently greatest among 45–65-year olds, the pension age and pension levels impact on carers. Also, ensuring that pension contributions/entitlements are maintained during periods of caring reduces risks of poverty for carers in their own old age.
Social (and health) services of general interest	Liberalisation of social and health services may lead to the marketisation of care. Not all carers will be able to afford market rates for services that might support them in their care responsibilities.
Prevention and active ageing	Preventive health strategies may reduce demands for care.
Corporate social responsibilities	Whether employers are 'carer-friendly' will affect carers' ability to combine paid work and care.
European Alliance for Families	Carers find themselves primarily within family networks.
Health strategy	Poorly-supported care can impair carers' physical and/or mental health. Disease prevention and healthy living policies may reduce demand for family care.
Life-long learning	Higher education is believed to lead to healthier lifestyles, thus potentially reducing needs for care.
(Economic) migration	Many legal (and illegal) migrants into and within the EU work as semi-professional carers, thus potentially filling gaps between formal services and family carers.
Demographic debates	These include solidarity between younger and older people (see for instance COM(2007)244).
Gender equality	Most care is provided by women working in low paid jobs or unpaid in family settings. Economic liberalisation and the creation of new care markets, including the provision of cash payments to support family care, risks institutionalising women in unpaid or very low paid care-giving roles.
New technologies (e-inclusion, e-care, e-health)	New technologies may alleviate burdens on carers by providing new solutions to existing problems. They may also reduce care responsibilities by increasing (and introducing new definitions of) healthy life years. On the other hand, new technologies may increase carers' responsibilities, through the transfer of medical care to the home.

Adapted from Tjadens *et al.* (2008)

1.3 Aims of this study

The growing EU recognition of the importance of informal and family care-giving provides the context for this study. The aims of the study were to compile evidence on:

- The prevalence of long-term (informal) care-giving within a family setting to dependent family members or relatives in various EU countries, including recent and anticipated trends. The study was to focus on the most ‘heavily burdened’ carers – those involved in intensive care-giving or without additional support.
- The socio-economic impact of care-giving on the households of family carers. Again, the study was to focus on the most ‘heavily burdened’ carers and also paying particular attention to gender inequalities in care-giving and its consequences.
- Measures aimed at alleviating burdens on family carers by:
 - supporting them in the provision of care and/or
 - compensating for the adverse socio-economic consequences of care-giving.

1.4 Original plans for carrying out the study

The study relied on identifying and compiling existing national and transnational sources of data, including official statistics and published primary research. The team’s ability to meet the objectives of the review therefore depended on the ready availability of relevant and comparable data from government and academic sources.

The study team originally planned first to examine published cross-national research datasets, including data on family care for older people collected in the course of the Eurofamcare study (www.uke.uni-hamburg.de/extern/Eurofamcare). The team planned to supplement this cross-national data with additional published data from between six and eight countries on ‘heavily burdened’ carers of both older and younger people. The selection of countries for in-depth study would be guided by various typologies of welfare state regimes, so that the in-depth evidence would include a range of different welfare systems. The selection of countries for in-depth study would also take into account the availability of expert informants who the study team could approach for help in identifying, collating and, where necessary, translating published national-level research data. It was anticipated that most, if not all, of these expert informants would be members of Eurocarers. They would be asked to supply information according to a template devised by the study team, in order to ensure consistency in the range of information collected.

1.5 Early challenges

Early analysis of Eurofamcare reports and other EU-wide data quickly revealed a number of methodological challenges:

- Different countries used different definitions and criteria to identify all carers, and ‘heavily burdened’ carers in particular. This variability also characterised the country-based National Reports produced for Eurofamcare.
- Some of the expert informants, though willing to help, reported that there was no data available from their country of the kind sought by the study team, over and above that available from the Eurofamcare study; in other countries relevant data were too old to be useful.
- Much of the available data, both from EU-wide sources and individual member states, was on carers of older people. Thus, although extensive data were available from the Eurofamcare project, this only covered the carers of older people. Similarly, a Eurostat (2007) report concentrated on people caring for their parents but excluded spouse or partner carers – a group that, as longevity increases, is likely to be increasingly involved in supporting older people. Information on carers of non-elderly disabled or ill people was much harder to find.
- In some countries there was no national research or census data at all on the numbers of carers. Instead, estimates of the numbers of carers were derived from data on numbers of older people; or were derived from administrative data, for example on the numbers of disabled or older people receiving a particular service or cash allowance.

These challenges are discussed in more detail in Chapter 2.

1.6 Revised study design

Early on in the study, the team concluded that the most extensive bodies of available data focused just on carers of older people or on people caring for elderly parents. Yet even here the available published evidence was widely divergent and not comparable across member states. Given that carers of older people/older parents were the most extensively researched groups of carers, even greater difficulties were anticipated in identifying data about carers of other groups of disabled or chronically ill people. The team therefore concluded that the original design of the study – particularly the intention to focus on a selected number of countries for in-depth study – was therefore unlikely to yield the desired volume, quality or consistency of data.

In an Interim Report to the European Commission, the study team therefore proposed adapting the original study design:

- The review was extended to include a wider range of cross-national data sources, covering more countries, than originally proposed. The decision to include more cross-national data was based on the expectation that data collected specifically for the purposes of making comparisons between countries was more likely to be consistent in the definitions and criteria used to identify carers and ‘heavily burdened’ carers, and in other parameters of the data. The team therefore drew more heavily than originally planned on published EU-wide data, including data from the Organisation for Economic Cooperation and Development, World Health Organisation, European Foundation for the Study of Living and Working Conditions and other FP5 and FP6 research to document the prevalence of carers; the prevalence and consequences of ‘heavily burdened’ care-giving; and the socio-economic impact of family care-giving. Despite extending the study to include this broader range of data, much of it nevertheless still focuses on informal care for older people. This data is reported in Chapter 3 (which focuses on data on carers of older people from the Eurofamcare study) and Chapter 5 (which reports findings relevant to carers of people of all age groups from other EU-wide studies).
- Because of the predominance of national and cross-national data on carers of older people (particularly from Eurofamcare, reported in Chapter 3), we drew on our network of expert informants to seek available data specifically on the prevalence of informal care, ‘heavily burdened’ care-giving and the socio-economic consequences of providing care for non-elderly people. Here the study team focused enquiries on a small number of countries where it was believed there was a reasonable likelihood of data being available. The selection of countries took into account two factors: the study team’s prior knowledge of research and national data sources in each country; and the availability of expert informants who were expected to be familiar with their country’s data and able, where necessary, to translate this into English. The selected countries were: Austria, the Netherlands, England, Italy and Belgium. Although there was some overlap between these countries and those covered by the Eurofamcare National Survey Reports, the selection of countries was guided by consideration of the likelihood of being able to obtain the data we were seeking. We asked our informants to provide data according to a standard information template, wherever possible. However we did not expect this data to be either comparable or comprehensive. This data is reported in Chapter 4, which focuses on carers of non-elderly people.
- We supplemented the contributions of our expert informants with a limited search of published literature from key social science databases. Electronic and subsequent hand searching aimed to identify research reports:
 - written in English but about or including data from the selected countries
 - of large-scale (rather than small scale, qualitative) empirical studies, conducted within the past ten years

- relevant to the prevalence or socio-economic impacts of care-giving, and 'heavily burdened' care-giving in particular, or reporting examples of good practice.

Full abstracts were obtained for 300 citations, of which 26 were considered potentially relevant. Even so, many of the latter did not provide sufficient details of carers' circumstances that would allow 'heavily burdened' carers to be identified. Nevertheless, a few of these reports were also cited in the information provided by the expert informants. These reports are also included in Chapter 4.

1.7 Examples of policy and practice measures to support carers

The study team took a broad view of the measures that could potentially support carers in the provision of informal care or help in alleviating the adverse socio-economic impacts of care-giving. As noted in our original proposals for conducting the study, these could include:

- employment and workplace-related measures
- services to support carers: so that they can continue in paid work; to relieve them of some of the burdens of care; or to give them additional knowledge and skills to enhance their care-giving role
- material support, including cash allowances and 'in kind' material support such as protection of pension entitlements or access to subsidised services.

The study team sent out a call to all members of Eurocarers and the expert informants for examples of 'good practice' in supporting carers and/or alleviating the adverse socio-economic impacts of care-giving. The team adapted a template from the Open Method of Co-ordination to collect a standard range of information on each example. The template requested information on:

- the purpose of the initiative
- the main outcomes of the initiative
- groups of carers and geographical region covered by the initiative
- whether the initiative provided health or social care support, financial or other material support, or was employment related
- whether any independent evaluation was available
- the informant's view on transferability to other regions/countries.

Twenty-one examples were received by the study team. Where appropriate, the robustness of any evidence on the effectiveness of these interventions was rated using a template developed by researchers at the University of Wollongong to assess the robustness of research evidence on carers' needs and interventions (Eager *et al.*, 2007).

In addition, a recent OECD report (Lundsgaard, 2005) was used to provide an overview of financial measures such as carer allowances, to support carers.

The examples of policy and practice measures are presented in Chapter 6.

1.8 Conclusions and structure of report

Informal and family care has recently developed a high profile within EU policy forums. In the context of anticipated trends of demographic ageing, family care is critically important in ensuring the sustainability of long-term care systems and limiting increases in public expenditure in member states. At the same time, however, family care responsibilities may impact on the future economic competitiveness of the EU by restricting the opportunities of a substantial minority of the working age population to engage in paid work and earn a taxable income.

Examples of the increasing profile of family care within EU policy include:

- The 2000 EU Charter of Fundamental Rights includes several clauses relating to freedom to work and to non-discrimination that have particular relevance for carers.
- The Open Method of Co-ordination (OMC) facilitates co-ordination between member states in areas where the EU has no legal remit. The role of family care is integral to OMC actions on social protection, social inclusion and the quality of health and long-term care systems.
- Support for carers has become a priority for European Ministers of Employment and Social Affairs.

Against this background, the Social Policy Research Unit (University of York) and Vilans, the Dutch Centre of Expertise on Long-term Care (Utrecht) were commissioned by the European Commission (DG EMPL) to compile evidence on:

- the prevalence of long-term informal care within families, focusing on the most 'heavily burdened' carers
- the socio-economic impact of care-giving on carers and their households, focusing on heavily burdened carers and gender inequalities
- measures aimed at alleviating burdens on family carers.

The study relied wholly on existing published data, both cross-national datasets and in-depth studies from selected countries. Early examination of available data found many shortcomings and methodological challenges. The most extensive data, within and across EU member states, related to carers of older people. The study was therefore extended to a wider range of cross-national datasets, covering more countries. This was complemented by in-depth data from a small number of countries

on the prevalence and socio-economic consequences of providing care for non-elderly disabled or chronically ill people.

In addition, information was sought on measures to support carers or alleviate the adverse effects of care-giving, including:

- employment and workplace-related measures
- services to support carers
- material support including cash allowances.

The methodological challenges encountered by the study team are detailed in Chapter 2. Chapter 3 summarises the data on informal and family care of older people, drawing primarily on the Eurofamcare study. Chapter 4 complements this with data on informal and family care of other groups of (non-elderly) disabled or chronically ill people obtained from expert informants in a selection of countries and supplemented by the results of our literature search. This is followed by an account of other EU-wide datasets that contain information on carers (Chapter 5). Chapter 6 describes examples of policy and practice measures to support family carers, rated according to the robustness of the evidence on their effectiveness and their potential transferability to other countries. Chapter 7 contains a concluding discussion and recommendations for policy and further research.

Chapter 2 **Methodological Challenges in Investigating the Prevalence and Consequences of Informal Care across Europe**

2.1 Introduction

As noted in Chapter 1, the research team encountered a number of challenges in carrying out the study as originally planned. These are discussed in detail here as they explain why, despite the amended study design described in Chapter 1, the data presented in subsequent chapters of this report are often variable, inconsistent and either partial or overlapping. These challenges are more than simply academic observations. They also give a strong indication of the issues that need to be addressed by both the EU and member states, if a more comprehensive, coherent and consistent body of data on informal care-giving is to be compiled in future. The implications and recommendations for future research are set out in detail in Chapter 7.

Although widely used, many of the terms used by the research team in responding to the EC requirements and setting the parameters of the study were subject to different interpretations and specifications. These interpretations often reflected the cultures, customs or institutional arrangements of individual countries. As the study depended entirely on existing published evidence, such variations had a major impact on the quality and comprehensiveness of the data that could be collated.

2.2 Who are ‘informal and family carers’?

There was no consistent or comparable definition of ‘informal and family carers’ used by governments and researchers in different countries. By definition, informal care-giving activities are embedded in, and arise from, long-standing kin and other relationships. Therefore criteria are needed to distinguish the **additional** care responsibilities that arise from illness, disability or old age from those activities associated with normal family obligations and reciprocities. For the purposes of this study, informal care was also distinguished from adults’ (parents’ and other relatives’) responsibilities for the care of non-disabled dependent children.

Criteria for identifying informal carers often include some element of time. For example, specifying a minimum threshold of time spent each week on care activities arising from disability or old age excludes those with only very light responsibilities, for whom the socio-economic consequences may be minimal and policy measures

considered unnecessary. Similarly, specifying the duration of care-giving activities excludes help provided because of temporary illness or incapacity.

Some studies identify carers indirectly, through the older or disabled person needing help, but this risks under-estimating the numbers of carers if it is assumed that each older or disabled person has only one carer. Other approaches may focus on the provision of particular kinds of help. This again has risks; if carers are defined as those providing help with personal care, then more female carers will be identified; if help with managing finances and other personal administration is included, then more male carers will be identified.

In some countries, informal carers are defined with reference to administrative categories, such as those who receive a specific service or benefit, or those who support the elderly or disabled recipients of a specific service or benefit. This is the approach in Austria, for example, where the number of carers is estimated by reference to the number of people receiving Long-Term Care (LTC) Allowance. While this approach may serve to exclude those who are ineligible for the Allowance because of only very light care responsibilities, it also excludes eligible non-applicants and it omits entirely carers of people who are just below the LTC Allowance eligibility threshold, who may have very substantial burdens.

One definition of family care (rather than 'carer') was proposed by Mestheneos and Triantafillou (2005a) for the Eurofamcare study:

'family care' is care and or financial support provided by a family member for a person 65-years of age or over needing at least four hours of personal care or support a week, at home or in a residential care institution.

Given the focus of the Eurofamcare study, it is not surprising that this definition relates solely to care for older people. However, the inclusion of financial support on its own as a criterion for identifying family care and the extension of care-giving responsibilities to institutional settings both suggest an unusually wide and inclusive definition that was not compatible with the aim of this study, to focus on 'heavily burdened' carers.

The definition of carer employed in this study is someone:

who provides help to someone with a chronic illness, disability or other long-term health or support need, outside a professional or formal framework.

This definition has a number of implications:

- Care is provided outside a formal professional relationship, whether or not other professional or volunteer services are also involved. Formal agreements over working hours, holiday entitlements, working conditions, pay or other benefits and

managerial hierarchies and accountabilities are all largely absent from informal care-giving situations. In some countries, it is possible for close relatives to be employed by the disabled or older person, using a 'personal budget' or similar arrangement (see Breda *et al.*, 2006; Pijl and Ramakers, 2007). In other countries, carers may be supported by a care allowance paid to the older or disabled person (Glendinning and Igl, 2009; Da Roit *et al.*, 2007; Timonen *et al.*, 2006). These informal care arrangements typically involve the provision of far more care than the hours covered by the payment received; they have therefore not been excluded from the scope of this study and are covered in Chapter 6.

- In formal or professional care-giving, the provision of care is usually the start of a relationship; but informal care situations arise because of a pre-existing relationship, often based on kinship or close friendship. Consequently, care-giving may begin gradually and become more intensive over time.
- Carers' activities are largely dictated by the (changing) needs of the person needing support. There is usually no limit to the range of care-giving tasks; these may include highly specialised nursing and medical tasks (Pickard *et al.*, 2003), as well as personal and domestic help. There is also no limit to the amount of time per day, month or year spent caring, or when during the day, night, weekday or weekend care is provided.
- Care-giving is not confined to any particular age-group; even children and young people may carry heavy responsibilities for care (Becker *et al.*, 1998).
- The definition does not specify a minimum number of hours per week or period of time spent caring, nor a specific set of tasks.

However, our definition does attempt to draw a distinction between paid and 'informal' care-giving. In the majority of instances, informal carers are close family members; less commonly, neighbours and close friends may also be involved. The study focuses on help given in the context of affective and/or familial affiliations and excludes care provided by migrants and others working within the black or grey economies of long-term care systems. In line with our definition, in most instances care will be unpaid, in the sense that carers are not formally employed or paid a full wage for the work that they do. However, as noted above, some family carers may receive some financial support from the care allowance or may even be employed by the care recipient, using the latter's personal budget (see Chapter 6).

2.3 What are 'heavy care-giving obligations'?

The study aimed to focus on carers with heavy care obligations, who are therefore likely to be at greatest risk of experiencing adverse socio-economic and other consequences. It was hoped to be able to use one (or more) of the following widely-used criteria for identifying 'heavily involved' carers (Becker and Becker, 2008):

- Carers providing care for the greatest number of hours per day and/or hours/days per week. Commonly used thresholds include caring for 20 hours or more, or 50 hours or more, each week.
- Carers providing help with personal care, either alone or in addition to helping with household and domestic tasks or instrumental activities of daily living.
- Carers living in the same household as the person receiving support.

However, these criteria are only approximate. The concept of 'burden' includes both objective and subjective elements that may interact or may vary completely independently from each other. Thus someone with an apparently heavy objective burden (in terms of the number of hours per week spent caring, the tasks involved or the duration of the care-giving episode) may not necessarily feel burdened. In contrast, others with relatively light responsibilities may feel extremely (over-) burdened. Reasons for these apparent inconsistencies may include the quality of the relationship with the person receiving care; felt motivations and rewards experienced from caring; and the presence of other competing commitments such as paid work. The Eurofamcare data presented in Chapter 3 uses both objective and subjective measures. It illustrates how objectively heavy care burdens – for example, caring for a spouse – may nevertheless also be associated with positive feelings and satisfactions.

Local factors – including levels of, and eligibility criteria for, welfare service provision and cultural expectations about kinship obligations – are also likely to affect carers' experiences of burden. Thus, where there is little formal service provision and care is assumed to be predominantly a private family responsibility, heavier care obligations and more severe socio-economic consequences may be expected than in countries where extensive formal services for older and disabled people are available.

Carers' responses to questions about the 'burdens' of care may also be influenced by the structure of surveys and the phrasing of questions within them. Positively formulated questions (for example 'Do you think you cope well?' or 'Are you willing to continue caring?') may elicit more positive responses than questions about negative aspects of the caring role. Moreover, if negatively worded questions are asked first in an interview, it is possible that these will lead to more negative overall responses than if the initial questions are more positive. It is not always clear how this issue has been tackled in the published research and therefore how far it should be taken into account in interpreting research findings.

However, even within any given welfare system or culture, some carers are likely to experience heavier care obligations than others, including:

- Socially or geographically isolated carers who have sole responsibility for supporting a disabled/older person.

- Carers who do not know about potential sources of services/support, or where the person they are caring for refuses to use these.
- Carers of people who are assessed as not being eligible for services. In some welfare systems, the availability of help from a family carer is taken into account in assessing an older or disabled person's need for formal services and support.
- Carers from ethnic minority groups, who may be unaware of services/support; be unable to access these; or find them culturally inappropriate.
- In addition, carers who are themselves very old or who have health problems of their own, are also likely to experience greater burdens.

Within this study, we encountered different criteria used to identify carers with 'heavy care burdens'. For example, data were available from some countries on the numbers of carers categorised according to the amount of time per week they spent caring, thus enabling carers spending the most time to be identified. Elsewhere, information on the number of hours spent caring was only available as a mean or modal figure. In a few countries, the duration of care-giving episodes was available as a further criterion for identifying 'heavily burdened' carers. In some countries, 'heavily burdened' carers are those eligible for or receiving a particular service or benefit or those caring for older or disabled people in receipt of a specific service or benefit. Other indicators of 'heavy care burdens' include data on subjective feelings of burden and whether or not working-age carers are able to combine care-giving with full- or part-time paid employment.

Most seriously, the study found that indicators of 'heavy care-giving burdens' were widely used as outcome variables and were not available as analytic variables that could allow a focus on the consequences of 'heavy care burdens'. This means that it is generally not possible to compare the socio-economic consequences of carers with lighter and heavier care burdens.

2.4 Estimating the prevalence of informal and family care

The definitions and criteria used to identify carers of course affect estimates of the prevalence of family and informal care across the EU. Thus very many families will have varying degrees of obligation and responsibility for the care and support of disabled, chronically ill or elderly relatives, and will regard these responsibilities as taken for granted aspects of family life. However, the important issue is how to identify the point at which such responsibilities start to have adverse effects on the health, well-being, socio-economic status and economic activity rates of care-giving family members, and thus become a legitimate concern for public policy. The point at which such adverse effects arise will vary between countries, depending to varying extents on local cultures and expectations about the role of families and on the availability of formal services for older and disabled people and carers. Nevertheless,

it is helpful if studies are able to use some kind of threshold or criterion to distinguish between carers carrying only light and more substantial responsibilities. Subjective measures of felt burden or poor quality of life would be one approach. Another approach would be to employ objective indicators, such as a minimum number of hours per week (say, 20 hours a week) that are actually spent on care-related tasks, so as to exclude very light commitments (for example, shopping for a neighbour once a week). It is also helpful if studies specify a minimum duration of care-giving, in order to exclude short-term care given during temporary periods of non-terminal illness. As will be illustrated in Chapters 3, 4 and 5, few sources of data on the prevalence of informal and family care meet these requirements.

Estimating the prevalence of informal care is also affected by the process of EU enlargement over the past decade. Whereas some data is available from studies carried out across the original (up to 2004) 15 member states, it is not necessarily safe to assume that these can simply be scaled up in direct proportion to the population of the enlarged, post-2007 EU27. Differences in demographic patterns and proportions of older people, differences in lifestyle and healthcare affecting the incidence of chronic illness and disability and, crucially, differences in levels of formal welfare services will all affect the extent to which families carry responsibilities for care. As we show in Chapter 5, there are considerable differences in all these factors between the older and newer member states. These differences may reduce the accuracy of EU-wide estimates that are based on data from only subsamples of member states; the assumptions used in arriving at such estimates need to be explicit.

2.5 The socio-economic impact of caring

A wide range of socio-economic consequences may result from family care:

- Carers may lose actual and/or potential income as a result of being unable to remain in employment; reducing their hours of work; taking more convenient but lower paid employment; being unable to return to the labour market after losing a job; or foregoing career opportunities and advancement. Moreover, constraints on labour market participation and earnings can have longer-term effects on carers' pension entitlements in their own old age.
- Extra direct costs associated with the provision of care, including contributing to extra disability-related expenses of the person receiving help, or purchasing additional services because of lack of time.
- The costs of professional care services to replace family care (for example respite care).
- Social costs, including social isolation and social exclusion.
- Adverse health effects, particularly on carers' mental health.

The incidence and severity of any of these impacts is likely to be affected by wider labour market factors and local welfare regimes. For example, carers may find it easier to combine care and paid work (and thus mitigate some of the adverse impacts of care-giving) where labour supply is relatively tight and employers thus more willing to accommodate care-related restrictions and flexibilities in order to retain valuable employees. The financial impact of caring may also be mitigated by national social security schemes that replace income lost because of caring, or by welfare services that support carers in sustaining their labour market position and career trajectories (see Chapter 6).

As with the concept of 'burden', the social and economic impacts of care-giving have both objective and subjective dimensions. Thus some of the material costs of care-giving may be counterbalanced by the rewards and satisfactions of being able to provide care for a close relative (Nolan *et al.*, 1996).

Because of these considerations, the study aimed, where possible, to identify evidence on the employment, financial, social, health and other aspects of carers' situations as compared to similar individuals and households with much lighter care responsibilities or currently without care-giving responsibilities. However, it was not possible from much of the available data to derive pan-European, quantitative evidence on the socio-economic consequences for carers carrying the heaviest burdens of care. Whatever the indicator of 'heavy care obligations' that was used (whether number of hours per week spent on caring, combining working and care, self-reported burden), there was no data on what the consequences are for carers with lesser or greater care responsibilities. For example, the Eurofamcare study (see Chapter 3) tends to focus on carers in general and from these identifies the proportions of carers spending more than a certain amount of hours each week/month in care-giving, or who combine paid work and care, or who perceive themselves to be heavily burdened. In other words, carers with the heaviest burdens were identified as a dependent variable; it was not possible to find research which treats heavily burdened carers as an independent variable.

A further weakness of the available data was the lack of information comparing carers' experiences of economic disadvantage or health status to those of the general population. Moreover, even where such comparisons were available, clear causal relationships were rarely established. Thus where there was evidence of an association between heavy care-giving responsibilities and labour market disadvantage, it was not clear whether the care-giving had led carers to withdraw from the labour market; or whether their prior lack of labour market activity had led to them taking on a major care-giving role in preference to, say, another relative who was currently fully employed. Similarly, there was a lack of robust evidence on the casual relationship between heavy care-giving responsibilities and poor health outcomes for carers; it may be that there is a complex set of inter-relationships

between decisions to take on and continue care-giving, poor health and disadvantage in relation to the labour market.

2.6 Policy and practice measures: alleviating burdens on family carers

As described in Chapter 1, the study team aimed to identify examples of good practice through the Eurocarers network and expert informants. The team sought examples of policy and practice measures that fell into one or more of the following categories:

- Services. These may be provided for the disabled/older person to alleviate some of the carer's responsibilities. Services might also be aimed at carers themselves to help sustain their care-giving role.
- Employment-related measures, such as rights to paid or unpaid care-related leave; opportunities for flexible working arrangements; and access to training and other support for carers to (re-)enter the labour market.
- Direct or indirect material support. This could include cash payments such as care allowances paid directly to the carer; payments that are 'routed' (Ungerson and Yeandle, 2007) through the disabled/older person; and 'in kind' material support, such as protection of pension entitlements or subsidies that reduce the full costs of services for carers.

Again, the criterion of 'good practice' is subjective and locally variable. Innovative practice in one context might be routine policy in another; this issue was also acknowledged by the Eurofamcare summary of examples of good and innovative practice in supporting family carers of older people:

Examples mentioned in one country as good or innovative might not be mentioned at all in other countries, not only because they are not available but also because they are already established as a regular service (Eurofamcare, 2006: 5).

An important issue considered by the study team was the evidence available to confirm claims of 'good practice'. For example, a measure might be widely perceived as highly innovative but nevertheless lack independent evidence of its actual impact or cost-effectiveness. This particular shortcoming unfortunately characterises many of the innovative examples included in the Eurofamcare good practice survey. In addressing this problem, the study team drew on a schema of evidence on interventions for carers compiled by the University of Wollongong (Eager *et al.*, 2007). The schema proposes the following ratings for different types of evaluation evidence:

1. **Well-supported practice** – evaluated with a prospective randomised trial.
2. **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication.
3. **Promising practice** – evaluated with a comparison group.
4. **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (for example pre- and post-testing, post-testing only, or qualitative methods) or historical comparison group (for example normative data).
5. **Emerging practice** – evaluated without an independent assessment of outcomes (for example formative evaluation, service evaluation conducted by host organisation).
6. **Profiles of carer population** (for example routine data).
7. **Eligibility for support** (for example legislation, policy).
8. **Carers' views** (for example surveys, interviews).
9. **Expert opinion** (for example peak bodies, government policy).
10. **Economic evaluation** (including service utilisation studies).

We have applied this schema to any evaluations or other evidence that we have been able to obtain on the effectiveness of the interventions and examples of good practice presented in Chapter 6. Each category or type of data gives a useful indication of how robust the evidence base is on the effectiveness of an intervention or initiative; for example, an evaluation designed as a prospective randomised trial is likely to yield much more robust evidence than one based solely on expert opinion or routine service activity data. However, again it should be noted that the study team did not have access to the original research reports or data from any of the evaluations. We were therefore unable to comment on how well any particular evaluation was conducted or how far the conclusions of any evaluation are actually supported by the data.

A further challenge in identifying examples of good practice is that some initiatives involve several different components; it is not necessarily clear which particular elements of an intervention or service – or which combinations of elements – may contribute to effective impacts and outcomes. Furthermore, some interventions or examples of good practice may be targeted at, and effective for, some groups of carers but less so for others. Again this consideration restricts the usefulness of the Eurofamcare good practice survey, which focused exclusively on measures for carers of older people; it is not clear how many of these interventions may be effective for carers of disabled or chronically sick people of other ages. Moreover, at

least some interventions may depend upon, or only be effective alongside, measures or interventions targeted at the person receiving care. In other words, identifying good practice measures requires a broad approach that takes into account the interdependency of care-givers and care-receivers (Yaffe *et al.*, 2002).

Finally, the study team struggled with the requirement that good practice examples should, ideally, be transferable from their local or national setting and applicable to carers in other countries. We have not found any criteria or indicators to help in assessing transferability. This constraint is particularly relevant in considering the employment and financial support measures presented in Chapter 6, as these are frequently embedded within national organisational and administrative systems (for example Huber, 2005).

2.7 Other methodological and practical challenges

The team encountered a number of other challenges in conducting the study.

2.7.1 Availability of comparable cross-Europe information

The Eurofamcare study, focusing on the family care of older people, is unique in providing both EU-wide data about family care for older people and in-depth information from a smaller number of countries. However, even here there were some shortcomings in the range, consistency and clarity of the data contributed by the participating countries. This means that the data presented in Chapter 3 occasionally does not specify clearly which groups of carers are covered by the national country reports, or contains other internal inconsistencies or discrepancies.

Extensive searching of websites for other pan-European data revealed that it seems unusual for EU-funded studies to be disseminated through clear, easily accessible reports on dedicated websites. In this respect, the Eurofamcare project appears somewhat unusual in that all key deliverables, outputs and reports are available on a dedicated website for free downloading. It was far more difficult to identify outputs from other EU-funded projects from FP4, FP5 or FP6, for example through the Cordis portal. This shortcoming restricts easy access to potentially relevant documentation and literature. The data that was nevertheless available is presented in Chapter 5.

2.7.2 Availability of comparable data on carers of non-elderly people

As noted in Chapter 1, demographic ageing is one of the key drivers behind current research and policy interest in informal and family care-giving. The study team therefore found it particularly difficult to obtain comparable data on carers of non-

elderly people. Expert informants in five case study countries (Austria, Belgium, England, Italy, and the Netherlands) were asked to provide data on carers of non-elderly people, who provided at least 20 hours per week care. The extent to which expert informants were able to provide such information varied. Their sources of data used different definitions and different minimum thresholds of the hours of care provided to identify informal carers. National-level data were not always available and there was some reliance on small-scale surveys in some countries. Moreover, definitions of ‘heavily burdened’ carers differed between countries and available data sometimes also varied according to the age or other characteristics of the care recipient.

Consequently, the data presented in Chapter 4 are far from comparable. Furthermore, some studies that were **not** specifically on carers of older people did not specify the age or other characteristics of the person receiving care. Consequently there was some overlap between data provided by the expert informants and that available from the Eurofamcare study (Chapter 3). We have attempted to distinguish between the evidence on the carers of older and non-elderly people; Chapter 4 therefore presents an overview of the prevalence, burden and socio-economic impact of caring on carers of non-elderly people that draws only on data that was not presented in Chapter 3; however, given the limitations of the available data, some overlap was unavoidable.

We also found apparent gaps in both national and EU-level data on specific groups of carers of non-elderly people, including parents caring for a disabled dependent or adult child; carers of people with severe mental health problems; and younger adults caring for siblings or spouses. These are significant shortcomings, as these are all groups who are likely to experience major, long-term tensions between care obligations and labour market participation and who are therefore at very high risk of social exclusion. Moreover, appropriate policy measures will be different for, say, parents caring for a severely disabled child; people caring for disabled working-age partners; and young carers (Becker and Becker, 2008).

2.8 Summary and conclusions

- There appears to be no consistent or comparable definition of ‘informal and family carer’ used by government and academic researchers in different countries. In this study, a carer was defined as somebody ‘who provides help to someone with a chronic illness, disability or other long-term health or support need, outside a professional or formal framework’.
- Commonly used criteria for identifying **additional** care responsibilities arising from illness, disability or age include the time spent each week and/or the duration of such activities, but these are often not the same between countries. In

some countries, numbers of carers are estimated from numbers of older people or from data on disability service or benefit recipients.

- The most widely-available data is on carers of older people, or people caring for elderly parents. There is a particular shortage of robust national or cross-national data on people caring for other groups of disabled people. Some national studies do not distinguish between carers of older people and carers of other groups.
- There are also no consistent criteria for identifying carers with the heaviest care-giving obligations, or those at most risk of adverse socio-economic disadvantage. Indicators of heavy care-giving burdens are widely used as outcome measures, not as analytic variables that allow a focus on the consequences of 'heavy care burdens'.
- Quantitative evidence on the socio-economic impact of heavy or intensive care-giving was also often not available. Even where associations between heavy care-giving responsibilities and adverse socio-economic circumstances can be demonstrated, clear causal relationships are rarely established.
- Research estimating the prevalence of informal care across the EU needs to specify a minimum number of hours per week spent caring, in order to exclude very light family responsibilities. Research also needs to specify clearly the member states from which estimates have been derived, and the assumptions used to extrapolate current EU-wide prevalence rates from a subset of member states.
- While there are extensive innovations in measures to support carers, there is a dearth of robust evaluation evidence on their impact and cost-effectiveness. Moreover, where multi-faceted interventions or support programmes do show positive outcomes, it is not clear which elements of the intervention have contributed to these benefits or the circumstances in which they can be replicated.

Chapter 3 **Prevalence, Burden and Socio-economic Impacts: Carers of Older People: Evidence from the Eurofamcare Study**

3.1 Introduction

This study has drawn on the groundbreaking Eurofamcare study as one of its main sources of information. This FP5 project focused on carers of older people only and consisted of two types of report: National Survey Reports for six countries, which formed the basis for the Trans European Survey Report; and National Background Reports from 23 EU countries, including the six countries covered by the National Survey Reports. The National Background Reports in turn formed the basis of a Pan-European Background Report. The selection of six countries for the National Survey Reports and Trans European Survey report was informed by a model of different welfare state approaches to the care of older people developed by Lamura *et al.* (2007) (see Chapter 5). Of every category of nations (apart from the Baltic states) at least one representative country participated.

The Eurofamcare study is unique in Europe as never before have so many data been gathered concerning family care for older people. This chapter summarises the key findings of the study in relation to the prevalence of care and 'heavily burdened' caregiving; and the socio-economic consequences of care.

First, however, it should be noted that the National Survey Reports and the National Background Reports each use different sources of information on carers:

- In the six National Survey Reports, 6,000 carers (1,000 per country) who cared for at least four hours per week for an elderly person were interviewed in depth. The six countries were Germany, Greece, Italy, Poland, Sweden and United Kingdom. The care recipients were 65 years and older and in need of at least four hours of personal care or support per week (a relatively low threshold, compared to other measures of 'heavily burdened' carers). Sampling in each country was undertaken in at least three different locations, covering both rural and urban areas. In addition, professional care service providers were asked in telephone interviews and/or postal questionnaires, using semi-structured interview guides, about their views and experiences of family care.
- In the 23 National Background Reports, experts were requested to supply information based on available published statistics and evidence. This means that the National Background Reports depended on definitions of carers used by other researchers and on data from different studies. Some of this data was relatively old; sometimes it also covered carers of non-elderly people.

As noted in Chapter 2, there appeared to be no consistent or comparable set of definitions used by governments and researchers in the different countries represented in the Eurofamcare study to help us to identify carers with particularly 'heavy' care obligations, for example in terms of the numbers of hours per week spent caring or the duration of care-giving episodes. Indeed, the criterion used by Eurofamcare to identify carers was very low – a threshold of four hours a week care, which is far from 'heavy' or 'intensive'. We have therefore used other indicators of 'heavy care obligations' which are available from the Eurofamcare study, including:

- reported subjective feelings of burden and well-being and indicators of burden such as depression and elder abuse
- the impact of caring on employment and income.

3.2 Prevalence of carers of older people according to Eurofamcare

3.2.1 EU-wide data

Data on the proportions of people in EU countries caring for older people are not available from the Eurofamcare study. However, Eurofamcare provided a clear picture of the **average** carer of an older person (Triantafillou and Mestheneos, 2006; TEUSURE, 2006):

- seventy-six per cent of main carers of older people were women
- the mean age of carers was 55 years old
- nearly 50 per cent of family carers were children of the older person, 22 per cent were partners/spouses
- forty-eight per cent of carers lived in the same household as the person cared for; 18 per cent lived within walking distance; about 25 per cent of carers lived further away from the care recipient than ten minutes by car or public transport
- many carers cared for 24 hours a week; the average was as high as 45 hours a week
- over two thirds of carers had provided care for more than two years, most often in Poland (74 per cent) and least often in the UK (60 per cent)
- forty-one per cent of carers were also in paid work
- the duration of an episode of caring for an older person was on average five years
- over a third of all carers of older people also cared for a younger person (varying from 60 per cent in Greece to nine per cent in Sweden).

3.2.2 Data from the National Background Reports

Data contained in the National Background Reports were not always restricted just to carers of older people. Some National Background Reports did not include any data about the prevalence of care-giving for older people. The following section summarises the data that were available.

UK

- One in four carers of older people cared for 20 hours a week or more.
- One in ten carers of older people cared for 50 hours a week or more.
- One in five carers cared for at least ten years.
- Forty-five per cent of carers cared for five years or more.
- Fifty-two per cent of all carers of older people cared for their parents(-in-law).

Ireland

- Forty per cent of carers cared for more than 20 hours a week, 27 per cent for more than 50 hours.
- Half of all carers looked after parents(-in-law), 25 per cent cared for a spouse, 25 per cent cared for other relatives, neighbours or friends.

Netherlands

- Standard administrative criteria define carers as those providing care for more than eight hours per week and/or longer than three months. 2.4 million (19 per cent) of the Dutch population older than 18 are carers according to these criteria. 750,000 care for more than eight hours a week and more than three months.
- Forty-four per cent of all carers are middle aged women caring for parents(-in-law).
- Among carers providing 20 hours plus of care a week, care for parents is most common. Twenty hours plus care each week is provided by one in ten carers of parents(-in-law).

Austria

- The criterion for identifying carers is the provision of 15 hours or more care per week. A quarter of carers of older people provided more than 15 hours care per week.
- Data on carers of Long-Term Care Allowance recipients showed that:
 - thirty-eight per cent provide up 20 hours a week care
 - thirty per cent provide 21-40 hours a week care
 - thirty-two per cent provide more than 40 hours a week care.

Italy

- There is no direct or proxy data on the number of carers spending 20 hours plus a week caring. The average number of hours of care provided is 92 per week, which presumably also includes care for children and relatives who are not old, sick or handicapped.
- Eleven per cent of people aged 50 plus cared for an older person.

Poland

- There is no national research on family carers, only regional studies. Estimates are derived from data on the numbers of disabled elderly people.

Czech Republic

- There is no national data on carers. Estimates derived from the number of disabled older people suggest 500,000 carers. No information is available on hours of care they provide each week or the duration of care-giving.

Sweden

- There is no national, representative data on carers; estimates have instead been derived from the numbers of disabled elderly people. There is no information available on hours of weekly care or the duration of care.

Slovenia

- There is no national research on carers. Estimates are derived from the numbers of disabled elderly people.
- One study found that 12 per cent of people aged 65 plus could not care for themselves, nor could 30 per cent of people aged 70-plus and 60 per cent of those aged 80-plus. Of those older people that received help from their relatives, two-thirds received help several times a week and half every day.

3.3 Burden and well-being

3.3.1 Definitions and research methods

As noted in Chapter 2, carer burden is a complex phenomenon. The following qualifications should be borne in mind in relation to Eurofamcare data:

- The data relates to objective indicators of being (over)-burdened, such as quality of life, hours of care delivered, risk of depression, elder abuse and so on. They do not necessarily indicate subjective feelings of being burdened.

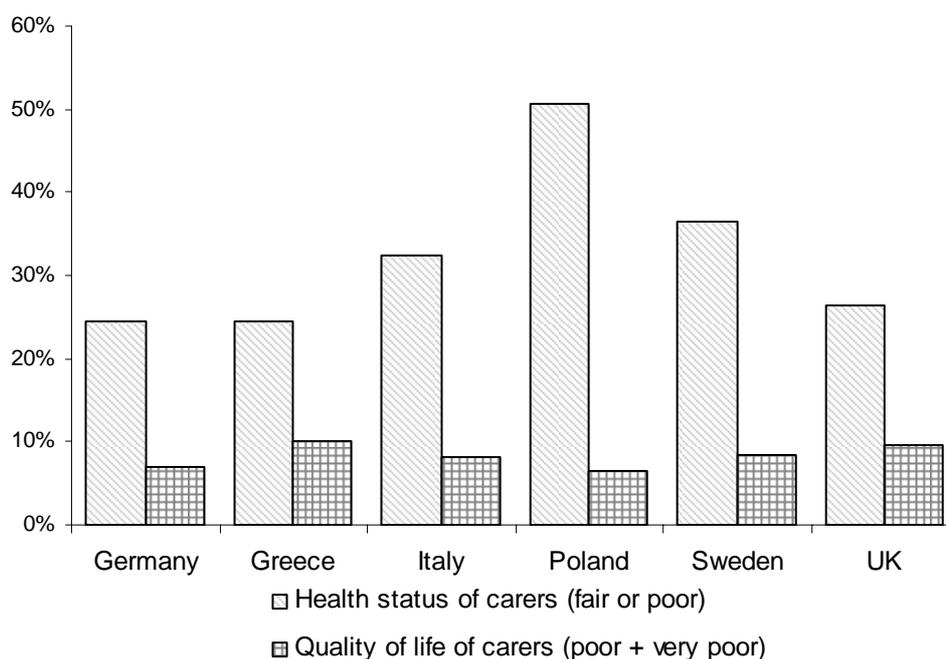
- The National Background Reports from 23 countries and the National Survey Reports from six countries used different measures relating to burden and well-being.
 - The six National Survey Reports made a distinction between objective and subjective burdens. Objective burden was measured by variables such as weekly hours of care and duration of care-giving episodes, co-residence or being a long-distance carer. Subjective burden was assessed by asking carers themselves to rate their own well-being, through:
 - perceived negative and positive aspects of the caring role
 - the COPE scale (McKee *et al.*, 2003), specifically designed to assess carers' perceptions of their caring role and identify needs for support
 - willingness to continue caring
 - carer quality of life, consisting of general health status and perceived quality of life over the previous two weeks.
 - For the 23 National Background Reports, experts were requested to provide information about positive and negative aspects of care-giving. The experts used available statistics and evidence on issues such as the rewarding aspects of care-giving; experienced burden (physical, psychological, social, financial); and indicators like abuse of older people that could be attributed to carers being overburdened.
- A further methodological problem is that data on health and well-being were not compared to other social groups or population norms, thus making it difficult to attribute poor outcomes to the experience of care-giving; other factors that predated the care-giving episode may also have contributed. It was also not possible to attribute these poor outcomes to a particular aspect of the care-giving situation such as the increased risk of poverty, poor quality relationship with the person receiving care, inappropriate housing or the age of the carer.

We summarise the main findings below.

3.3.2 Main findings of Eurofamcare on burden and well-being

3.3.2.1 Prevalence of poor health and well-being

Eurofamcare presents clear evidence on the perceived quality of life and health status of carers of older people.

Figure 3.1 Health status and quality of life of carers of older people

Source: Eurofamcare, 2006

Although an average 80 per cent of carers in the six Eurofamcare National Surveys reported that they coped well even in difficult circumstances, in five of the six countries where the issue was measured in the National Survey Reports, many carers claimed their health status was only fair or poor (see Figure 3.1).

Some ten per cent of carers in the countries participating in the National Surveys reported poor or very poor quality of life. According to the Trans-European Survey Report, the highest quality of life was reported by carers in the UK and Sweden (UK 65 per cent; Sweden 67 per cent). The lowest quality of life was reported by carers in the family-based Mediterranean care cultures (Greece 50 per cent; Italy 51 per cent). Eurofamcare tentatively concluded that the high percentages for Sweden and UK may indicate the positive role of good service support and active public policies to support family carers.

The prevalence of depression and anxiety among carers was also reported in most of the 23 National Background Reports. Indeed, National Background Reports for France and Portugal reported that the prevalence of depression among carers was twice as high as in the rest of the population. Conflicts with spouses or children because of the lack of time for them, and social isolation and feelings of loneliness, were commonly reported. More than half the carers of older people across Europe also reported problems keeping in touch with friends; feeling 'trapped' by their care-giving responsibilities; worse emotional well-being; or said that care-giving was too demanding (Lamura *et al.*, 2007). Carers frequently reported physical health

problems resulting from demanding care activities (lifting, washing/bathing). Older carers especially ran a higher risk of health problems; a 63 per cent higher risk of mortality (Schulz and Beach, 1999) has also been found among those carers experiencing strain. Other frequently reported complaints include loss of energy, sleep deprivation, stress or panic attacks, pain, depression, headaches and weight changes. Carers also reported psychological problems, including poor concentration, feeling anxious, guilty, insecure or depressed.

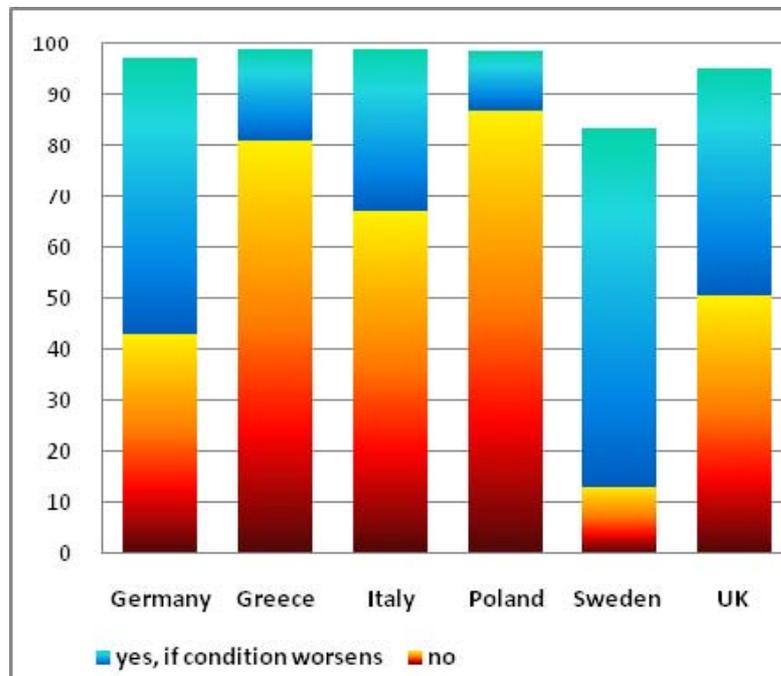
The National Survey Reports also found that in France and Portugal the prevalence of depression among carers was twice as high as in the rest of the population.

Another approach to assessing levels of felt burden in the National Survey Reports was to ask about carers' willingness to continue providing care. However, perceptions of social desirability, the availability of care homes and wider cultural factors are all likely to affect carers' responses to these questions, in addition to their experiences of burden. Altogether, over half (58 per cent of carers) were unwilling to consider placing the older person in a care home, but this figure varied widely between countries. Swedish carers were more willing than others to consider care home placement. In Poland and Greece, carers were barely willing to consider placement at all, under current circumstances (see Figure 3.2a). Overall, almost 61 per cent of carers said they were willing to continue caring unconditionally, even if this meant having to provide more care (Figure 3.3).

In both Germany and Sweden, the proportions of carers willing to consider placement in a care home were lowest, but the unconditional willingness to continue caring was also lowest, compared to the four other countries. The UK took an intermediate position in both issues, whereas in Greece, Italy and Poland the refusal to place in a care home was highest, just as with carers' reported willingness to continue caring.

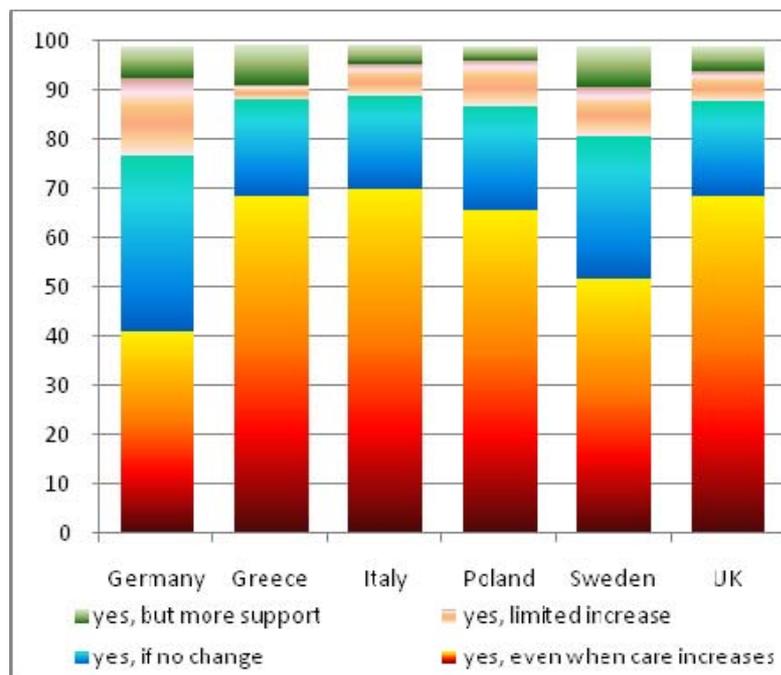
Figure 3.2 Some possible (counter-)indications for burden of care: willingness by carers to either place older person in a care home and willingness to increase care over the next year

Figure 3.2a Willingness to consider placing in a care home



Source: TEUSURE (2006)

Figure 3.2b Willingness to increase care over the next year



Source: TEUSURE (2006)

3.3.2.2 Prevalence of poor health and well-being among women carers

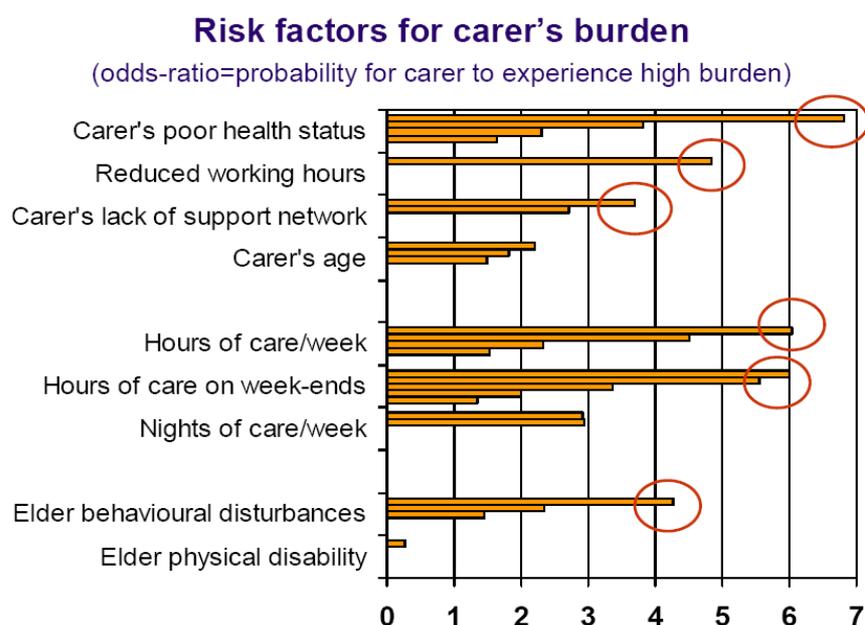
Women predominated amongst 'heavily burdened' carers of older people. On average, two-thirds of carers of older people in the 23 EU countries included in the National Background Reports were female. For example, the conclusion to the Italian Background report states: 'Where data are available for heavy care for the most dependent, the numbers of women rise. For example in Italy women are on average 61 per cent of carers, but 81 per cent of heavy end carers.' (This conclusion was based on the proportion of carers receiving a care allowance.) The criterion of receiving a care allowance as a means of identifying heavily burdened carers showed similar phenomena in other countries: 91 per cent of 'heavily burdened' carers were women in Luxembourg; 83 per cent in Spain; and 81 per cent of carers of terminally ill people in Germany were women. Some countries reported that women carers' feelings of distress were more severe than those of male caregivers.

3.3.2.3 Factors increasing risks of poor health and well-being

Lamura *et al.* (2007) showed that the risks of carer burden increased where carers and people receiving care shared the same household; where high levels of care were provided; when the care recipient had behavioural problems; when carers suffered from depression and low self esteem; where carers and care recipients had been in conflict in the past; and when the carer did not feel supported by social services (Figure 3.3). A reduction in working hours was also a high risk factor predicting carers' feelings of burden; this affected women more than men.

Other risk factors associated with 'heavy burdens' were mentioned, for example the duration of the care-giving episode (Italy, Spain); with weekly hours of care (UK); between the age of the carer and burden (Germany). Evidence was also reported about the relationship between extrinsic motivations to provide care (duty, moral obligation, no alternative available) and subjective feelings of burden (Finland, Netherlands). In many countries, correlations between the type of care needed by the older person and felt burden were found; cognitive impairments and total immobility seemed to be most burdensome. Spouse carers were among the most heavily burdened carers of older people; they were likely to be sole carers and to suffer from health problems themselves.

Figure 3.3 Risk factors predicting carers burden, Eurofamcare¹



Source: Lamura *et al.* (2007)

On the other hand, Eurofamcare data suggested that religion may function as an antidote to negative feelings of depression or anxiety in some countries, such as Malta and Poland. However the impact of religious beliefs was complex, as the findings for Spain showed; religion kept depression at bay for spouse carers, but not for daughters(-in-law) caring for older people. It may be that religion only helps to keep depressive feelings at bay for a generation that is truly convinced of the notion that it is better to give than to receive.

The Trans-European Survey Report also suggested that the relatively high quality of life reported by carers in Sweden and the UK may reflect the impact of services and public policies to support family carers. However, low levels of subjective burden and well-being are not simply related to the existence of supportive policies and services. Expectations of state support that do not materialise can add to feelings of burden, as is alleged to be the case in the Czech Republic where the legacy of state care has led to disappointment among carers of older people.

Variations in preventive factors may also play an important role, as illustrated by the case of Poland, also a country with a legacy of state care. Here, supportive policies are not well developed, but the existence of multi-generation households and a strong religious conviction seemed to function as countervailing factors.

¹ The graph was taken from a PDF version of a presentation. The circles in the graph represent points of interest in the original presentation, not in the course of this report.

3.3.2.4 Consequences of poor health and well-being among carers

The quality of caregiving can risk being impaired as a result of carers feeling overburdened. One possible outcome is thought to be an increased risk of elder abuse. Across the six countries covered by the Eurofamcare National Survey Reports, caring out of a sense of duty, obligation or because there was no alternative were linked to caregiver strain and may therefore represent risk factors for elder abuse (Lamura *et al.*, 2007).

Secondary data on elder abuse in the National Background Reports confirmed the suggested connection between exhausted carers and elder abuse. For example, the report from Slovenia stated that 50 per cent of older relatives were responsible for the abuse of older people and 75 per cent of abuse was caused by exhaustion. Research in Belgium among 523 elderly people showed that one out of five older people had experienced some kind of violence; 60 per cent of reported violence came from family members.

Evidence on elder abuse was limited and its availability varied between countries; it was not always clear that data on the prevalence of elder abuse was restricted to that attributed to informal carers

3.4 Impacts of intensive care for older people on carers' employment and income

3.4.1 Definitions and methods

The Eurofamcare National Background Reports from 23 countries and the National Survey Reports from six countries used different sources of data on carers and employment:

- In the National Survey Reports, 6,000 carers were asked about their employment status. In a follow-up survey a year later, carers were asked to report changes in their employment status due to caring.
- In the National Background Reports, experts drew on available previously published data on:
 - percentages of working and non-working carers
 - reductions in working hours or stopping work altogether
 - impacts of caring on professional careers
 - general population employment rates (by age and gender)
 - retirement ages.

Often, only general rates of employment and retirement ages were available and only very seldom was information about all relevant items provided. Some of the available data was contradictory.

3.4.2 The impact of care-giving on employment

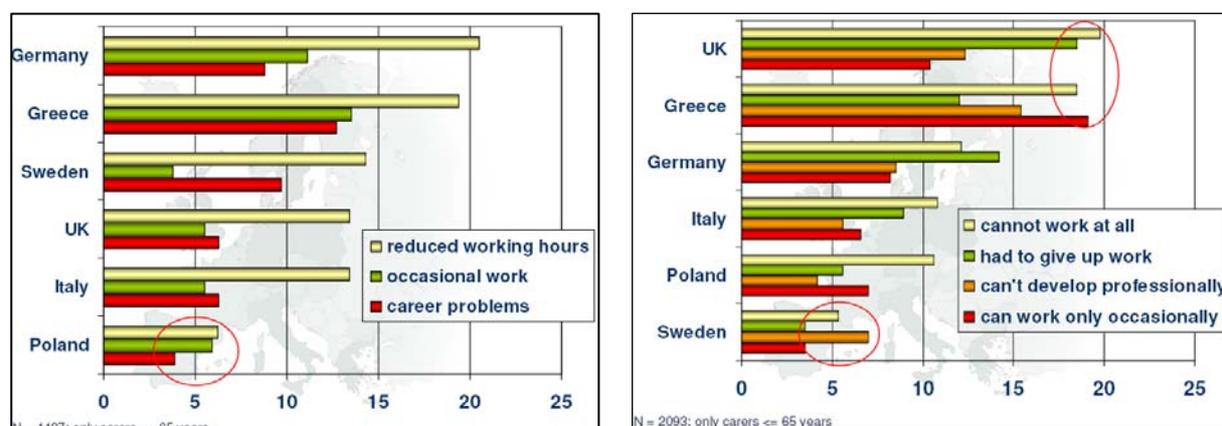
In most countries retired people, housewives, part-time workers (mostly women) and the unemployed are likely to bear the brunt of care-giving for older people. Factors contributing to this situation include both 'push' and 'pull' drivers. For example, high unemployment in Eastern European countries, linked to the transition from communism to a market economy, may have pushed people in the over-50 age group into early retirement. Once retired, it may be hard to resist the 'pull' factor of a relative needing care. State retirement age, unemployment in the 50-plus age group, and the prevalence of part-time work all seem relevant factors in assessing the size of a potential reservoir of people who might be a resource for care-giving, particularly for older people.

Not surprisingly, gender is a key variable in patterns of paid work and caring (see also Chapters 5 and 7). Women are predominant in care-giving in all Eurofamcare studies and are therefore particularly likely to experience adverse impacts on their hours of paid work, their earnings or their ability to continue in paid work at all. The extent of these disadvantages is likely to vary between countries, depending on wider labour market opportunities, particularly for women.

Although people who are retired or unemployed, housewives or part-time workers are most likely to have heavy care responsibilities, nevertheless some carers with heavy care commitments are also in paid work. On average, 41 per cent of carers of older people in 23 EU countries are in employment (Triantafillou and Mestheneos, 2006). Sweden has the lowest percentage, 33 per cent (most carers for older people in Sweden are spouse carers). The highest percentage is Greece, where nearly 47 per cent of carers are in employment.

However, even where carers manage to combine paid work with heavy care obligations, the socio-economic impact of care-giving is still considerable (Lamura *et al.*, 2007). In Germany, UK and Sweden almost one in four carers had reduced their working hours, mainly because of caring for the older person.

Figure 3.4 Restrictions reported by working (left) and non-working (right) carers², as reported by Eurofamcare



Source: Lamura *et al.* (2007)

The Eurofamcare National Survey Reports showed that in most countries noticeable proportions of employed family carers of older people experienced restrictions because of their care-giving responsibilities. In Germany, one in five carers had had to reduce their working hours due to their care responsibilities; ten per cent could only work occasionally; and eight per cent experienced restrictions due to caring that prevented them developing careers or studies. In Greece, in contrast, only ten per cent of working carers reduced their working hours (self-employment often provided flexibility); 20 per cent of carers said they could not develop their careers; and 15 per cent could only work occasionally. In Italy, 13.6 per cent of carers reported reducing their working hours. Of the non-working carers, more than half were retired and 7.3 per cent unemployed; 8.7 per cent reported that it was impossible to do paid work; 8.7 per cent reported having to give up work because of caring; 5.3 per cent could not pursue a career or studies; 4.9 per cent had to opt for occasional jobs only. In the UK, 24 per cent of carers had reduced their working hours a year after the first survey.

Difficulties with the labour market were also reported by non-employed carers of working age, who, because of their care responsibilities, were unable to work at all. Of British carers, 20 per cent had had to give up work; 18 per cent of British and 15 per cent of Greek carers had been unable to advance their careers; and other carers could work only occasionally (19 per cent in Greece). These problems were less widespread among Swedish carers (of whom only a few were not employed) and Polish carers, most of whom were early retired people.

² The graph was taken from a PDF version of a presentation during the 2007 International Gerontological conference in St. Petersburg. The circles in the graph represent points of interest in the original presentation, not in the course of this report.

The six National Survey Reports showed the changes in occupational status among carers of older people one year after the baseline survey of 6,000 family carers. On average, 88 per cent of all working carers in the six countries managed their caring responsibilities without reducing their working hours during the year between the two surveys, but this was especially true for the Polish (95 per cent), Italians and Greeks (both 90 per cent). In other countries, the proportions of those who had restricted their working hours were much higher. In Germany, UK and Sweden almost one in four carers had reduced their working hours mainly because of caring for an elderly person.

A majority of non-working carers (on average 67 per cent) reported having stopped work for other reasons than caring; however it may well be that they took on caring because they were not working. The highest proportion of people reporting having stopped working for reasons other than caring was found in Poland (95 per cent), where the unemployment rate is high (17.5 per cent in 2005) and the proportion of the population that is retired/pensioner is also high (in 2005 almost every fourth Pole was a retiree or a pensioner).

3.4.3 Differences between countries in the impacts of care on employment

In Eastern European and some Southern European countries, there are far fewer opportunities for reduced working hours compared to Nordic and Western-European countries, according to Eurofamcare data. Consequently, in Western European and Nordic countries the proportions of carers who reported reduced working hours were much higher.

It is likely that in Western European and Mediterranean countries carers pay the price of reduced working hours, quitting work, doing occasional jobs only or foregoing career opportunities. In Eastern European countries, reducing working hours is often impossible because of a lack of part-time jobs and of opportunities to (temporarily) reduce working hours. As social services in Eastern Europe are also underdeveloped, Eastern European working carers of older people are more likely to struggle with full-time employment and demanding care responsibilities. However, Eastern European countries are also characterised by low labour market participation and early retirement ages, especially for women, so there is a reservoir of potential carers. An exception is Slovenia, which resembles Portugal in having high employment rates for both men and women.

In contrast, Nordic countries are characterised by high employment rates of men and women and late retirement ages, so there is no reserve reservoir of potential carers. There is also less need for such a reservoir because public services provide most care and support for older people; the clearest example of this pattern is in Denmark. However, this distinctive Nordic picture may be diminishing as rapid population

ageing means that professional help is no longer provided so generously and more demands are made on carers (Johansson, 2004).

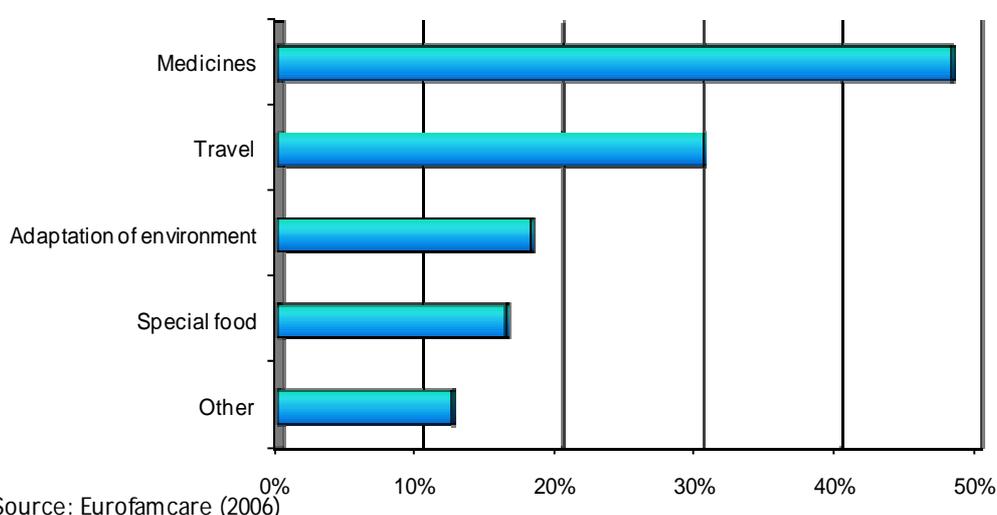
Most Western European countries have opportunities for part-time work and a relatively low retirement age, although this is beginning to change as a result of policies to stimulate longer working lives. The availability of part-time work and direct support services for carers may help carers to combine caring and employment, although no hard evidence on these issues is available. In these countries, the economic impact of caring takes the form of reduced working hours, reduced earnings and social protection benefits and foregone career opportunities.

The Mediterranean countries (often described as family based) are characterised by relatively low labour market participation, especially among women. Women often work part-time and/or leave the labour market when they have young children. In their fifties they become prime candidates for caring for older people. The clearest examples are Spain and Malta. An exception is Portugal, which has high employment rates for both men and women and full-time work is the norm for both sexes. In this respect, Portugal resembles the pattern of the Eastern European countries.

3.4.4 The impact of care-giving on carers' incomes

The impact of caring on carers' incomes can be deduced from the data on the restrictions on carers' labour market participation. Carers also reported financial problems caused by caring: the cost of medicines, extra travel, telephone, heating, (out of pocket) payments for health care, and loss of (delayed) income if carers could not combine work and care (Tjadens *et al.*, 2008).

Figure 3.5 Percentage of carers with additional costs due to caring for an elderly person



3.5 Summary and conclusions

3.5.1 Limitations of the data in identifying the effects of intensive care-giving for older people

In the most recent European research project, Eurofamcare, it was not possible to find direct pan-European, quantitative evidence on the socio-economic consequences of care-giving among those carers carrying the heaviest burdens of care. Whatever the indicator used (number of hours per week spent on caring, combining working and care, self-reported burden), there was no data available on the consequences for carers with lesser or greater care responsibilities. Neither was it possible to find data linked to time use or the type of caring activities as potential indicators of (objective) burdens of care that could be used to assess their socio-economic impacts.

Like other research, Eurofamcare tends to focus on carers in general and from these identifies the proportions of carers who spend more than a certain amount of hours each week/month in care-giving, or who combine paid work and care, or who perceive themselves to be heavily burdened. In other words, carers with the heaviest burdens are identified as a dependent variable; we have been unable to find research which treats heavily burdened carers as the independent variable. Moreover, definitions and experiences of 'heavy burden' are often related to welfare regimes and used as an outcome measure rather than as an independent variable.

A further methodological issue is that responses to questions about subjective burden and well-being may be influenced by the way questions are phrased. Positively formulated questions like 'Do you think you cope well as a carer?' or 'Are you willing to continue care-giving?' may invite more positive responses than questions about the negative aspects of the caring role.

The order in which positive and negative questions are asked may also influence responses. It is not always clear how this issue has been tackled in the published research and, therefore, how far it should be taken into account in interpreting the findings.

3.5.2 Summary of key findings on carers of older people

Many countries do not have data on the prevalence of care-giving for older people. It is also difficult to identify 'heavily burdened' carers of older people, 'burden' is rarely used as an independent variable. Many countries, particularly from Eastern and Southern European and Nordic countries, lack data on carers' employment and incomes.

3.5.2.1 Who are carers of older people?

- Carers with the heaviest responsibilities for supporting older people are more likely to be women.
- Carers are often in their fifties or older.
- Carers are predominantly (early) retired people, unemployed people, housewives or part-time workers.
- Carers of older people are most likely to be their children or spouses; half of all carers share the same household as the older person.
- The European average number of hours spent caring for an older person is 45 hours per week, but with big variations between countries. Care-giving for more than 20 hours per week is likely to risk negative impacts on carers' employment.
- The average duration of a period of care-giving for an older person is five years.
- A third of carers of older people also care for another person.
- In the National Survey Reports for five of the six countries, many carers claimed their health status was only fair or poor.

3.5.2.2 Indicators of care burdens and their consequences

- More than half the carers of older people across Europe reported difficulties keeping in touch with friends, felt 'trapped' by their care-giving responsibilities, reported worse emotional well-being or said care-giving was too demanding. However, 80 per cent of carers said they coped well.
- Nevertheless, depression and anxiety among carers were reported by large proportions of carers in the National Background Reports from 23 EU countries. In France and Portugal it was reported that the prevalence of depression among carers was twice as high as in the rest of the population. Conflicts with spouses or children because of the lack of time for them, and social isolation and feelings of loneliness, were commonly reported.
- Religion may function as an antidote to feelings of depression or anxiety in some countries.
- The quality of care-giving may be impaired as a result of carers feeling overburdened and several National Background Reports linked excessive burdens on carers to an increased risk of abuse of older people.
- Caring out of duty, obligation and lack of perceived alternatives may increase carers' felt stress and experience of burden and thereby increase risks of elder abuse.
- Factors relating to the care-giving situation that appear related to carers' felt burdens include cognitive impairments and the total immobility of the older person. Spouse caring is also linked with high levels of felt burden; felt burdens

also increase with the duration of the care-giving episode and the number of hours spent caring each week.

- The highest quality of life is reported by carers in the UK and Sweden (UK 65 per cent, Sweden 67 per cent). Poland and Germany occupy intermediate positions. The lowest quality of life was reported by carers in the family-based Mediterranean care cultures.
- The relationship between burden and well-being on the one hand and the existence of support policies on the other is not straightforward. Higher than average quality of life reported by carers in the UK and Sweden may reflect public policies and services to support carers. However, expectations of support that do not materialise can add to feelings of burden.
- Although people caring for an elderly spouse are likely to have already retired, they are much more likely than other carers to suffer from health problems and chronic conditions themselves.

3.5.2.3 Financial consequences of care

- According to Eurofamcare estimates, 41 per cent of carers of older people in 23 EU countries were employed.
- However, on average 88 per cent of all working carers in the six countries in the National Survey Reports struggled with caring responsibilities without reducing their working hours. Variations between countries in reported difficulties were likely to reflect inter-country differences in opportunities for part-time work and the availability of services for carers that would help them combine caring and employment.
- In addition to lost or reduced incomes, carers also reported additional financial costs of caring, including paying for medicines, extra travel, telephone, heating, and (out of pocket) payments for health care for the older person.

Chapter 4 Prevalence, Burden and Socio-economic Impact: Carers of Non-older People in Five Selected Countries

4.1 Introduction

In contrast to the previous chapter, which concentrated on carers of the elderly, this chapter aims to focus on the provision of informal care for non-elderly people in five European countries: Austria, Belgium, England, Italy and the Netherlands. As explained in Chapter 1, these countries were selected because the study team anticipated that relevant national data would be available and because of the availability of expert informants who could access, collate and, where necessary, translate data for this study. The groups of carers under examination in this chapter include carers of working age adults, parent carers of disabled children and young carers under the age of 18. Given the locations of the study team, the study was able to draw on additional sources of data on young carers and parents caring for disabled children in England/UK and the Netherlands. We have tried as far as possible to focus on carers of non-elderly people who are providing 20 or more hours of care per week, as a minimum threshold for identifying carers who are ‘heavily burdened’.

A number of caveats are in order. As noted in Chapters 1 and 2, most data on informal carers focus on carers of older people. Of the remainder, much of the data we were able to obtain on carers in the five member states reported here do not differentiate between carers of older people and carers of other groups. Neither do the data always distinguish between carers in terms of hours of care or levels of involvement. Consequently, some of the data reported in this chapter may relate to carers of all people of all age groups (including older people) and/or carers who would not necessarily be described as ‘heavily burdened’. Consequently, there may be areas of overlap or duplication between the data presented here and that reported in Chapter 3. For purposes of clarification, every effort has been made to indicate exactly which group of carers the data presented below relates to. Finally, because different data sources tend to use different definitions of ‘carer’ and also categorise carers’ levels of involvement in different time bands, the country-specific data presented here are not easily comparable.

4.2 Data sources

Expert informants provided the research team with relevant data on carers of non-elderly people in Austria, Belgium, England, Italy and the Netherlands.

Austria

Data relating to unpaid informal carers supporting all age groups in Austria was derived from three sources:

- Information was extracted from national datasets on beneficiaries of the federal Long-Term Care (LTC) Allowance, a welfare benefit awarded to individuals assessed as requiring at least 50 hours of care per month due to a physical, mental or psychiatric disability or sensory impairment. The benefit is paid at one of seven levels, and is determined by a medical assessment of the applicant's monthly care needs. Whilst about 400,000 people receive the allowance, only about ten per cent are under the age of 60 (Petzl, 2003: 250). Taking into account only those who receive levels 2-7 (that is, more than 75 hours of assessed care needs per month), this figure is further reduced to about 320,000 people.
- A survey of 1,151 relatives caring for recipients of the LTC Allowance (Pochobradsky *et al.*, 2005). However, as almost 90 per cent of LTC beneficiaries are aged above 60, carer respondents were very likely to be looking after older people.
- A micro-census survey conducted in 2002/2003, which provided nation-wide data on individuals caring for frail, disabled or chronically ill relatives of all ages (Kytir and Schrittwieser, 2003). Whilst the survey covered carers of all people of all age-groups, the level or extent of care was not specified. This means it is likely that the survey included respondents who provided relatively minor levels of assistance as well as intensive care-giving.

Belgium

Data about carers in Belgium came from two sources:

- The tenth wave (2001) of the Panel Study of Belgian Households, which contains a number of questions about informal care provided for people of all ages who are ill, disabled or elderly. These data were originally reported in the Eurofamcare National Background Report for Belgium (Declercq and Van Audenhove, 2004).
- A postal survey on 'Informal care in Flanders' conducted in 2003 by the Population and Family Study Centre, as part of a wider study on care-related issues in Flanders (PFSC, 2003). Questionnaires were sent to a representative sample of people aged 25 to 79 who were registered by the Flemish care insurance scheme as informal carers of a severely disabled person, living at home and in receipt of a care allowance. To be eligible for an allowance, the care recipient has to have a long-term and severely reduced ability to care for themselves. Registered carers have to provide help for at least three days a week (alone or together with other informal carers). The survey response

provided usable information on 2,685 caregivers. The original dataset contained no information on the age of the care recipients. For the purposes of our present study, a sub-sample of substantially-involved carers (that is, people caring for 20-plus hours per week) was selected which, based on the age of the care-giver and the relationship between carer and care recipient, is likely to comprise carers of people of working age (n=346).

England

- Data from England was drawn primarily from population-based sources, including the 2001 Census, the General Household Survey and the British Household Panel Survey. However, these data relate variously to England alone, England and Wales, the UK or Great Britain which makes comparisons difficult. Where appropriate, geographical coverage is explicitly stated below. Generally, these datasets do not distinguish between carers of older people and other groups of carers. However, Pickard's (2008) analysis of the General Household Survey 2000/01 is exceptional in that it focuses exclusively on informal care for younger adults, that is, people aged 18 to 64 years, in England provided by adult carers (aged 16 and over). Furthermore, Pickard's analysis distinguishes different levels of involvement of care-giving (that is, all carers and carers providing 20 hours a week or more care).
- Other data sources on all groups of carers (that is, including carers of older as well as younger disabled people) include large scale surveys conducted by, or on behalf of, Carers UK, a large national carers organisation.

Italy

- In Italy, caring is considered traditionally to be a duty of the family (Zanobini, Manetti and Usai, 2002; CISF, 2007; Melchiorre *et al.*, 2001). However, there is no national survey data in Italy on relatives or friends caring for non-older people for at least 20 hours per week. For the purposes of this study, data on Italian carers – of people both below and above 65 years of age – was obtained from various reports produced by the Italian National Institute of Statistics (ISTAT).
- In Italy, information systems on disability are rather fragmented and incomplete. Only recently, has the 'Disabilitaincifre' project begun to collect systematic data on the numbers of disabled people; the types of disability; and the needs of disabled people and their carers from sources that are scattered across many different administrative and scientific sources (www.disabilitaincifre.it).

Netherlands

- Information about Dutch carers was taken from two large-scale surveys of informal care by the Social and Cultural Planning Office of the Netherlands (de Boer *et al.*, 2003; de Boer *et al.*, 2009). The data reported in this chapter is taken from the 2001 survey and concentrates on individuals with 'heavy' care-giving responsibilities, defined as people who provide care for a minimum of eight hours per week **and/or** have been caring for more than three months (de Boer *et al.*, 2003). These criteria are a relatively low threshold for identifying 'heavily burdened' carers, but are consistent with eligibility criteria for the Dutch long-term care insurance scheme. These criteria are also not necessarily applicable to carers whose situations are documented in the latest 2009 report (de Boer *et al.*, 2009). The sample (n=2485) for this latter survey was accessed from a larger group of respondents taking part in the (2007) Labour Force Survey (LFS) conducted by Statistics Netherlands. The minimum age for the LFS survey is 18 years, which means that the data will not include information about children and young people under the age of 18 with care-giving responsibilities. The data from both surveys are based on carers supporting people of all age groups; in neither case was it possible to extract figures specifically relating to carers of non-older people.

4.3 Prevalence data on carers

There are conflicting estimates of the number of carers in **Austria**. Percentage distributions from national survey data indicate there are between 352,500 carers (Pochobradsky *et al.*, 2005) and 425,900 carers (Kytir and Schrittwieser, 2003) of people of all ages. The expert informant from Austria suggests that the number of carers looking after people of working age for 20 or more hours per week is likely to be around 50 per cent of carers of people of all ages, that is, between 176,000 and 213,000 people. However, this figure is likely to be an over-estimate of the numbers of heavily involved carers, as it is based on the hours of assessed care needed by the disabled person, rather than the actual care provided, which is likely to be less. For instance, it is known from the micro-census data that three-quarters of carers taking part in that survey provided less than 15 hours of care per week (Kytir and Schrittwieser, 2003; Hörl, 2005).

The Italian National Institute of Statistics estimates that in **Italy** there are approximately 529,000 disabled people between the ages of six and 64 living in the community (ISTAT, 2008). Given that caring is traditionally considered a family responsibility, and that it can be assumed that data on family members of disabled people are a reasonable proxy of information about care-givers in Italy, then it can be estimated that there are about 529,000 carers (with different levels of involvement) of non-older people in Italy.

National-level data indicate that in the **Netherlands** in 2001 there were 3.7 million carers (out of a total population of about 16 million) (de Boer *et al.*, 2003). Of these, 2.4 million people provided care for more than eight hours per week **and/or** had been caring for more than three months (thus defined for present purposes as 'heavily involved'). Some 750,000 carers provided care for more than eight hours per week **and** had done so for more than three months. Some 1.3 million carers looked after people under the age of 55 years.

As far as carers in England are concerned, analysis of data from the 2001 Census shows that there were 5.2 million carers of people of all ages in **England** and **Wales**, including over one million providing care for more than 50 hours per week (National Statistics Online, 2003). Analysis of the 2000/01 General Household Survey data shows that in **England** 4.4 per cent (about 1,615,000) of people aged 16 and over provide informal care to a sick or disabled person aged 18 to 64 years (Pickard, 2008: Table 1). Of these, 1.6 per cent (590,000) care for 20 or more hours a week.

According to the Panel Study of Belgian Households, 5.89 per cent of the **Belgian** population above the age of 16 were informal carers for someone of any age who was ill, disabled or elderly in 2001 (PSBH, wave 10, reported in Declercq and Van Audenhove, 2004).

4.3.1 Age of carer

The two data sources for **Austria** both indicate that just under 30 per cent of carers are in the age group 60 to 74 years (Pochobradsky *et al.*, 2005; Kytir and Schrittwieser, 2003). However, the findings diverge in relation to carers aged 75 years and over. Pochobradsky *et al.*'s (2005) survey of relatives caring for beneficiaries of the federal LTC Allowance (the majority of whom are older people) estimated this group comprised 14 per cent of all carers, compared with 19.7 per cent in the micro-census survey of carers of people of all ages (Kytir and Schrittwieser, 2003). The figures for carers in the age range 45 to 59 years were equally dissimilar: 37.6 per cent (Pochobradsky *et al.*, 2005) compared with 31.3 per cent (Kytir and Schrittwieser, 2003). According to Pochobradsky *et al.* (2005), the median age of female carers is 57.8 years, while male carers have a median age of 60.5 years.

In **Belgium**, over one-quarter of carers looking after people of all ages who were ill, disabled or elderly in 2001 were aged 66 years and above; over 50 per cent of carers were in the age range 46 to 65 years (PSBH, wave 10, reported in Declercq and Van Audenhove, 2004). In comparison, just ten per cent of carers registered by the Flemish care insurance scheme as looking after a disabled person of working age were in the age range 65 to 79 years; just over 70 per cent of carers were aged 45 to 64 years (PFSC, 2003).

In the **Netherlands**, in 2001 49 per cent of 'heavily involved' (according to the Dutch criteria) carers of people of all age groups were aged 35-65 years, with 17 per cent aged between 55 and 65 (de Boer *et al.*, 2003).

Census data for **England** and **Wales** shows that the age group with the largest proportion of people providing care to people of all ages is people aged 50-59 (National Statistics Online, 2003); more than one in five people aged 50-59 years provide some unpaid care. Pickard (2008) has used General Household Survey 2000/01 data to look at the probability of providing care to younger adults (18 to 64 years) in England. Her analysis suggests that 2.7 per cent of people aged 45-64 provide care for a younger disabled adult for 20 and above hours per week, compared to 1.3 per cent of people aged 65-84 years and 1.1 per cent of people aged 16-44 years.

Data on the age distribution of carers in **Italy** is not available.

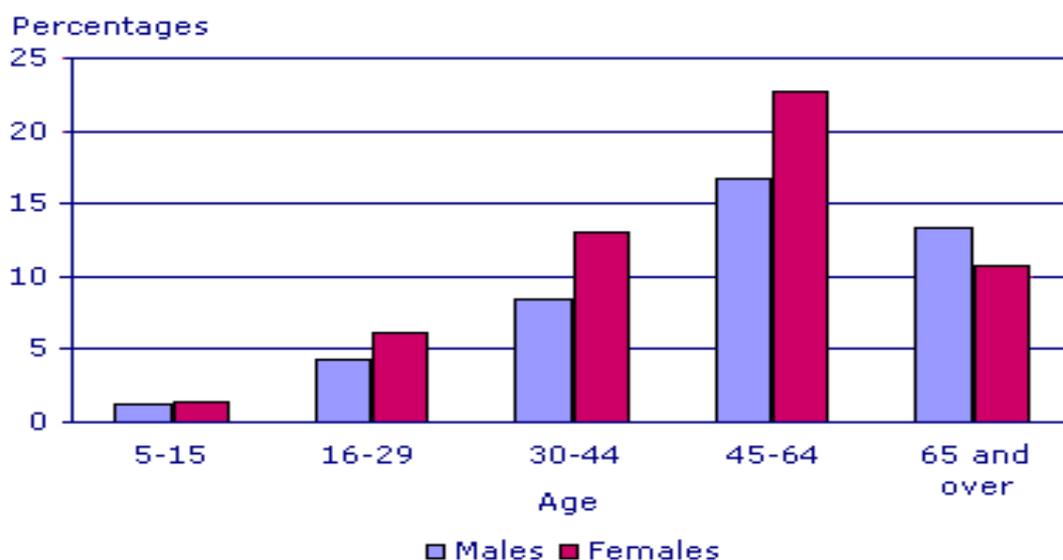
4.3.2 Gender of carers

Throughout each of the five countries under focus, informal carers caring for people of all ages are predominantly female. For example, in **Austria**, the proportion of female carers of people of all ages is reported to range from approximately 66 per cent (Kytir and Schrittwieser, 2003) to nearly 80 per cent (Pochobradsky *et al.*, 2005).

Similarly, nearly 70 per cent of **Belgian** carers of people of all ages are female (PSBH, wave 10, reported in Declercq and Van Audenhove, 2004); the equivalent figure is slightly lower, at 67 per cent, for carers of working age people taking part in the 2003 survey of carers registered by the Flemish care Insurance scheme (PFSC, 2003).

Analysis of Census 2001 data for **England** and **Wales** shows that a greater proportion of women than men are carers for people of all ages (see Figure 4.1 below). About one in four (25 per cent) women in their fifties provide care compared with 18 per cent of men (National Statistics Online, 2003). The pattern changes in later life, where men are more likely than women to be carers among those aged 65 and over.

Figure 4.1 Carers of people of all ages by age and sex, England and Wales



Source: 2001 Census

Although the majority of ('heavily involved') carers for people of all ages in the **Netherlands** is female, the proportion is lower than in other countries at 58 per cent (de Boer *et al.*, 2003).

Data showing the breakdown of male and female carers in **Italy** is not available. However our expert informant reported that most care-giving is undertaken by family members, typically females.

4.3.3 Relationship of carer to main care recipient

In **Austria**, Pochobradsky *et al.*'s (2005) survey of carers of beneficiaries of the LTC Allowance showed that the majority (just over 41 per cent) of care-givers were spouses or partners, followed by adult children(-in-law) (nearly 32 per cent) and then siblings (11 per cent). Not surprisingly, given that the most recipients of the LTC Allowance are over the age of 60, parents comprised less than six per cent of carers.

In **Belgium**, the Flemish care insurance scheme survey found that 54 per cent of carers of people of working age were the spouse/partner of the care recipient, and 29 per cent of carers were the child of the person cared for (PFSC, 2003).

In **England**, Pickard's (2008) analysis of 2000/01 General Household Survey data found that the largest single group of carers of people aged 18 to 64 providing care for more than 20 hours per week are spouses or partners (60.4 per cent). They are followed by children of the disabled person (19 per cent), parents(-in-law) (11.9 per cent) and 'others', including siblings (8.7 per cent).

This pattern differs in **Italy**. Drawing on figures for the living arrangements for disabled people aged between six and 64 years, we can surmise that the largest group of Italian carers of people of this age group are the parents of disabled adult children, followed by the adult children of working age care recipients and partners of the disabled person (ISTAT, 2008). Close relatives are reported to provide care to over half the disabled people under 65 years of age who live alone; a further 25 per cent receive care from friends, neighbours and other acquaintances (ISTAT, 2003).

In the **Netherlands**, the majority of all ('heavily involved') carers look after a parent or parent-in-law (de Boer *et al.*, 2003).

4.4 Burden and well-being

This section looks at the prevalence and consequences of 'heavily burdened' care-giving. A number of proxy indicators of 'heavy burden' are used in the various data sets: co-residence with the care recipient, the amount of time spent caring, the duration of the caring relationship, the type of care provided, and whether the carer looks after more than one person.

4.4.1 Co-resident carers

In **Italy**, approximately 92 per cent of disabled people between the ages of six and 64 live with other people (ISTAT, 2008). The overwhelming majority of household residents are family members and, given cultural expectations in Italy about family obligations in relation to the provision of care, it is reasonable to assume that the majority of co-resident relatives take on a care-giving role. Only 3.9 per cent of disabled people under the age of 45 live alone. This figure increases to 12 per cent of those aged 45-64, largely due to the mortality of parent carers.

The figure for co-resident carers is also relatively high for carers in **Belgium**. In the Flanders study of carers of people of working age, 88 per cent of carers lived with the person they cared for (PFSC, 2003).

The study of carers of beneficiaries of the LTC Allowance in **Austria** (who are primarily older people) showed that about two-thirds of carers live in the same dwelling as the person they look after; about 20 per cent of carers can reach the residence of the older or disabled person within 15 minutes; and the remaining ten per cent would take about 30 minutes (Pochobradsky *et al.*, 2005).

Pickard's (2008) analysis of the General Household Survey 2001/02 data shows that in **England** some 56 per cent (925,000) of all adult carers of people aged 18 to 64 live with the person they care for. Of those carers of working-age adults who care for

a minimum of 20 hours per week, 87 per cent (510,000) are co-resident. These figures are higher than the equivalent figures relating to carers of care recipients of all ages (Maher and Green, 2002). Pickard (2008) argues that:

the relatively high proportion of spouse carers among those caring for younger adults helps to explain the relatively high proportion of co-resident carers, since all but a few spouses/partners are co-resident with the care-giver (Pickard, 2008: 4)

By contrast, it is reported that 20 per cent of ('heavily involved') carers of people all ages in the **Netherlands** are co-resident with the person they care for (de Boer *et al.*, 2003). Of this group, 14 per cent look after their partner; two per cent look after their child; and three per cent look after other family members (parents, siblings). The other 80 per cent of carers take care of someone living in a separate household, including 44 per cent who care for parents(-in-law) and 12 per cent who care for a friend.

4.4.2 Time spent caring

According to the micro-census data documenting carers in **Austria** of frail, disabled or chronically ill relatives of all ages, only one-quarter provide care for 15 or more hours per week (Kytir and Schrittwieser, 2003). Pochobradsky *et al.* (2005) showed that, as one might expect, the higher the level of assessed care needs for recipients (mainly older people) of the LTC Allowance, the more intensive will be the amount of care provided. To give an example, only 42.7 per cent of carers of beneficiaries of care levels 1-3 of LTC Allowance provided 24-hour care, but this figure increased to 69.7 per cent for carers of those in receipt of the four higher levels (4-7) of LTC Allowance.

Analysis of the tenth wave of the Panel Study of Belgian Households showed that on average, carers of people of all ages in **Belgium** spend 17.5 hours per week on caring tasks, with a minimum of one hour and a maximum of 99 hours per week (PSBH, wave 10, reported in Declercq and Van Audenhove, 2004). Over one-third (34 per cent) of all carers of people of working age in the Flanders study reported caring for more than 90 hours per week. This is the largest single time band of amount of care provided, followed by those who cared for 20-29 hours (21 per cent).

By comparison, data from the 2001 Census for **England** and **Wales** shows that 68 per cent of carers of people of all age groups care for up to 20 hours per week, 11 per cent care for 20-49 hours per week, and 21 per cent (over one in five carers, 1.09 million carers) provide care for more than 50 hours per week (ONS, 2003).

In 2001 carers meeting the relatively low **Netherlands** threshold of 'heavily involved' carers of people of all age groups cared for an average of 19 hours per week (de Boer *et al.*, 2003). Working carers provided an average of 15 hours of care per week, and non-working carers provided an average of 25 hours of care. The 2009 report (de Boer *et al.*, 2009) differentiates the amount of care provided according to relationship between the carer and the care recipient:

- caring for spouse/partner: average 45 hours per week
- caring for (disabled) child(ren): average 37 hours per week
- caring for parent(s-in-law): average 16 hours per week
- caring for another family member: average ten hours per week.

We were unable to obtain any data on time spent caring for **Italy** that would have allowed us to identify the proportions or numbers of carers who spent substantial amounts of time each week providing care for non-elderly care recipients.

4.4.3 Duration of caring relationship

The burdens experienced by carers may be expected to increase the longer the duration of the care-giving relationship; over time, carers are likely to be at increased risk of stress, loss of paid work and social exclusion. Although some data was available from the five selected countries on the duration of the current care-giving relationship, this does not necessarily imply that care has been provided at the same intensity over that period. For at least some carers, the demands of care-giving are likely to have increased as, for example, spouses with degenerative conditions deteriorate. On the other hand, data on the duration of care-giving relationships is unlikely to capture the experiences of people who provide care for a succession of different people over time and who therefore experience a very long period as a carer, overall.

Analysis of the General Household Survey 2000 showed that in **Great Britain** one in five (21 per cent) of carers of people of all ages had provided care at some level for a relative or friend for at least ten years (Maher and Green, 2002). Nearly half (45 per cent) of all carers had been in a caring role for five years or more. Of carers looking after someone in the same household, 27 per cent had cared for that person for at least ten years, compared with 19 per cent of those looking after someone in a separate household.

In **Belgium**, the Flanders study of carers of people of working age showed that 14 per cent of carers had been caring for between 15 and 24 years; another 14 per cent had undertaken care-giving responsibilities for between 25 and 34 years; and 18 per cent had cared for five to nine years. The largest number of carers (33 per cent) had been caring for less than four years.

The latest report (de Boer *et al.*, 2009) from the **Netherlands** distinguishes between the length of time carers of people of all age groups spent care-giving by the relationship between the carer and the care recipient:

- caring for spouse/partner: average duration just over five (5.1) years
- caring for (disabled) child(ren): often more than nine years
- caring for parent(s-in-law): average duration five years
- caring for another family member: average duration almost four years.

According to our expert informants, data on the duration of caring relationships was not available in either **Austria** or **Italy**.

4.4.4 Care-giving activities

Care-giving can cover a wide range of activities. Personal care tasks such as bathing, dressing and toileting are more likely to be experienced as 'burdensome' than providing help with practical activities of daily living alone. On this basis, personal care is more likely to be related to intensive care-giving.

Carers of recipients of LTC Allowance levels 4 to 7 in **Austria** (mainly older people) were most commonly responsible for practical activities (Pochobradsky *et al.*, 2005). For example, over 90 per cent of carers helped with activities such as shopping, laundry, cleaning and food preparation. Slightly under 90 per cent of carers assisted with personal care such as dressing and washing, and administering medication; just under three-quarters of all carers (73.3 per cent) helped with toileting and incontinence.

In **Flanders**, carers of working age adults provided three main types of assistance (PFSC, 2003). In terms of socio-emotional help, these included: being present (95 per cent); supporting in case of distress (90 per cent) and providing transport or company (90-92 per cent). Help with practical activities involved cooking/preparing dishes (95 per cent); running errands (94 per cent); laundry (89 per cent); paperwork/administration (88 per cent); cleaning (87 per cent); and looking after pets (51 per cent). Carers were less likely to provide help with personal care, including supervision of medication (88 per cent); bathing (81 per cent); and toileting (68 per cent). Likewise, data from the tenth wave of the Panel Study of Belgian Households confirmed that Belgian carers of people of all ages who were ill, disabled or elderly provided both practical and personal care; the most common activity reported by over three-quarters (76.25 per cent) of carers was listening to stories and complaints (PSBH, wave 10, reported in Declercq and Van Audenhove, 2004).

The data from the General Household Survey 2000 shows that in **Great Britain** over two-thirds (71 per cent) of carers of people of all age groups provide practical

assistance such as shopping, preparing food and laundry (Maher and Green, 2002). Some 60 per cent of carers supervised or kept an eye on the person they were caring for and 55 per cent provided company. Just 26 per cent of carers assisted with personal care such as washing; 22 per cent administered medication; some 35 per cent of carers gave physical help, for instance with walking or getting in and out of bed.

Table 4.1 below sheds light on the type of care provided by carers of people of all ages in different care-giving situations in the **Netherlands** (de Boer *et al.*, 2009). The kind of care provided varies, depending on the social relationship between the carer and care recipient. The differences are smallest for emotional support/supervision and 'accompanying on visits', although distant family and friends do tend to provide this type of support much less than other, closer carers. For the other types of support, the intensity of the care provided generally decreases as the social distance between care-giver and care recipient grows.

Table 4.1 Types of care according to social relationship with the person requiring care, 2007 (in %)

	<i>Emotional support and supervision</i>	<i>Accompaniment with visits</i>	<i>Household care</i>	<i>Accompaniment with arranging affairs and administration</i>	<i>Personal care</i>	<i>Nursing care</i>
Partner	79	90	93	61	50	40
Parent(-in-law)	87	86	82	77	26	26
Child	86	83	68	61	46	40
Rest	78	56	61	41	14	13
Total	83	78	77	62	29	26

Source: de Boer *et al.* (2009)

In terms of gender, there is hardly any difference between male and female care-giving activities. In the **Netherlands**, women (79 per cent) provide slightly more help with domestic chores than men (74 per cent), but men (68 per cent) assist more in administrative tasks than women (58 per cent).

Relevant data about the type of assistance provided by care-givers in **Italy** is not available.

4.4.5 Caring for two or more care recipients

The information available from four of the five countries under examination suggests that, on average, ten per cent of carers look after two or more disabled or older people. Given that the data exclude 'normal' child care responsibilities, it is possible that some carers may also be involved in these activities over and above providing care for two or more individuals.

In **Austria**, according to micro-census data, about one in ten (9.1 per cent) carers of people of all ages provide assistance to at least two care recipients (Kytir and Schrittwieser, 2003). Pochobradsky *et al.* (2005) reported that 12.3 per cent of carers of recipients of the LTC Allowance look after two or more individuals. Given the high proportion of older people who constitute LTC Allowance recipients, this is perhaps not surprising – a carer may well be supporting more than one elderly relative or in-law. It is not clear, however, how many carers are supporting two non-elderly people, or perhaps one elderly and one non-elderly person.

Data from **Italy** suggest that a similar proportion of carers (9.2 per cent) look after more than one disabled family member (ISTAT, 2005). However, these data refer explicitly to the number of non-disabled people who live in families where two or more members are disabled; not every such individual will undertake substantial care-giving commitments. Thus, the figure for carers with multiple caring roles for Italy may be an over-estimate.

General Household Survey 2000 data for carer households in **Great Britain** indicate that one in ten households contained carers of people of all age groups who looked after more than one person living with them (Maher and Green, 2002).

The tenth wave of the Panel Study of Belgian Households contained no clear data on how many people in **Belgium** are cared for by each carer (PSBH, wave 10, reported in Declercq and Van Audenhove, 2004). However, the survey of carers of working age adults registered by the Flemish care insurance scheme indicated that 16 per cent of carers looked after more than one person (PFSC, 2003).

In the Netherlands, one in five carers for people of all ages support more than one person (de Boer *et al.*, 2009). Half of these carers look after three or more people with a care need. These parallel carers ('veelhelpers') spend most time looking after a parent(-in-law) and often care for a long-term sick person as well.

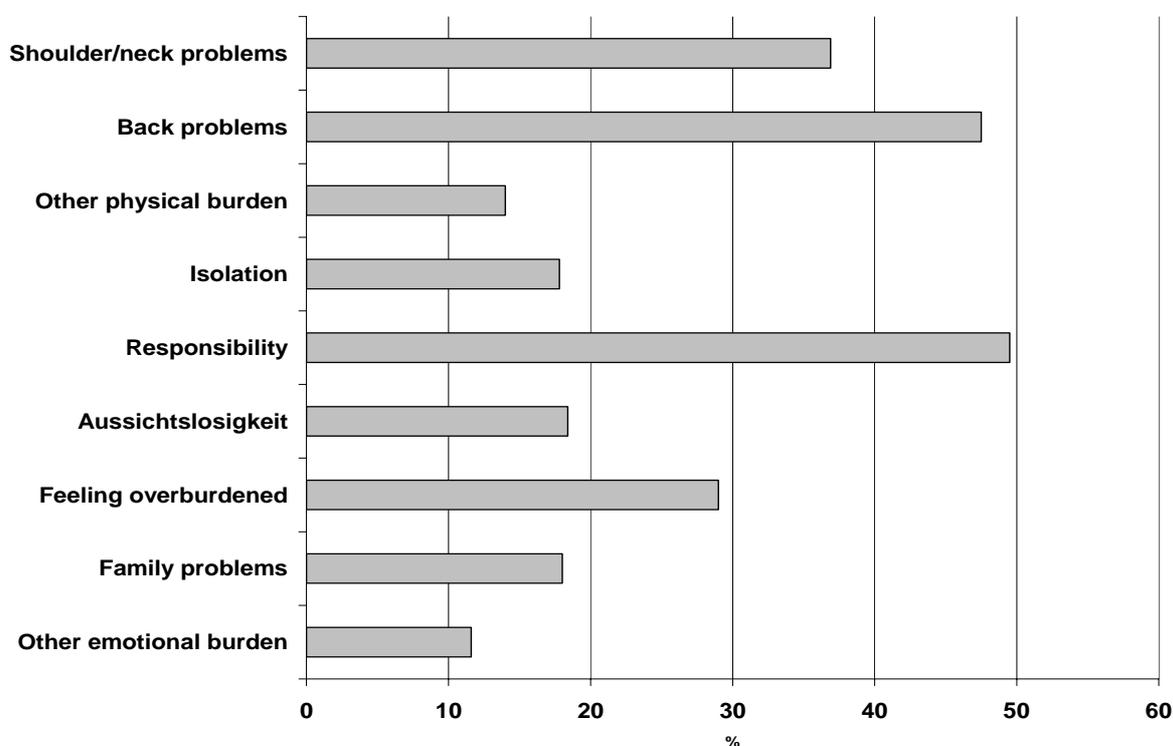
4.4.6 The impact of caring on health

It is well documented that carers report negative impacts on their health associated with care-giving. However, the available data does not always allow us to relate

health outcomes to the actual level of burden. Thus where data on health problems is provided for all carers, these are likely to under-estimate the health problems experienced by carers with substantial caring commitments.

Informal carers of recipients of the federal LTC Allowance in **Austria** (mainly older people) reported significant negative impacts of caring in relation to a range of indicators of health and well-being (Pochobradsky *et al.*, 2005). As can be seen from Figure 4.2, physical problems related primarily to back and shoulder/neck conditions; emotionally, carers were more likely to report heightened feelings of responsibility and feeling over-burdened.

Figure 4.2 Burdens and negative impact of caring reported by carers (multiple answers)



Source: Pochobradsky *et al.* (2005)

Note: 'Aussichtslosigkeit' can be translated as hopelessness or pointlessness

As shown in Table 4.2 below, people taking part in the survey of carers of people of working age registered with the **Flemish** care insurance scheme reported a range of negative impacts on their health and social wellbeing (PFSC, 2003).

Table 4.2 Caregiver burden as perceived by carers in Flanders

<i>Statements about providing informal care</i>	<i>% mainly/entirely agreeing with statement</i>
I find it emotionally taxing	73
I find it physically taxing	68
My social life is suffering as a result	56
I have too little time for myself as a result	51
My health is suffering as a result	41
My family life is suffering as a result	41
I am exhausted as a result	29

Source: PFSC (2003)

Data from the General Household Survey 2000, which covers **Great Britain**, revealed that among carers of all age groups who spent a minimum of 20 hours per week caring, half reported having a longstanding illness and over one-third (35 per cent) said that their illness limited their activities (Maher and Green, 2002). As Table 4.3 shows below, carers increasingly reported that their health was affected by caregiving activities as the number of hours per week spent on caring increased.

Table 4.3 How the carer's health has been affected by the number of hours spent caring per week

	<i>Number of hours spent caring per week</i>			
	Under 20 %	20-49 %	50 or more %	Total* %
Feels tired	12	34	52	20
Feels depressed	7	27	34	14
Loss of appetite	1	5	8	3
Disturbed sleep	7	24	47	14
General feeling of strain	14	35	40	20
Physical strain	3	10	24	7
Short tempered	11	29	36	17
Had to see own GP	2	8	17	4
Other	2	4	2	2
Health not affected	72	39	28	61

* Total includes a few people who could not estimate the number of hours

Source: Table 6.3, Maher and Green (2002)

Hirst (2004) found similar evidence in his secondary analysis of the first ten waves (1991-2000) of the British Household Panel Survey, the sample for which includes

adults living in private households in England, Scotland and Wales. The analysis showed that of those who cared for people of all ages for at least 20 hours per week:

- Caring-related inequalities in health increased progressively with the amount of time spent on caring activities each week.
- Carers' cumulative involvement in care-giving over time (the number of care-giving episodes involving care for different people), and marked increases in the intensity of caring activities, were also associated with increased risks of emotional and mental health problems.

There is no national data in **Italy** on the impact of care-giving on carers' health and well-being.

In the **Netherlands**, in 2001 just eight per cent of 'heavily burdened' (according to Dutch criteria) carers reported feeling 'very heavily burdened' or 'over-burdened' by their caring duties (de Boer *et al.*, 2003). The level of felt burden increased when carers provided help over many hours and long periods; when caring for a parent or child; or when the carer was the only person involved in supporting the disabled person. However, this figure stands in stark contrast to the 2009 survey on care-giving, which found that 45 per cent of carers experienced moderate to extreme burden related to caring (de Boer *et al.*, 2009). Around 17 per cent reported feeling 'strangled' by their own sense of duty and had difficulty in combining care-giving with other work and family responsibilities. This group was considered to experience serious 'over-burdening'. The report suggests that how burdened a carer feels is determined to a large extent by the intensity and complexity of the care. Family carers who provided care because of a lack of alternative options, or because they wanted to prevent the admission of an elderly parent to a care home, were particularly likely to experience care-giving as 'burdening'. The same was true of those who did not want or dare to ask other people for help; and for those caring for a partner or child. Caring for neighbours or friends was experienced as much less burdensome than caring for parent(s-in-law), a disabled partner or disabled child.

4.5 Socio-economic impact of caring

Just as carers of older people face negative consequences on their ability to work and/or their financial situation (see Chapter 3), so too do carers of other groups of disabled or chronically ill people. Although there is a clear association between care-giving and its impact on employment, the causal relationship is not always clear. As explained in Chapter 2, it is not always the case that care-giving causes adverse socio-economic effects. It is possible that some people may take on care-giving responsibilities **because** they are currently out of work or face very limited labour market opportunities, for example because of their own poor health. Other carers may experience poverty not as a direct consequence of caring but because they

share a household with a chronically ill or disabled partner whose own earning potential has been severely restricted.

Moreover, the socio-economic impact of caring is likely to vary according to gender, and the availability of part-time or flexible work opportunities – itself gender-related in many countries. Above all, the socio-economic impact of caring is likely to be modified by the availability of work-related measures that recognise care responsibilities, and by services and financial benefits that at least in part substitute or compensate for informal care. The availability, levels and coverage of these measures vary very considerably across EU member states, including the five countries examined in this chapter. Details of some measures to mitigate the socio-economic impact of care-giving are presented in Chapter 6.

Unfortunately data was not always available on the differential impacts on male and female carers, or on the socio-economic consequences experienced by those carers experiencing the heaviest ‘burdens’ of care-giving.

4.5.1 Impact of caring on employment

A study looking at the situation of caring relatives of recipients of the LTC Allowance in **Austria** (mainly older people) found that 56 per cent of carers had been in paid employment prior to caring, but at the time of the survey only 32 per cent of respondents were still working (Pochobradsky *et al.*, 2005). Unsurprisingly, the higher the care needs of the care recipient, the higher the incidence of non-working carers. Some 32 per cent of carers of individuals receiving the lower levels of the LTC Allowance were in full-time employment, compared with only 26 per cent of beneficiaries of higher levels of the allowance.

In **Flanders**, just under one-quarter (24 per cent) of carers of people of working age registered by the Flemish care insurance scheme were in paid employment (PFSC, 2003). Men were more than twice as likely to be in paid employment as women (37 per cent compared to 18 per cent). The majority of carers were either housewives/househusbands (28 per cent) or retired (22 per cent). Fourteen per cent of all carers (that is, carers of all ages and ability/disability) reported that they were not in paid work as a consequence of their care-giving. This figure rose to 31 per cent for those carers of working age who were physically able to work (that is, carers below state pension age, unemployed, housewives/husbands). Finally, while only six per cent of all carers reported reducing their hours of work or temporarily withdrawing from the labour market because of care-giving, this figure increased nine-fold to 54 per cent among those carers who reported being on sick or temporary leave, or who currently worked part-time.

In the **Netherlands**, almost two-thirds of 'heavily involved' carers of people of all ages are also in paid employment (de Boer *et al.*, 2003). Almost one-fifth of all carers (19 per cent) reported negative impacts of caring on their employment. For example, six per cent reported a reduction in their working hours; five per cent reported giving up work altogether because of caring duties; and three per cent reported that they could not work additional hours even though they would like to. The latest study of care-giving in the **Netherlands** revealed that the likelihood of reduced working hours is largest for those individuals caring for their partner (de Boer *et al.*, 2009). The intensity of care also plays a role: those who care for many hours per week often have reduced working hours. Remarkably, the duration of care-giving appears to have an effect that is contradictory to expectations: those who have provided care for longer than three months are less likely to have reduced their working hours than those who have been providing care for a shorter period.

As reported in Arksey *et al.* (2005), analysis of the 2001 Census data for **England** and **Wales** shows that caring affects participation in the labour market among those whose care-giving extends beyond 20 hours per week. Census data indicate that only about half of carers of people of all ages who spend between 20 and 49 hours caring per week were in employment in 2001, compared with about six out of ten non-carers. Among those caring for 50 or more hours per week, only three out of ten were in paid employment. Compared with non-carers and those caring for less than 20 hours, carers spending between 20 and 49 hours per week were less likely to be in work and more likely to be looking after the family or home. Those caring for 50 or more hours per week were most likely to be retired, looking after the home or family, or permanently sick or disabled. Thus, the proportion of carers in work falls as the hours of caring work increase.

Arksey *et al.* (2005) also noted that Heitmueller and Inglis' (2004) examination of the impact of care-giving on carers' earnings from employment, based on 12 years' data from the British Household Panel Survey (1991 to 2002), found that carers in general have longer periods of absence from the labour market than non-carers, but 'once employed, they have longer spells in the labour market, suggesting that carers are less mobile in general' (Heitmueller and Inglis, 2004: 7).

The 1994/95 Family and Working Lives Survey, based on a nationally representative sample of adults aged 16 to 69 in **Great Britain**, asked about the effects of caring responsibilities (for people of all ages) on respondents' work arrangements. Subsequent analysis found a significant gender difference in the impact that starting to care had on employment (Henz, 2004). Women were almost twice as likely as men to stop work altogether (17 per cent compared to nine per cent). Conversely, men were more likely than women to report that they continued working with no impact on their employment situation despite starting to care (46.4 per cent compared to 31.9 per cent), whilst women were more likely than men to say that they continued not working (35.8 per cent compared to 30.4 per cent).

National data from **Italy** suggests that around 217,000 disabled people aged six to 64 years live with their parents (ISTAT, 2008). For parents of adult disabled children, the duration of care-giving is likely to be very extended, leading to a greater impact on labour market participation. Of those disabled people aged between six and 44 years, 73.6 per cent live in the community with their parents. Of those living in two-parent households, 61.2 per cent of fathers are employed and 32.3 per cent retired; the majority of mothers are classified as housewives (62.5 per cent), with only 22.9 per cent in employment (compared to 41.4 per cent of women with non-disabled children). In single-parent households, 92.2 per cent of single fathers are retired (none were classified as being in employment), while 39.3 per cent of single mothers were housewives, 29.9 per cent were retired and only 18.2 per cent were employed (compared to 41.7 per cent of single mothers with non-disabled children).

4.5.2 Impact on finances

It is well known that caring can have negative financial consequences for carers and former carers (McLaughlin, 1993; Carers UK, 2007) People who give up work to care may become financially dependent on the care recipient, for example if they depend on the care recipient for an income from a care allowance (see Chapter 6). This dependency can be a source of anxiety for many carers, particularly if there are concerns that the care recipient may move into a residential or nursing home or die (Glendinning, 1990). There is some evidence from Austria that the magnitude of the financial impact of care-giving increases with heavy or substantial care-giving responsibilities.

Austrian data about carers of beneficiaries of the LTC Allowance (mainly older people) show that approximately 20 per cent of carers do not have an income of their own (Pochobradsky *et al.*, 2005). The majority of these carers (nearly 92 per cent) are female and typically comprise wives without a pension entitlement of their own who are therefore dependent on the pension (or other income) of their husband. Carers of LTC Allowance recipients assessed as needing lower levels of care are more likely to have an income of their own (78 per cent) than carers of people requiring higher care levels (69 per cent). One in five carers of LTC Allowance recipients reported having no income of their own; for a further 25 per cent this was below €700 a month; in total, therefore, almost half of carers of LTC Allowance recipients are at serious risk of poverty.

In the **Flanders** study, 16 per cent of all carers of working age people reported a loss of earnings because of care-giving (PFSC, 2003). Among those carers who had reduced their hours of work or temporarily ceased working in order to care, the proportions reporting a loss of earnings because of care-giving rose to 86 per cent. Of those who reported a loss of earnings due to care-giving, one-third (33 per cent) reportedly lost €1,000-€1,500 per month, while 26 per cent lost €250-€500 per

month, and 22 per cent lost €500-€750 per month. Some carers also reported additional costs related to caring such as transport, telephone, nursing supplies (for example, incontinence pads) and laundry.

Comito (2006) estimated that in **Italy** a family spends on average an additional €16,000 on assistance, health care services, prostheses and other medical devices for a disabled family member. A 2007 study reported that a family with a disabled member needs an income 2.16 times higher than families without disabled members in order to reach a similar level of well-being (Mancini *et al.*, 2007). National survey results indicate that, in comparison to families without disabled relatives, families with disabled members aged six to 64 are more likely to consider the house where they live to be too small; report living in a house in a poor condition; and have low or inadequate economic resources (ISTAT, 2008). On a majority of indicators, families with a disabled member aged six to 34 experienced the worst socio-economic conditions (such as not having a telephone or the house being too small). In relation to living arrangements, the worst conditions were reported where disabled family members lived with both parents and those where the disabled person lived alone. In comparison, those living in single parent households or those living with a partner and no children appeared to fare better.

In **Britain**, Heitmueller and Inglis' (2004) analysis of the British Household Panel Study found that being a carer was associated with lower hourly wages, when other factors were controlled for. Moreover, the longer the duration of the care-giving episode, the bigger the negative effect on earnings. However, neither the number of hours of care provided per week nor the characteristics of the person receiving care (older person, disabled child, chronically ill spouse) had a statistically significant effect on earnings. This suggests that the number of hours per week spent caring and the carer's relationship with the person receiving care are important factors affecting the decision about whether to participate in the labour market, but do not affect wage rates. Nevertheless, it appears that carers may be 'systematically disadvantaged with respect to pay' (Heitmueller and Inglis, 2004: 18).

Other data from **Great Britain** reports relevant findings for carers of people of all age groups. Econometric analysis of the 1990 General Household Survey found that the negative effect of informal caring on the hourly wage rate was considerably greater for men than for women (Carmichael and Charles, 2003). Parker and Lawton's (1994) analysis of 1985 General Household Survey data also showed that the adverse effect of caring on earnings was greater for male than for female carers. Analysis of the 1990/91 General Household Survey confirmed that carers have a lower average hourly wage rate than non-carers. Male carers who are co-resident with the person they are caring for and men caring for more than 50 hours per week had markedly lower hourly wage rates than non-carers. Male carers living in a separate household from the person receiving care had a broadly similar wage rate

to non-carers. The pattern was similar among women, but the variation reported was smaller (Evandrou, 1995).

A study by Carers UK (2007) reported that carers (of people of all ages) lost an average of €12,300 (approx) in earnings in the year prior to the survey (carried out between December 2006 and January 2007) due to giving up work, cutting down hours of work or taking a more junior position. Those caring for the highest number of hours per week lost out on the most money. Carers in their late fifties and early sixties faced the biggest loss in earnings. Men lost an average of about €15,200 compared to an average of around €11,200 for women. Those caring for a parent or partner lost the most earnings, although the variation according to who they were caring for was not great. Furthermore, some carers reported struggling to pay for essential services such as gas, electricity or the telephone (30 per cent); being unable to afford essential household repairs (30 per cent); and using their own income or savings to pay for services for the person they were caring for (35 per cent).

In the **Netherlands**, 72 per cent of ('heavily involved') carers of people of all ages reported incurring additional expenses as a result of their care-giving (de Boer *et al.*, 2003). Fourteen per cent reported additional expenses of over €1,000 per year. Almost one in five (19 per cent) of all carers reported losses in income as a consequence of their caring role, mainly because of negative impact on their ability to participate in the labour market (see above). In total, seven per cent of carers reported financial problems as a consequence of their caring activities.

4.6 Specific groups of carers of non-older people

As mentioned in section 4.1 above, the data presented in this chapter has been supplemented by additional data from England/UK and the Netherlands relating to young carers and the parent carers of disabled children. However, some of these data may have been included in the above national data.

4.6.1 Young carers

The term 'young carer' refers to children under the age of 18 who carry out (unpaid) care-giving activities and responsibilities over and above what would typically be expected of young family members. The concept of young carer is contentious, with some commentators arguing that additional adult-like care responsibilities experienced by young people reflect a lack of services to support ill or disabled people in their parenting roles (Olsen, 1996; Olsen and Tyers, 2004). This tension is acknowledged in UK government policy. The Westminster government's vision for carers, for example, includes the intention that by 2018 'children and young people

will be protected from inappropriate caring and have the support they need to learn, develop and thrive' (HM Government, 2008: 10). Whilst young carers frequently look after a parent, the care recipient may also be a sibling, grandparent or other relative who is disabled or has a chronic illness, mental health problem or other condition requiring support (Becker, 2000). Like adult carers, young carers may undertake a wide range of care-giving activities including domestic, emotional, general nursing-type help and intimate care.

Prevalence of young carers

The 2001 Census showed that in the **UK** some 175,000 children and young people under the age of 18 look after other family members (ONS, 2003). Prevalence rates for young carers vary across the four countries making up the UK. As can be seen in Table 4.4 below, the lowest proportion of child carers aged between five and 17 is found in **England** (1.7 per cent) and the highest in **Northern Ireland** (2.5 per cent). The Census also shows that the majority of young carers provide less than 20 hours of care per week. Whilst the Census figures are higher for young carers than previous estimates, in fact the figures are likely to be an under-estimate because of Census methodology (Becker, 2007).

Table 4.4 Number and proportion of children under the age of 18 who are carers in the UK by hours caring per week

	<i>Number caring for 1-19 hrs</i>	<i>Number caring for 20-49 hrs</i>	<i>Number caring for 50+ hrs</i>	<i>Total number caring</i>	<i>Proportion who provide informal care (%)</i>
England	116,823	12,284	10,092	139,199	1.7
Wales	8,854	1,029	861	10,744	2.2
Scotland	13,511	1,826	1,364	16,701	2.1
Northern Ireland	6,666	974	712	8,352	2.5
Total number of young carers in UK	145,854	16,113	13,029	174,996	2.1
Total number as % of all young carers in UK	83	9	8	100	

Calculated from Office for National Statistics (2003) Census 2001 data, in Becker 2007; see also Becker and Becker 2008

Data on young carers are more limited in the **Netherlands**, but a recent report suggests that 28 per cent of children and young people between the ages of 12 and 25 years grow up with a family member who is chronically ill or disabled (de Veer and Francke, 2008). Of the 694,000 to 810,000 children growing up with a parent with moderate or severe illness or disability, some 95,000 to 190,000 are estimated to have care-giving responsibilities.

There are no official (or rough) estimates of the number of young carers in **Europe** as a whole, although Eurostat data suggest that around a quarter of children in Europe live in families where there is illness and/or disability (Becker *et al.*, 1998). Becker's (2007) research reported in Table 4.4 above suggests that around two per cent of children under 18 years in the UK are young carers. In Australia, 3.6 per cent of all people under the age of 18 are young carers; some 3.2 per cent of all US households with a child between the ages of eight and 18 include a young carer (Becker, 2007). On these bases, it is probably reasonable to estimate that between two and four per cent of children and young people (aged under 18 years) in **Europe** are likely to be young carers (Becker, personal communication).

Socio-economic impacts of caring

We were unable to locate any evidence on the impact of care-giving by young people according to the intensity or level of care provided. However, there is evidence suggesting that young carers in both **England** and the **Netherlands** can experience a range of negative outcomes, irrespective of the number of hours of care involved. These include low self-esteem; greater susceptibility to depression both in childhood and in later life; restricted opportunities for social and leisure activities; and limited education, training and employment opportunities and aspirations. Dutch research suggests that girls perform more 'hands on' care and feel more burdened than boys. Those who grow up with a parent with a psychiatric disorder are at risk of developing psychiatric problems themselves, including eating disorders, behaviour disorders and attention deficit disorder (Tielen, 2004). Equally, children of parents who are addicted are also at risk of developing some kind of addiction.

Not surprisingly, caring responsibilities have the potential to have significant negative impacts on the education of many young carers; declining school performance in turn has the potential to lead to difficulties in finding and sustaining paid work. Analysis of a three per cent sample of anonymised 2001 Census records for the **UK** revealed that, among young adult carers aged between 16 and 24 years, care-giving reduced the likelihood of being a student and taking part in further or higher education, particularly for young women (Yeandle and Buckner, 2007). Furthermore, it also reduced their chances of being in either full- or part-time employment.

At the same time, there is evidence from both England and the Netherlands that care-giving can give rise to positive outcomes, such as developing children's knowledge, understanding, sense of responsibility, early independence, practical competencies and a range of life, social and care-related skills (Dearden and Becker, 2000; Tielen, 2004). Other positive aspects include the development of stronger family bonds.

4.6.2 Parent carers of disabled children

Prevalence of parent carers

This final evidence section of the chapter focuses on care of dependent sick or disabled children (aged under 16). Analysis of the 2001 Census showed that in **England** and **Wales** 4.3 per cent (448,000) of all children under the age of 16 have a limiting long-term illness (Buckner and Yeandle, 2006). Some 34 per cent of sick or disabled children live in households where there is no adult in paid work; this compares with 18 per cent of children who are not sick or disabled. Of all families with a sick or disabled child:

- 54,000 have at least one carer in the household providing up to 19 hours unpaid care per week
- a further 158,000 have at least one carer in the household providing 20 or more hours unpaid care per week
- in some 250,000 families with a sick or disabled child, no-one describes themselves as a 'carer' (other research shows that parents of sick or disabled children do not necessarily describe themselves as 'carers')
- in 44 per cent of families, two parents both provide unpaid care.

Research on working carers and care leave in the **Netherlands** reports that of those carers in paid employment (almost two-thirds of all carers), approximately 50,000 (6.25 per cent of all working carers) also care for a sick or disabled child for at least 20 hours per week (Souren, 2007).

Socio-economic impacts of caring for a sick or disabled child

The 2001 Census data for **England** and **Wales** (Buckner and Yeandle, 2006) shows that, in comparison with parents whose children are *not* sick or disabled, parent carers providing at least 20 hours of care per week are older and are much more likely to be in poor health and/or have a long term limiting illness or disability themselves. Both men and women, but particularly women, are considerably less likely to be in paid employment. Furthermore, parent carers who work and also care for at least 20 hours per week are slightly more likely than employed parents who do not have a sick or disabled child to work part-time; just as likely to be working long hours (48 hours or more per week); more likely to be employed in low-skilled, low-paid 'elementary' jobs; less likely to be in managerial or senior positions; and more likely to be in jobs less than two kilometres from where they live.

A study in **England** involving two large-scale surveys and in-depth interviews with a sub-sample of respondents tracked parent carers of sick or disabled children over a four-year period (Stiell *et al.*, 2006). The study showed that most parent carers reported that care-giving had an adverse impact on their own employment, including a negative impact on relationships with colleagues and a feeling that progression opportunities were denied to parents in their situation. Whilst some parent carers had

changed their working arrangements and/or reduced their hours of work to accommodate their care-giving responsibilities, many felt forced to look for a different type of work or to change their job. Many parent carers reported tiredness and stress as among the most difficult aspects of combining work and care for a sick or disabled child.

This evidence endorses the findings of an earlier survey (Contact a Family: Acton Shapiro, 2003) of over 2,000 parents of a disabled child in the **UK** which showed that:

- Almost one quarter of respondents felt that having a disabled child had caused major problems in their relationship or led to marital breakdown.
- Around three-quarters of respondents had experienced stress/depression and/or tiredness/lack of sleep, and over a half had experienced financial difficulties – the vast majority attributed these experiences to having a disabled child.

Research from the **Netherlands** on working carers providing more than 20 hours of care per week show that some 50,000 carers are looking after a disabled child (Souren, 2007). This research indicates that parents of disabled children tend to provide more hours of care than those who care for either their parents or their partners. For example, 20 hours or more of care per week is provided by four out of ten parent carers of disabled or chronically ill children (compared with three out of ten spouse carers and one out of ten carers of parents(-in-law)). Furthermore, the duration of the care period tends to be longer for parents caring for disabled children, compared to that of adult children caring for their parents. Taken together, the data suggest that in the Netherlands parents of children who are disabled or chronically ill tend to have the heaviest caring commitments.

4.7 Summary and conclusions

Expert informants in five countries - Austria, Belgium, England, Italy and the Netherlands – provided the research team with national data on the prevalence and impact of care-giving. They were asked to supply information specifically in relation to individuals with a substantial care-giving role for non-elderly people, if such data were available. In the event, there is some overlap with the previous chapter (Chapter 3), as available data were not always specific to carers of the non-elderly. Even where data on carers of non-older people could be supplied, it was not always possible to know the extent to which caring for a dependent disabled child, spouse or other family member affected the intensity and duration of care-giving, or any subsequent impact on employment and income. Some carers of non-elderly people, such as parents of disabled children, are likely to be caring for a very long time, and longer than carers of older people; the cumulative impact on their labour market participation and financial situations is difficult to assess from cross-sectional data.

Our country-specific review of information about care-giving found the following:

- There is a lack of data available specifically related to carers of non-older people, particularly those with substantial caring responsibilities. In some countries, for example Italy, no data are collected specifically on carers; instead, prevalence rates are estimated from data on the households of disabled people.
- The majority of carers (of people of all ages) are aged 45 years and above. However this conclusion is drawn from evidence that includes carers of older people as well as carers of non-elderly people; nevertheless, carers of non-elderly people are likely to be of working age. Carers are predominantly female.
- With the exception of the Netherlands, the majority of carers in the five countries under review live with the person they look after. Furthermore, co-residence with the care recipient is an indicator of heavy or substantial caring responsibilities (Becker and Becker, 2008).
- There is some limited evidence from England and Belgium to suggest that carers with substantial responsibilities for working age people are more likely to look after their partners than care for other (close) relatives or friends.
- Data from Austria, Italy, Great Britain and Belgium suggest that, on average, ten per cent of carers look after two or more disabled or older people.
- Carers are more likely to provide practical support, such as help with domestic tasks, than personal care such as bathing and dressing, which can be experienced as more onerous and burdensome. However, again this conclusion is based largely on evidence of carers of people of all ages.
- Carers in all five countries report negative impacts on their physical health and emotional well-being. Evidence from England suggested that as the intensity of care-giving increased, carers (of people of all ages) are increasingly likely to report health problems.
- Care-giving can negatively affect participation in the labour market, especially for people caring for more than 20 hours per week. People caring for their partners are also particularly likely to reduce the number of hours worked. There is evidence of differential impacts according to gender; women are more likely than men to stop work altogether.
- Carers' financial situation is affected detrimentally by care-giving; the longer the duration of the period of care-giving and/or the higher the number of hours of care provided, the larger the negative impact on carers' earnings. Again, there is a gender effect in that male carers tend to be more adversely affected than female carers; the financial situation of co-resident male carers with substantial levels of involvement can be particularly affected in comparison with non-carers.
- Across Europe, there are likely to be between two and four per cent of children and young people with care-giving responsibilities for a disabled or ill relative.

Their education and training are likely to be affected, which means that in turn it can be difficult for them to find and sustain paid work.

- There is evidence that parent carers of disabled children have substantial caregiving responsibilities, with subsequent negative outcomes. They are likely to experience poor health themselves and are less likely to be in paid employment than parents without a disabled child. Those who are able to combine work and care tend to be slightly more likely to work part-time, and work in low-paid, low-skilled jobs.

Chapter 5 Other European Data on Carers

5.1 Introduction

Chapter 3 of this report summarised the key findings of the Eurofamcare project in relation to the prevalence and socio-economic impact of caring for older people, especially for carers with the heaviest burden. However, a number of other studies (EU-wide or wider) also have relevance to the aims of this study. First, there are studies that do not focus specifically on the situations of informal and family carers, or aim to provide evidence on the prevalence or socio-economic consequences of care-giving, but that nevertheless contain relevant information. Because family care-giving is not the main focus of these other projects, the data that can be extracted from them and that is presented here is somewhat fragmented. Second, some cross-national studies do focus on carers' issues but approach them from a different angle, or include a wider group of carers than the Eurofamcare project, which focused only on the family care of older people.

Some Europe-wide surveys focus on citizens' normative beliefs about who should be responsible for care. While such data may provide insights into the social and cultural contexts of family care, this chapter focuses instead on hard data about actual practice and its consequences.

There is an increasing body of knowledge concerned with ageing; with integrated care (see for instance the PROCARE and CARMEN projects); with the projected costs of long-term care, in which assumptions concerning the future contributions of carers are critically important (for example the 2006 EPC projections; Grammenos, 2005; Comas-Herrera *et al.*, 2003); and with workforce issues related to long-term care (for example van Ewijk *et al.*, 2002; Escobedo *et al.*, 2002; Fujisawa and Colombo, 2009). The OASIS project (Lowenstein and Ogg, 2003) focused on autonomy in old age and intergenerational solidarity, particularly the roles of adult children in supporting elderly people. However, adult children constitute only some of all those with care responsibilities. Other studies such as the SHARE project focus on the ageing population, older people and their needs for and receipt of care (including informal care). Here, the focus is not explicitly on informal care but more on the context in which informal care takes place (within an overall model of care provision) (see for instance Pommer *et al.*, 2007a).

Finally, current available data on time-use across Europe does not specify caring (other than child-rearing) as a specific category. As far as it is recognised, it is included in overall measures relating to how people spend their free time, of which 'volunteering and help' is but one category (see for instance, Eurostat, 2007).

While all these studies include at least some groups of informal carers, they do not focus specifically and explicitly on the circumstances of carers or the socio-economic impacts of caring, particularly for those who are most heavily involved.

Recently, OECD attention has turned to carers as an integral – and the biggest – part of the long-term care workforce (Fujisawa and Colombo, 2009). However, these authors, too, make critical remarks about the lack of available data.

5.2 Carers: prevalence and characteristics

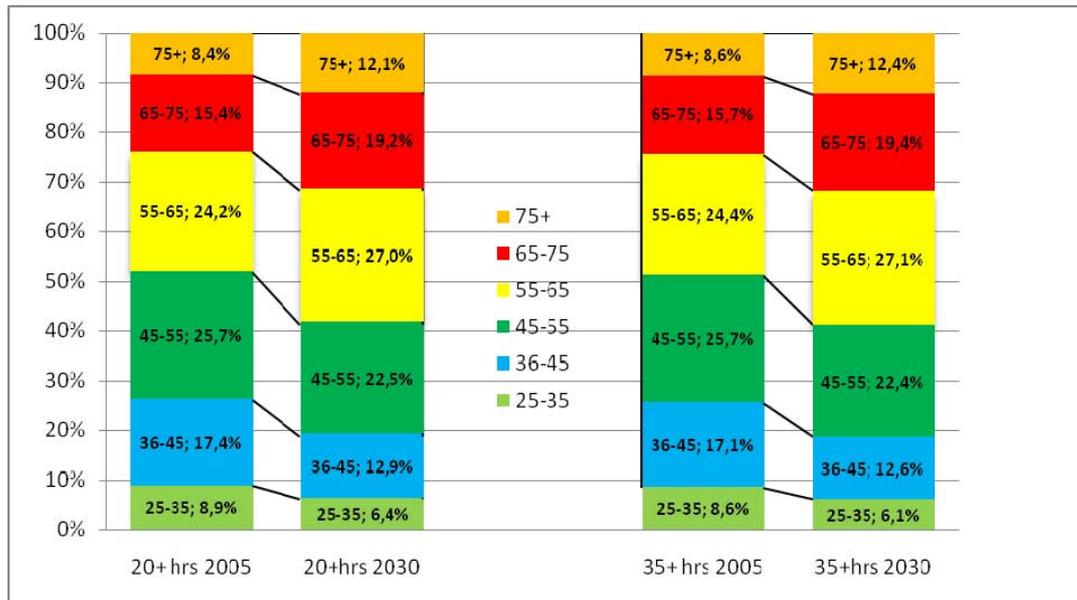
5.2.1 Prevalence of informal care across Europe

Estimates of the numbers of carers across Europe and their roles depend on definitions of ‘carer’ as well as on the geographic coverage of available research data. The most recent source of EU-wide data concerning carers is the Second European Quality of Life Survey (EQLS) (Anderson *et al.*, 2009). The EQLS does not provide data on the actual number of carers in Europe, but does provide some relevant proportions. A quarter of people aged 18-plus in the EU27 plus CC3 report some ‘involvement in care for an elderly or disabled relative’. When this is recalculated to include only those who report they are involved in caring on a daily basis, this leads to the estimate that some 32 million people care on a daily basis – an over-estimate, given the basis of the EQLS.³

Another estimate is based on Alber and Köhler (2005), using the First European Quality of Life Study, which found that about a quarter of the population (aged 18-plus) was involved in caring. This leads to an estimate of 100 million carers in (the then) EU. If we were to re-calculate this in the current enlarged EU, using data provided by Anderson *et al.* (2009) this would amount to some 125 million carers in Europe.

³ The calculation led to an estimate of 33 million people caring on a daily basis in the EU27 in 2007, using the EQLS percentage and drawing on Eurostat online data: 500 million inhabitants in the EU27 in 2007 and a male/female ratio of 100/104.9. As the target group for the EQLS is 18 years or over, whereas the calculation is based on the total European population (including children), this was an over-estimate. On the other hand, as the EQLS does not include people below age 18, it will by definition omit young carers. Nevertheless, the overall-effect will remain an over-estimation. We adjusted the final outcome with one million people to take these effects into account.

Figure 5.1 Current status (2005) and future (2030) ‘heavy’ carers (in hours per week spent caring), by age category (25 years and above)



Source: Grammenos (prognosis: EU Baseline scenario) (2005; adaptation Vilans).

Grammenos (2005) uses a stricter definition of caring: people aged 25-plus who are involved in caring for at least 20 hours (wide definition) or 35 hours (stricter definition) per week. This leads him to conclude that in 2005 within the EU there were 19 million carers, of whom over nine million provided more than 35 hours care per week. However, the study uses a variety of databases⁴ and Grammenos does not specify the geographical area that this calculation covers; does it include, for example, the EU25, the (then) CC3 and/or Norway?

Grammenos estimates that by 2030 the numbers of carers will have grown to 21 and 11 million respectively (Figure 5.1). Even with the uncertain geographical boundaries, it is nevertheless clear that the categories of carers providing 20 hours a week care and those providing 35 hours a week care will both contain more older carers. In 2020, 24 per cent of carers caring for 20-plus hours per week will be 65-plus; by 2030, this will have grown to 31 per cent. Carers aged 65-plus will also constitute 31 per cent of all carers who care 35-plus hours each week by 2030. The risks of taking on heavy caring responsibilities will increase for the age category 55-65, whereas younger age groups will become significantly smaller proportions of the caring population, because of overall demographic developments.

⁴ According to a footnote (Grammenos, 2005: 79), Grammenos used Eurostat (2001) data, as well as SHARE-data and several national UK-studies and probably databases used in a previous study (he refers back to Grammenos (2003) but the use of databases is not specifically clarified there), such as the (now discontinued) European Community Household Panel and ‘national health interview surveys’.

These trends will have consequences for the way carers can (and need) to be supported. When carers themselves become older, the risk increases that their physical condition is decreasing. Their physical stamina will not be as it used to be, whereas heavy care tasks will not be able to be postponed.

The report of the second European Quality of Life Survey (Anderson *et al.*, 2009) shows that in the EU27, three per cent of people stated that they cared for an elderly or disabled relative several times a week, four per cent did this once or twice a week and eight per cent provided care less than once a week. In the EU27 some nine per cent of women aged 18-plus provided care for a relative on a daily basis, compared to four per cent of men. In the NMS12, 5 per cent of men provided care on a daily basis as compared to three per cent in the EU15 (Table 5.1).

Table 5.1 Proportion of population in Europe, caring for elderly/disabled relatives on a daily basis

	EU27		EU15		NMS12		CC3	
	Men	Women	Men	Women	Men	Women	Men	Women
Caring for elderly/disabled relatives	4	9	3	9	5	9	4	8

Q.36: How often are you involved in any of the following activities outside of paid work? Figures indicate percentage of people who record care or domestic duties every day.

Source: Anderson *et al.* (2009)

5.2.2 Age and care-giving

Daily involvement in caring for an older person is highest for the 50–64 age group (nine per cent), followed by the 35–49 age group (seven per cent) and those aged 65 years and over (six per cent). Anderson *et al.* (2009) found the latter a surprisingly low percentage and suggest that among this age group caring for one's partner in one's own home may be under-reported. These findings are consistent with the first EQLS, which reported that the probability of taking on informal care responsibilities peaked in the middle of the life-cycle in both the ACC and EU15 countries. These findings are also consistent with the work of Grammenos (2005, see above) and with the Eurofamcare study (see Chapter 3).

5.2.3 Gender and care-giving

The gender bias of caring is clear. Not only do men provide less care on a daily basis than women, the care they do provide is also less intensive and involves different activities from women carers. Men spend on average 11 hours and women 15 hours each week caring for elderly or disabled relatives (Anderson *et al.*, 2009). Similar gender patterns are apparent in the intensity of care provided by working carers (Table 5.2).

Table 5.2 Caring for elderly/disabled relatives in EU27, as per cent of those in employment (aged 18-plus), by gender

	<i>Men</i>	<i>Women</i>
Several times a week	6	11
Once or twice a week	5	6
Less often than once a week	9	10
Never	78	71
Don't know	2	2

Source: Anderson *et al.* (2009)

5.2.4. Co-resident and extra-resident carers

Once we distinguish between care rendered inside and outside one's own household, some differences between families of nations do become visible. Now, we clearly see two separate worlds of care in Europe – care at home is given much more frequently in acceding and candidate countries, whereas external care tends to be more frequent in EU countries.

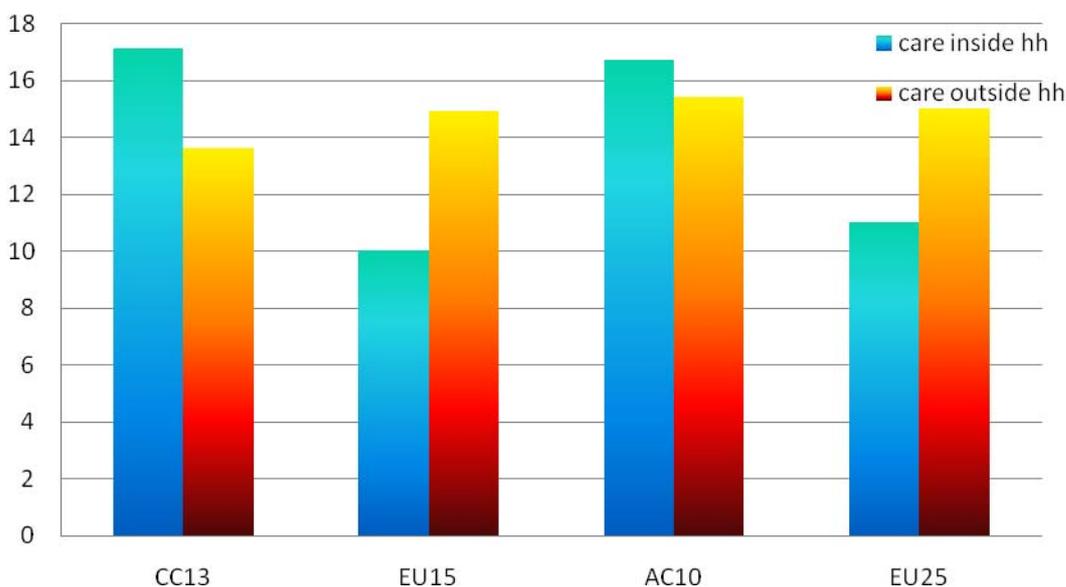
(Alber and Köhler, 2005: 58)

Care provided by co-resident informal carers is frequently given by people aged over 60 – the partners and older children of very elderly people. According to the available data, this pattern appeared especially common in the (then) candidate.

Co-resident care-giving is likely to involve heavier burdens than caring for someone in a separate household. Whereas the latter may lead to problems juggling with time, travel, costs of caring and other commitments, co-resident caring is often associated with more intense and/or emotionally challenging care tasks, a longer duration of the care episode, fewer additional sources of support and possibly also more demanding care tasks. According to Alber and Köhler (2005), people aged over 60 in the (then) ACC 13 countries more often provided co-resident care than their counterparts in the EU (Figure 5.2). In several acceding and candidate countries, about one in five people over 60 provided co-resident care. Among EU countries, only older people in

Germany reported a similarly high frequency of co-resident care (Alber and Köhler, 2005: 62-63).

Figure 5.2 Patterns of co-resident and extra-resident care across Europe



Source: Alber and Köhler (2005, adaptation Vilans)

Differences between countries in the incidence of co-resident and different household care-giving could reflect the poorer health of older people in the (then) acceding countries, their poorer living conditions, low social services provision, different economic activity patterns, or a combination of these (and other) factors. Alber and Köhler note that:

both types of informal care (for elderly people and for children) are more prevalent in ACC 13 countries, so that the probability of encountering typical 'sandwich generation' problems with dual care responsibilities (upwards to parents and downwards to children) is higher there.
(Alber and Köhler, 2005: 61)

However, this could also reflect the fact that multi-generational households are more common in Eastern and Southern European countries than in the EU15 (Kohli *et al.*, 2005; Attias-Donfut *et al.*, 2005). It is therefore somewhat surprising that Alber and Köhler focus on East-West differences only.

5.2.5 Co-resident and extra-resident care-giving and employment status

In general, unemployed people are more often carers than those in other employment status categories (Alber and Köhler, 2005). However, a more nuanced picture emerges when we take into account where care is provided. In a majority of countries, retired people are the most common category of carers providing care within the same household; this probably reflects the role of elderly people caring for their spouses. Where care in a separate household is concerned, it is generally employed and unemployed people (that is, working age) people who are the largest group of carers. In only three EU countries are retired people the most common category of people providing care outside the household.

Table 5.3 Location of care and employment status

	<i># of countries where working persons are the prime carers category</i>	<i># of countries where retired are the prime carers category</i>	<i># of countries where unemployed carers are the prime carers category</i>
Caring inside the household	1	10	16
Caring outside the household	12	3	12

Source: Alber and Köhler (2005: 63; adaptation Vilans)

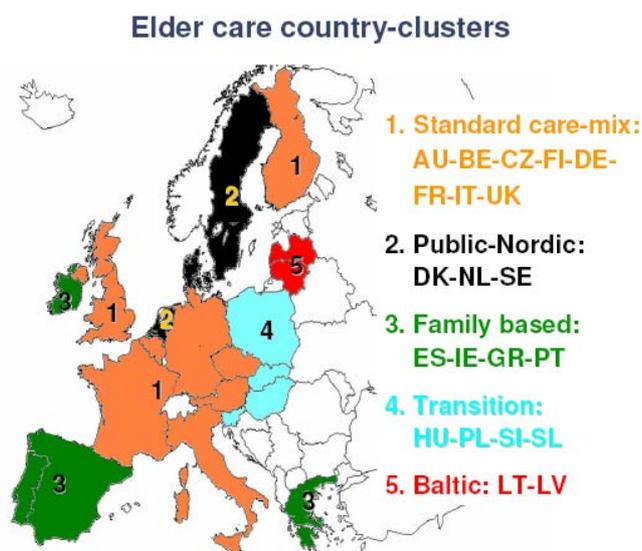
However, Alber and Köhler make no distinction between those who had a job and lost it (possibly due to caring responsibilities) and those who may be part of the potential workforce but have never worked and remain as full-time housewives. Thus the category 'unemployed' might conceal a crucial differentiation between different kinds of carers. Furthermore, Table 5.3 is based on an ordinal scale of country proportions. Sometimes the differences in proportions between two of the three categories were small.

5.3 Care cultures across Europe

Almost all authors using multi-national data sources differentiate between different 'care cultures' across the EU27, or other geographical units, depending on their databases. Relevant factors used to construct these care culture typologies include housing and living conditions; culture and expectations about the role of (extended) families in relation to care; expenditure on health and long-term care; religious and/or social background; average healthy number of life years; labour market and gender variations. Thus Alber and Köhler (2005) hypothesise an East-West divide, as do Mette (2006) and Schoenmaeckers and Vanderleyden (2006). In contrast, authors

drawing on the first wave SHARE data hypothesise a North-South divide (Pommer, *et al.*, 2007b), in which pressures on carers are much bigger – and even legally enforceable – in the Southern European countries. In a later publication Pommer *et al.* (2007a: 14) distinguish ‘three types of care regimes ... : a family type (Mediterranean), a mixed type (Continental) and a public type (Scandinavian).’

Figure 5.3 Clustering of elder care countries across Europe



Source: Lamura *et al.* (2007)

Lamura *et al.* (2007), using a combination of quantitative European data sources, extended the typology of ‘eldercare countries’ to distinguish Baltic countries from the so-called ‘transition countries’. This led to five categories of countries (see Figure 5.3). For instance, in the familistic countries, elderly people are at high risk of poverty. This will give them limited options to ‘buy’ care, thus placing them – when a need for care arises – at the mercy of informal carers. Similarly, when the average income level in a given country is low, the chances are that public long-term care provision may be lacking in both quantity and quality, whereas out-of-pocket payments may relatively be high.

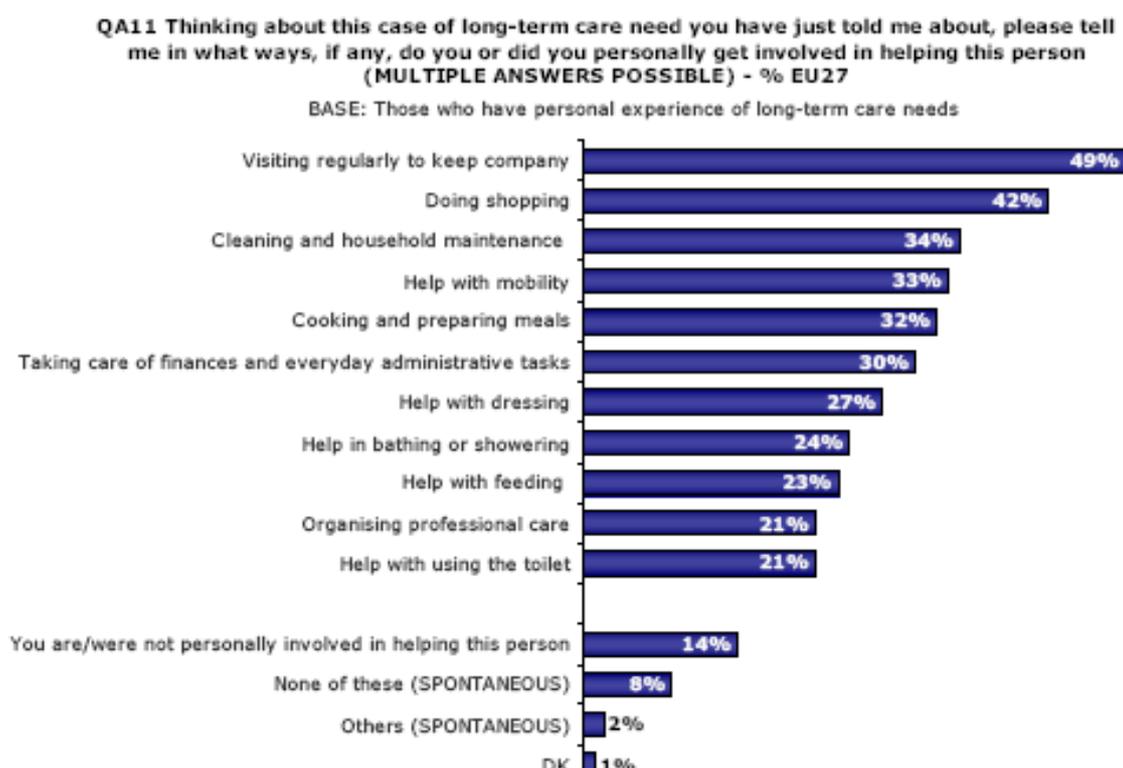
What these and other typologies make clear is that the objective burdens for carers may differ across Europe, with a heavier burden for those in countries with fewer (public) resources available and higher proportions of their populations consisting of older and very elderly people. Both East-West and North-South divisions are apparent, with carers in South-Eastern Europe having the fewest resources around them and thus experiencing the most onerous care situations.

5.4 Caring: activities and meaning

5.4.1 Caring activities

The Eurostat study on health care and long-term care (2007) provided unique EU-wide information on the activities involved in care-giving (Figure 5.4). Those who had (had) caring responsibilities were asked what kinds of activities they were or had been involved in. Carers mentioned an average of 3.5 activities each; when visiting to keep company was excluded, carers mentioned almost three activities on average each. Carers on average mention 0.95 activities that are considered personal care (help with dressing, bathing/showering, feeding, using the toilet). One in five carers helped by organising professional care. Including help with finances and administrative tasks, half of all carers undertook logistic tasks.

Figure 5.4 Caring activities across EU27, in per cent of carers having performed the activity over the last year for a parent (in law)



Source: Eurostat (2007: 84)

5.4.2 Elder abuse

Respondents were also asked about the likely perpetrators of poor treatment, neglect or abuse of older people (Table 5.4).

Table 5.4 Persons perceived to be most likely to carry out poor treatment, neglect or even abuse against an elderly person (maximum two answers); data EU27 (2007)

<i>Informal domain</i>	%	<i>Formal domain</i>	%
Children of elderly person	23	Care workers/home help/nurses	
Spouse/partner of elderly person	8	working in the person's own home	30
Siblings of elderly person	5	Staff in a care home	32
Acquaintances	11	Hospital staff/nurses	11

Source: Eurostat (2007)

After domiciliary and care home staff, children were considered to be most likely potential perpetrators of poor treatment, neglect or abuse, perhaps reflecting the predominant role of children in the care of frail older people. Almost half the inhabitants of the EU27 (47 per cent) considered maltreatment of elderly persons as 'fairly or very widespread', although this was based on opinion only, not actual incidence of maltreatment. Unfortunately, the data cannot be correlated with actual caring experience (nor with actual experiences of receiving informal or formal care).

5.5 Caring and employment

5.5.1 Caring and income

Anderson *et al.* (2009: 35) report an inverse relationship between caring and income; a higher proportion of people in the lowest income quartile (eight per cent) are involved in caring than in other income quartiles. In the highest income quartile the proportion of carers is lowest (three per cent).

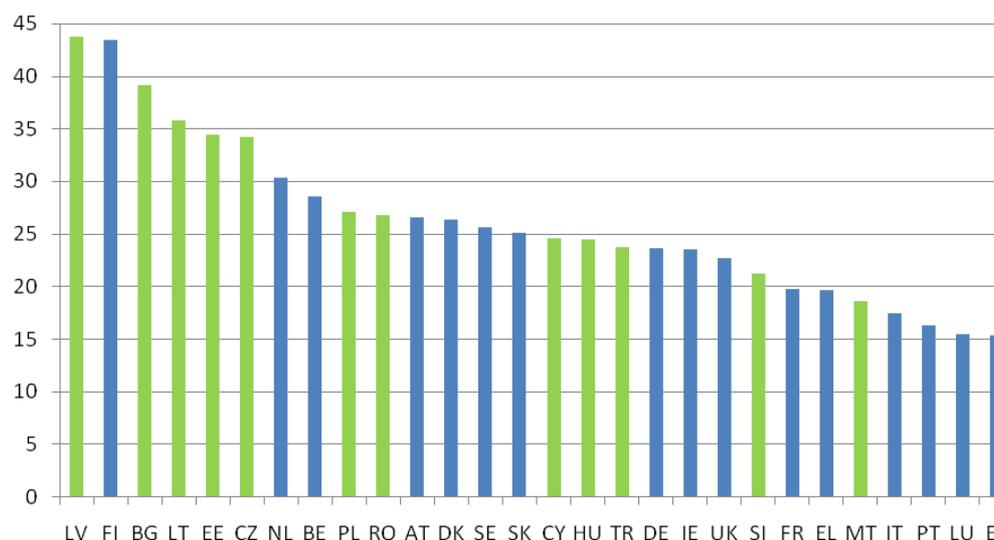
The European Health, Care and Long-Term Care study report was published in late 2007. It is mainly focused on opinions of EU27 and current CC3 country citizens but also includes some factual data on care-giving. Participants were asked if caring for a parent had affected their jobs. Only five per cent reported such consequences; three per cent had switched from full- to part-time working and two per cent had stopped working completely. A further eight per cent anticipated possibly switching from full- to part-time working or giving up work entirely in future in order to care for their parents. As noted elsewhere (Tjadens *et al.*, 2008), these data tend to underestimate the relationship between caring and employment: both working and non-working carers' responses were included; non-working carers were not asked if caring had limited their employment opportunities; and the question only covered care for parent(s) and excluded care for spouses, children or other disabled or chronically ill people.

Moreover, the Eurostat data are not broken down by gender; we have therefore turned to other data sources.

5.5.2 Data from the first and second EQLS

As discussed in previous chapters, across Europe a substantial proportion of carers are employed (and thus need to juggle both areas of life). This is substantiated by other data-sources. For instance, Alber and Köhler (2005) show that in Latvia, almost 45 per cent of carers are employed, whereas in Luxemburg and Spain no more than 15 per cent of carers are employed (Figure 5.5). Unfortunately these data do not show whether employed carers are in full- or part-time paid work and, if the latter, how many hours a week they work.

Figure 5.5 Proportion of carers who are employed for (the then) EU25 (darker grey) and CC13 (lighter grey)



Source: Alber and Köhler (2005; adaptation Vilans)

Table 5.5 Number of hours per week spent by employed/working carers aged 18-plus on caring for an elderly or disabled relative

	<i>Men</i>	<i>Women</i>
CC3	9	9
NMS12 ⁵	9	11
EU15	8	11
EU27	8	11

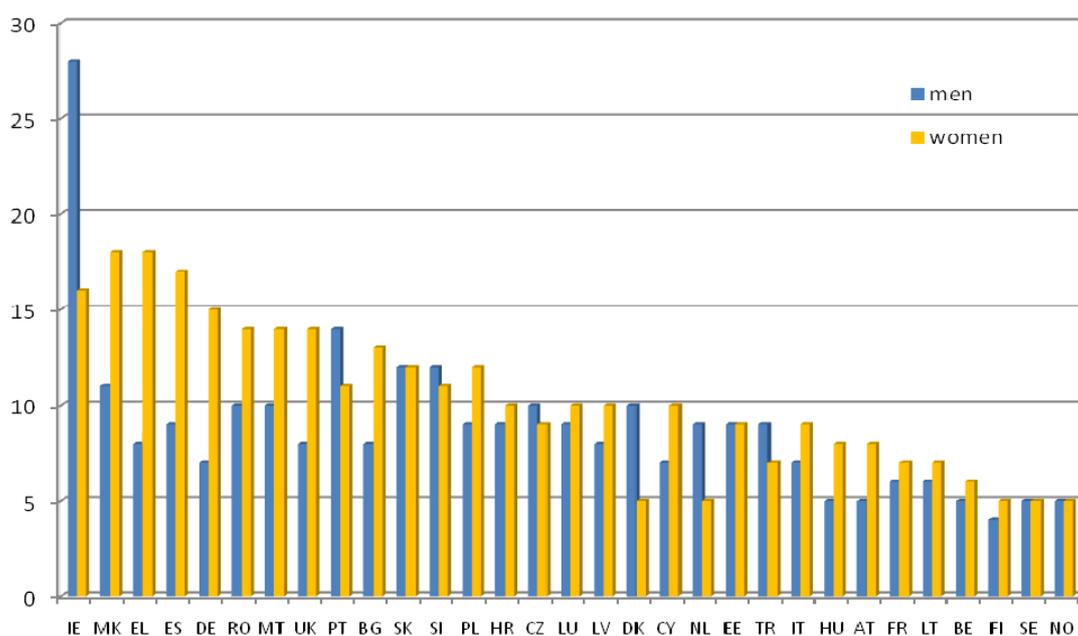
Source: Anderson *et al.* (2009)

⁵ Some would argue that it is more correct to re-name this category as EU12. We think that this might lead to confusion; the phraseology NMS12, just as other phrases (for example, EU15), has become standardised terminology. Furthermore, we follow the original authors here.

In the EU 27, employed men who also care for an elderly or disabled relative spent on average eight hours per week caring. Employed care-giving women spent 11 hours per week caring. In the NMS12 these data are the same. In the CC3 working caring women spent fewer hours per week (nine) caring (Anderson *et al.*, 2009: 24).

The efforts of working carers are not evenly distributed across Europe. In the Scandinavian countries (Finland, Norway and Sweden), and, to a lesser extent, in Latvia, France, Austria and Hungary, working carers spent the least number of hours caring per week: five to eight hours maximum. On the other hand, working carers in Ireland (especially men: 28 hours each week), and female carers in Former Yugoslav Republic of Macedonia, Greece, Spain, Germany and Romania, Malta and the UK spent most hours – from 14 to 18 hours per week – on care activities. We cannot relate these data to the number of hours spent in employment. It could be that those people caring more hours work fewer hours per week. However, part-time work, especially for men, is not so common as to be able to explain these outcomes.

Figure 5.6 Number of hours spent caring per week, working carers by gender and country



Source: Anderson *et al.* (2009; adaptation Vilans)

Irish working carers seem somewhat different from other working carers; they reported 28 hours of caring per week (Figure 5.6) compared to 15 hours care by working female carers. In several other countries working male carers also appear to spend more hours caring per week than working female carers (Portugal, Slovenia, the Czech Republic, Denmark, the Netherlands, Turkey). It is hard to distinguish any pattern in these data.

Unfortunately the results of the second EQLS do not give any information about the proportions of carers who feel they carry particularly heavy burdens, nor about the socio-economic impacts of care-giving on this group of carers. The report on the first EQLS (Alber and Köhler, 2005) had similar gaps; it also did not ask any questions about the intensity of caring, specific caring tasks or the duration of caring episodes. Data are also unavailable about the reasons why informal and family care was needed. Despite these shortcomings, at least in relation to the direct aim of our current study, the authors recognised different patterns of caring across Europe.

5.5.3 Further EU-wide evidence on caring and paid work

This section describes further evidence on the relationship between caring and work, from SHARE, ECHP and AGIR.

5.5.3.1 Survey of Health, Ageing and Retirement

The Survey of Health, Ageing and Retirement (SHARE) is an international, multi-stage survey of people aged 50-plus, but excluding those in nursing and care homes (Bolin *et al.*, 2007). This means the survey does not capture situations where a residential care placement has resulted from the inability of a family carer to continue supporting an older person. Currently SHARE is producing its third wave of data. The first wave of data collection which took place in 2004 provided 'baseline' data. However, these data were gathered in 11 EU member states, part of the (then) EU15, and data collection is currently being extended to other countries. It cannot be assumed that data obtained from the original 11 EU participating countries can be extrapolated to newer member states and/or the EU as a whole.

Crespo (2007) reported findings on the labour market participation of carers. Focusing on middle-aged women, the author found clear and substantial relationships between intensive caring and reduced labour market participation. For caring in general (without taking the intensity of care-giving into account), there was no such relationship and this was true in both Northern and Southern EU15 countries. However, when care becomes more intense, a pattern becomes clear; labour market activity appears to decrease by 30 per cent in Southern European countries and by 30 per cent to 40 per cent in Northern European countries. (This association gives no indication of causality – it may be that people who are already economically inactive are more likely to take on care responsibilities.)

5.5.3.2 European Community Household Panel Survey

The European Community Household Panel Survey (ECHP) also found a clear association between care responsibilities and lower female labour market participation. Moreover,

... single women with elderly care responsibilities may incur a greater risk of old-age poverty resulting from less attachment to the labour force and hence lower pension savings. The results indicate that this is a significant possibility in Germany, Greece, Italy and the Netherlands. ... The presence of state dependence means that short-term policy interventions, such as increased labour market flexibility to care for an elderly person, may have longer-term implications

(Viitanen, 2005: 20)

However, these data are from 1994-1997. Not only has the EU expanded since then, but EU actions on gender equality, discrimination and labour market participation may have had an impact as well.

5.5.3.3 Aging, Health and Retirement in Europe

The FP5 project on Aging, Health and Retirement in Europe (AGIR), using a variety of national databases, also examined the relationship between caring and employment. The study found that:

On average only 1.2 per cent of caregivers reported that the reason for stopping the job was looking after old persons in 2001. Among currently inactive care-giving people, the share (1.7 per cent) was a little bit higher. The majority of care-giving people never worked before (item: not stopping a previous job). That could be a sign that the hypothesis that caregivers are mostly family-oriented women is true.

(Schultz, 2004: 94)

These findings are slightly anomalous. According to Schultz, a majority of carers were not working before they started caring. However no data is presented on whether carers who were working had reduced their working hours⁶.

The complex relationships between caring and employment, and the effects of intervening variables such as gender and age, were further spelt out by Schultz:

Working caregivers spent on average around 12 hours per week on care-giving, unemployed persons spent around 19 hours and inactive people spent around 23 hours The number of care-giving hours increases with age independently from the activity status. Inactive people aged 70-plus spent the highest amount of hours care-giving – 25 to 26 hours per week.

Caregivers at home are mostly women, who do not work. They also spend more time care-giving than men. Normally working women spent on average 13.6 hours on care activities, unemployed women spent 19.7 hours and inactive women spent 24.6 hours per week in 2001. The highest amount of care-giving hours were spent by inactive women in the older ages. The level of disability increases with age and therefore the intensity of care-giving. ... Normally working women spent on average 13.6 hours on care activities,

⁶ The Eurofamcare project (Chapter 3) shows evidence of a much bigger impact, as do separate national data. For instance in the UK, 78 per cent of the carers aged 56 to 60 had given up (some hours of) work to care; (Holzhausen and Pearlman, 2000, reported in Carers UK, 2002).

unemployed women spent 19.7 hours and inactive women spent 24.6 hours per week in 2001. The highest amount of care-giving hours were spent by inactive women in the older ages.

(Schultz, 2004: 94)

SHARE data was also used by Bonsang (2008) in estimating the probabilities of becoming a carer and of receiving informal care. Within parent-child relationships, where the adult child is the potential carer, larger distances between the homes of parents and child leads to lower provision of informal care. Bonsang concluded that older individuals and those with low education levels, compared with younger people and people with higher educational levels, are more likely to provide informal care. On the receiving side, Bonsang concluded that individuals living alone are more likely to receive informal care. This finding seems somewhat puzzling, given the predominance and high probability of becoming the main carer for a disabled or chronically ill spouse. Bonsang also found that older people with higher levels of disability were more likely to receive informal care compared to those with lower levels of disability; and that wealthier parents received less informal care while homeowners received more. Bonsang does not provide any explanation for these somewhat contradictory findings. However, Bolin *et al.* (2007) shed some light on Bonsang's findings:

We find that informal care is a substitute for paid domestic help. However, the substitution effect tends to disappear for elderly people suffering from heavy disability. Finally, nursing care appears as being a weak complement to informal care whatever the disability level. These findings have a cost implication: based on our results, encouraging informal care will have only significant effects among elderly with low disability and for unskilled care. As a result, such policies are likely to have limited effect on the long-term care expenditures in Europe.

(Bolin *et al.*, 2007: 13)

5.6 'Sandwich' or dual-responsibility carers

Since the 1990s (Jenson and Jacobzone, 2000; Alber and Köhler, 2005), so-called 'sandwich' carers – those with responsibility for both child care and care for a disabled or older person – have gained increasing attention, particularly from the perspective of policies to reconcile work and family life. The SOCCARE study focused on these 'dual-responsibility' carers (Kröger, 2003). SOCCARE consisted of a qualitative study of double-responsibility carers in five European countries. It is useful because it provides qualitative, rather than quantitative, data and because on the whole other research into care-giving (including Eurofamcare) does not explicitly acknowledge these additional care responsibilities.

Kröger (2003: 14-17) estimates that a quarter of 'dual-responsibility' carers have very heavy responsibilities. However, given the qualitative nature of the research, this estimate is not elaborated further.

Kröger also contrasts the involvement of wider supportive networks in helping with childcare with the sense of individual responsibility that was often apparent in relation to the care of an older or disabled person; the latter had much greater consequences for carers' personal and professional lives. Moreover, Southern European carers were found to 'appear to sacrifice time with their children to care for elderly relatives, despite their associated feelings of guilt and regret; families in the UK and Finland (or) with small children instead are more likely to use their own family responsibilities as a justification for not becoming the principle caregiver' (Kröger, 2003: 86).⁷

5.7 EU-wide evidence relating to support for carers

One of the key conclusions of the SOCCARE project was that:

families are generally satisfied – though not with everything – with the way economic assistance is organised, **no matter what level of quality or generosity** they provide. In other words, it appears that families reason within a national standard of viable alternatives and measure their own unsatisfied needs with respect to what their welfare system could easily cover (Kröger, 2003: 10; author's emphasis)

This is a highly relevant outcome when considering the possible benefits of supporting carers. It implies that carers in countries with relatively low levels of available public support might welcome any measure to support them, whereas carers in countries with relatively higher levels of public services might require more sophisticated forms of support. Moreover, Kröger concluded that:

Unlike their northern counterparts, who are accustomed to the recognition of specific rights to assistance for certain kinds of needs, the participants in these [southern European] countries appear to be responding to an environment in which assistance is based on arbitrary and subjective criteria. (Kröger, 2003: 14)

Subjective feelings of burden and resentment appear to increase when caring duties are 'imposed' on carers and when no other family member steps in (p. 40). Jenson and Jacobzone (2000: 34) report similar findings, that carers who feel unsupported may experience greater feelings of burden.

⁷ This pattern coincides with more generous public long-term care systems in the Northern European countries as opposed to the Southern European countries. Therefore, one might conclude that the generosity of social protection and more specifically public long-term care – systems, has consequences for the way child-care is organised within (wider) families.

Both Kröger and the OASIS study also point to the potentially negative relationship between family care-giving and formal social support, where entitlements to services or financial support for a disabled or older person are inversely related to the amount of informal help received. Consequently those providing the most informal assistance are penalised, as the person receiving care is less likely to receive formal social protection and welfare services: 'family caring resources are "counted" only in so much as social protection systems use them punitively, as "demerits" against an individual's right to assistance' (Kröger, 2003: 92). Similarly, the OASIS study concluded that the substitution theory, by which formal care services – if available – replace informal care provision, seems to hold no ground. On the contrary, the study concluded that the provision of formal care services actually supports family care and enables family members to express their solidarity with the person in need in different ways and forms (Lowenstein *et al.*, 2003). The SHARE data reported by Bonsang are consistent with this. Bonsang concluded that there are substitution effects, especially related to household chores; however, these substitution effects seem to disappear when an older person's care needs increase.

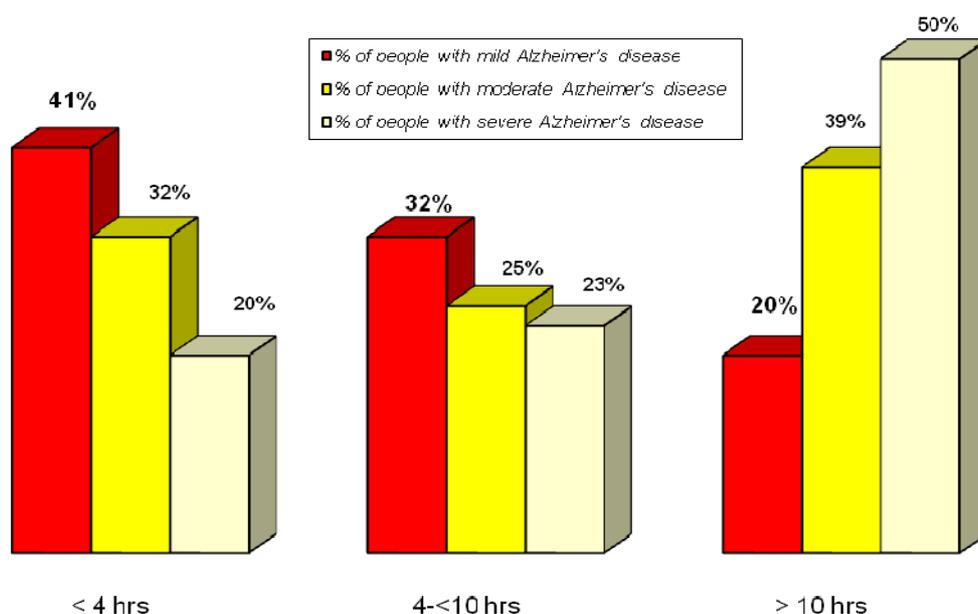
5.8 Caring for a person with dementia

Alzheimer Europe (2006) provides data on carers of people suffering from dementia. The organisation estimates that between 1.14 per cent and 1.27 per cent of the European population⁸ suffers from diagnosed dementia (Alzheimer Europe, 2006), 86 per cent of whom are cared for at home. However, behind these data is the assumption that often a period of several years elapses before a formal diagnosis is obtained, during which time needs for care gradually increase. Thus, the data from Alzheimer Europe is likely to underestimate the numbers of people suffering from dementia and the care they receive.

Generally, spouse carers of people with dementia will be elderly themselves and, although they do not have to manage the competing pressures of care and paid work, they are at risk of poor health because of their own old age. The period between the initial onset of symptoms and a formal diagnosis of dementia may be both extended and stressful for carers, especially as services are unlikely to be available yet. This stress adds considerably to carers' experiences of burden (Tjadens and Duijnste, 1999). Moreover, the level of care provided, in terms of hours per day, increases with the severity of the symptoms (Figure 5.7). Given that the average period of care-giving for an older person is estimated to last for five years (Eurofamcare, 2006), this suggests a very heavy, long-term burden; indeed the duration of care for people with dementia may last up to nine years.

⁸ It is not clear what is meant by 'European population'.

Figure 5.7 Hours per day caring for someone with Alzheimer’s Disease



Source: Alzheimer Europe (2006)

Figure 5.7 illustrates the intensity of caring for a person suffering from dementia. In early stage Alzheimer’s disease more than half of carers already spend more than four hours per day caring – that is, over 28 hours per week and are thus ‘heavily involved’ according to the criteria adopted for this project (see Chapter 1). As Alzheimer’s disease progresses, the burden increases, with half of the carers spending more than ten hours per day (70 hours per week) caring.

Four out of five carers of people suffering from dementia feel that the standards of formal professional services for people with Alzheimers’ disease are unacceptably low (Alzheimer Europe, 2006), adding to the pressure on the informal sector.

5.9 Summary and conclusions

This chapter has summarised other relevant data sources – mainly European – over and above Eurofamcare (see Chapter 3).

- There is a clear lack of EU-wide (or wider) data concerning carers.
 - Depending on the definition used, estimates of the number of carers in Europe vary from 100-125 million to 19 million carers (caring 20-plus hours per week).
 - Data on the socio-economic impacts of care-giving are hardly available. Conclusions in this area need to be drawn by inference. Nevertheless, it is likely that adverse socio-economic consequences of care are more prevalent in lower income groups.

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- More data is also needed on the coping strategies, age of carers, experiences of carers from ethnic minorities, experiences of carers in rural environments and other groups of carers who are likely to be particularly disadvantaged or experience particularly heavy burdens of care.
 - Across Europe, carers performed on average almost three different caring tasks (excluding social visits). Almost every carer was involved in personal care such as help with getting dressed, feeding, washing or bathing or going to the toilet. Half of all carers help with administrative tasks (finances, administration, dealing with professional care).
 - Care patterns vary across Europe, with a tendency for more co-resident care to be provided by people aged 60-plus in the former accession countries (CC13) than in the former EU15. The incidence of dual responsibility 'sandwich' care was also higher in the CC13 countries. A quarter of 'dual responsibility' carers have very heavy care responsibilities (Kröger, 2003).
 - Caring is a predominantly female activity. Nevertheless, amongst working carers both men and women can be heavily involved in caring. In some countries, working male carers spend more hours caring per week than working female carers.
 - Carers are a very diverse group. Their situations vary according to the age and gender of the carer and the person receiving care; the kin and generational relationship between carer and care receiver; the health and prognosis of the care recipient; the socio-economic and labour market status of the carer; and the availability and accessibility of formal health and long-term care services. All these factors will shape carers' experiences; the impact of care on their well-being and socio-economic circumstances; and will also suggest different policy responses.
 - Employed carers are a major group of all carers. But the relationship between caring and employment is complex and still under-researched:
 - five per cent of the total European population suffered job consequences because of caring; three per cent switched from full-time to part-time work; two per cent stopped working
 - when caring becomes more intense, the labour market activity of middle-aged women decreases by at least 30 per cent.
 - Despite the above, most carers are unemployed or retired (the term 'unemployed' probably conceals several population categories, see also Schultz, 2004).
 - The majority of carers are middle-aged or older. Projections show that substantially more older (65-plus) carers will provide very intense care (35-plus hours per week) in 2030, mostly for a spouse in the same household. Even now most same-household care is provided by older carers, suggesting very heavy care burdens.

- Caring for a person suffering from Alzheimer's disease is intense, long-lasting and often time consuming (over 70 hours per week).

Chapter 6 Policy and Practice Measures to Support Carers

6.1 Introduction

This chapter describes a range of policies and practice measures designed to support and alleviate burdens on family carers, including financial support for carers; services and other types of support; and work-based measures. Given the increased risks of reduced labour market participation, poverty and adverse psychological and physical health associated with informal care that have been documented earlier in this report, it is important to consider measures that support carers across a wide range of policy domains.

The chapter starts with an overview of the main types of financial support for carers. These measures are widespread across many western European and Scandinavian countries; the chapter also includes examples from North America and Australia that are potentially transferrable to the European context.

Material and financial measures that can directly or indirectly alleviate the adverse socio-economic impacts of care vary widely. Generally, the more inclusive a payment's eligibility criteria are, the lower the level of the payment (Tjadens, 2004). Measures differ widely according to their underlying rationale, target group, eligibility criteria, interactions with formal care services, level of payment and whether they are means-tested or not. They are often embedded in the social protection and welfare systems of individual countries, so their transferability to other countries is limited. Indeed, there are a few instances in which measures offering financial support for carers are available at regional level and do not even extend across the country as a whole. Moreover, the objectives of financial measures can also vary widely, depending on countries' labour market structures; the extent to which formal long-term care services are available; and, critically important, attitudes towards the roles of families (and women within families) in caring for older and disabled people. This diversity of policy objectives also makes evaluating the effectiveness of measures difficult.

In the first part of this chapter, therefore, we have set out five main models of financial support for carers. The aim is not to provide comprehensive accounts of each model, but to highlight their salient features and underlying principles. We discuss the advantages and drawbacks of each; and we illustrate these models with examples from EU and other countries (see also Glendinning *et al.*, 1997; Jenson and Jacobzone, 2000; Tjadens, 2004; Kerschen *et al.*, 2005, Lundsgaard, 2005; Glendinning, 2006; 2009 Ageing Report). We draw particular attention to interactions

between the different models of financial support and opportunities for continued labour market participation by carers; and also with carers' opportunities to receive supporting services at the same time as receiving cash payments.

In many instances, the primary objective of some of the financial measures that benefit carers is actually to provide additional financial support for the older or disabled person to help meet the additional costs of needing care; benefitting carers, if at all, is a secondary aim. The levels of many financial benefits and allowances are also very low. This means they are unlikely to act as incentives to begin caring – such decisions are likely to have been prompted some time earlier by the disabled or older person's developing need for care and not by the perceived financial rewards available. The low level of financial benefits also limits their capacity for enhancing carers' welfare and overcoming the risks of reduced earnings and poverty that carers are exposed to (see Chapters 3 and 4). Finally, measures providing financial compensation or support to carers have disproportionate implications for women, partly because women constitute the majority of carers and partly because the low level of payments does little to challenge the gender distribution of caring work and related gender inequalities.

The third and fourth sections of this chapter describe examples of 'good practice' designed to alleviate burdens on family carers, through the provision of innovative services (Section 6.3) and through work and employment-focused measures (Section 6.4). For each example we include a brief description; details of any evaluation and outcomes (where available); and comments on the potential transferability to other areas and/or EU member states.

As the research team was based in England and the Netherlands, the team was aware of possible biases towards good practice examples from these countries. Therefore particular efforts were made to obtain examples from across a range of EU countries. As described in Chapter 1, we did this by asking for examples from all the organisations and individuals involved in Eurocarers, as well as from our expert informants who provided data for Chapter 4. This strategy helped us to access information about interventions that might otherwise have been unavailable to us because of language restrictions. However, it did mean that we could not check the quality and accuracy of the material we received, or how up-to-date it was.

We asked for examples of good practice measures for all groups of carers, not just for carers of older people. In considering whether to include examples that we were provided with, particularly some that appeared to be very similar, we gave preference to measures that had been subject to some kind of evaluation; measures that extended the range of countries represented; and measures that appeared to have potential transferability to other regions or countries.

Some of the initiatives described in Sections 6.3 and 6.4 were pilot projects and we are unable to confirm whether they are still on-going. It is also possible that some highly effective measures that are embedded within mainstream provision within a particular country or welfare system were no longer thought of as 'good practice' initiatives and so we were not told about them.

Evaluations were available for some of the examples we were sent; others had not been evaluated and may be best thought of as 'good ideas' rather than examples of 'good practice'. To help assess claims of 'good practice' for each of the measures included in this Chapter, we have used the University of Wollongong schema described in Chapter 2, which identifies ten different ratings of strength of evidence (Eager *et al.*, 2007).

As noted in Chapter 2, in most cases we did not have access to any primary research reports, not least because of language issues, so we are unable to comment on the quality of the actual evaluations or whether the conclusions drawn can be fully substantiated by the evaluation data. Generally we found a lack of economic evaluations, which in turn leads to a dearth of evidence on cost-effectiveness. However, we have included examples of measures that appear to be effective, even though they may lack information about the balance between cost and benefits.

6.2 Financial payments to carers

6.2.1 Personal budgets or consumer-directed employment of carers

Instead of receiving services, an older or disabled person needing support can choose to receive a personal budget of an equivalent value to purchase care themselves, either from a nursing or care agency or by directly employing a carer themselves. There is increasing interest in personal budgets as a means of increasing choice and flexibility in long-term care; such schemes exist in the UK, Netherlands, some US states and the Flanders region of Belgium. In the Netherlands and Flanders (and to some extent in the UK) the personal budget recipient can employ a close relative, including a spouse, parent or child, to provide care. The relationship between care receiver and carer thus becomes one of employer-employee; in the Netherlands, employment by a personal budget holder above a minimum number of hours per week must be regulated by a formal contract setting out terms and conditions of employment (holiday rights, periods of notice and so on). Older people may be more reluctant than younger disabled people to take on employer responsibilities, so schemes in many US states and in England involve intermediary agencies that manage payroll, taxes, recruitment and training (OECD, 2005). However, older people are more likely than younger disabled people to employ relatives as their service providers (Wiener *et al.*, 2003).

The level of the personal budget is usually calculated by setting the number of hours of care that the disabled or older person is assessed as needing against an hourly rate (at least the legal minimum wage), thus in principle offering appropriate economic rewards for care. However, carers employed in this way report an increased sense of obligation and increased difficulty in negotiating time off or setting other boundaries to their care-giving commitments (Breda *et al.*, 2006). Consequently the overall value of the care provided usually far exceeds the payment received.

The sustainability of this arrangement relies on a continuing good relationship between employer and employee. Carers will also be financially vulnerable if the older or disabled person dies, enters hospital or long-term care. Personal budgets may attract new family members, for example, newly retired relatives, into care work. However, carers employed by personal budget-holders occupy a marginal position between the formal and informal care workforce; formal training or career advancement schemes are very rare; and carers who have spent a period employed by a personal budget holder may find themselves disadvantaged when they try to re-enter the formal labour market. Carers employed by personal budget holders may also find they are not able to access any formal care services to support or relieve them in their role.

Employing family carers through a personal budget is not universally popular. In the Netherlands, only about ten per cent of all those receiving social insurance-funded long-term care support opt to receive this in the form of a personal budget. In 2007 one-third of budget holders relied only on care provided by relatives, one-third only on care provided by care organisations and one-third on a combination of the two (Da Roit and Le Bihan, 2008). Older people are more likely than younger budget-holders to employ relatives rather than use agency services.

6.2.2 Care allowances paid to the older or disabled person

Here the cash payment is made to the disabled or older person, with no formal requirement as to how it is used; the only obligation on the recipient may be to acquire adequate care. In many instances, however, the allowance will be paid to or used by a family carer.

Care or attendance allowances are paid in Germany, Austria and France. In Germany, an older or disabled person eligible for long-term care insurance can choose between service 'assignments' up to a specified value or a lower, non-taxable cash benefit (or a combination of the two). The cash benefit option has always been more popular because beneficiaries prefer family care to formal services from strangers. However there is no obligation on the disabled or older person to give the cash benefit to the carer; there is evidence that it is not always transferred in full (Wiener *et al.*, 2003); and in other households it may simply be added to the joint

household income rather than constituting an independent source of income for the carer.

The Austrian Care Allowance is a similar unconditional benefit paid to an older person whose only obligation is to secure appropriate levels of care. Lower income families may use the benefit to support a family carer; professional families are more likely to use it to employ a live-in carer through the 'grey' labour market. In both instances, the low level of the Allowance institutionalises care-giving as women's work (Kreimer, 2006).

Supporting informal care through care allowances has many of the drawbacks of the personal budget approach; carers are likely to find themselves financially dependent on the person they are caring for. Moreover, Lundsgaard (2005) argues that such payments can create an incentive trap, attracting informal carers away from the formal market if the interactions between informal care payments, taxes, unemployment benefits and other income transfers are not well controlled.

On the other hand, it is possible to add benefits specifically for informal carers to a care allowance, although again these can only be accessed if the disabled or elderly person qualifies for the care allowance. In Germany, informal carers of long-term care insurance beneficiaries who opt for the cash benefit are entitled to four weeks break each year (with the insurance paying the costs of break respite care) and can have their pension and accident insurance contributions paid if they are not in full-time paid work and providing 14-plus hours care per week. Recent German reforms have increased funding for voluntary sector respite care centres; reduced the threshold so that respite care can be received after six months instead of a year; and introduced training courses for carers and retraining courses for carers wishing to return to paid work.

It is in principle possible in both Austria and Germany for care allowance recipients also to use some formal services, which helps to relieve the burdens on carers. However, in Austria the continuing shortage and high costs of formal services make extensive reliance on informal care inevitable. This situation both restricts carers' labour market participation and the traditional gender division of responsibility for care (Kreimer, 2006)

6.2.3 Care allowances paid directly to the family carer to replace lost earnings

The UK, Ireland and Australia all offer benefits as part of their national social security system to replace the earnings lost by carers who are unable to work or have only minimal earnings because of their care responsibilities. Here, care-giving is treated as a labour market risk similar to unemployment or sickness; carers are assumed to be members of the labour market and have entitlement to an income in their own

right. However, the level of the payment is usually very low and eligibility often depends on a strict test of carers' means and assets; it therefore offers only minimal social protection.

This income maintenance model is not compatible with carers' continuing labour market participation; eligibility criteria assume the carer has no paid work and probably no other source of income either. On the other hand, it does not preclude either carers or the people they are supporting from also receiving services.

A variation on this approach is to provide carers with income during a temporary leave of absence from work, along with rights to return to the same job. This is described along with other work-related measures in Section 6.4.3 below.

6.2.4 Paying carers instead of formal social service provision

Here, family care-giving is formalised within a quasi-employment relationship but it is the local municipality that acts as the employer rather than the care recipient (as with the personal budget model). This model operates in a number of Scandinavian countries (Jenson and Jacobzone, 2000; OECD, 2005). It reflects the high levels of female labour market participation in these countries; their continuing relatively high levels of publicly-funded services; and the challenges of delivering formal social services in sparsely populated rural areas.

In Finland, for example, the Informal Carer's Allowance is awarded on the basis of an older person's need for care but is paid directly to the carer by the municipality; the carer contracts with the municipality to provide an agreed level of care according to a care plan. The vast majority of carers employed in this way are spouses or other close relatives and a third are aged 65-plus (Martimo, 1998). Levels of Care Allowances are lower than the costs of formal home care services; they offer no incentive to continue caring but are believed to encourage carers to continue their existing care-giving responsibilities.

Carers employed by Finnish municipalities are entitled to three free days a month during a period when the nature of the care they have provided has been demanding. The municipality is responsible for providing substitute care, usually in a nursing home, but there is a huge lack of tailored, individual and suitable substitute care options. Some municipalities have developed alternative care at the care recipient's home by allowing a relative or friend of the family to take on the role of 'substitute carer'; such work is paid for by the municipality.

6.2.5 Paying carers in recognition of their care-giving responsibilities

There are a few examples of payments to carers simply in recognition of their care-giving work.

In the Netherlands an annual 'Compliment for carers' (formally known as the 'arrangement appreciation family care') payment was introduced in 2007. All carers supporting people eligible for long-term care insurance benefits could receive the Carer Compliment, which was worth €250 (tax-free). However, in its first year, only ten per cent of those expected to be eligible applied; this was believed to be partly due to the application process, which depended on insurance beneficiaries nominating a carer and was also lengthy and bureaucratic. Eligibility criteria have therefore been relaxed somewhat; it is now estimated that 266,332 carers might receive the Compliment, although its value may be reduced slightly (Vijfvinkel *et al.*, 2008).

The Australian Carer Allowance is an income supplement paid simply in recognition of the carer's role; it is paid directly to carers who provide full-time care on a daily basis for a disabled adult, older person or child. It is a universal benefit, not dependent on the carer's income or assets, and is not taxable. It is simply intended to help with the extra costs associated with care-giving. Carers who receive the Allowance may also be eligible for Carer Payment, an income replacement benefit for carers who have no other source of income (Howe, 2001). Carer Payment is means-tested on all income and assets other than the family home. An individual can claim Carer Allowance for each person that they care for, but they can receive only one Carer Payment. Virtually all recipients of Carer Payment are entitled to Carer Allowance. The Carer Allowance can be received by carers whether they have paid work or not. There is therefore no loss of benefit, and potential disincentive, for carers who remain in, or move into, paid work.

6.3 Services to support carers

Many of the examples of good practice provided to the study team were of services to support carers provided by public sector or voluntary organisations. The location of such initiatives, in the public or voluntary sector, reflects different welfare state regimes. Thus examples from Nordic and Western European welfare states reflect a more extensive professional care system; in contrast, the examples from Austria and Italy display a more family-based care orientation. Where possible, the strength of evidence on the effectiveness of each initiative is rated using the schema developed by the University of Wollongong (Chapter 2).

6.3.1 Meeting Centres Support Programme, the Netherlands

(Evidence rating 2: Supported Practice)

Description

The Meeting Centres Support Programme (MCSP) was initiated in Amsterdam in 1993; there are now 46 Meeting Centres in six provinces in the Netherlands. The Programme integrates different types of support for people with mild or moderate dementia and their carers. There is a special activities programme and psychosocial programme for people with dementia to help them cope with the dementia; and information, emotional, social and practical help for their carers. Integrated support means that each dementia patient and carer is looked after by one professional staff worker. The Programme is provided by a small team of professionals (two or three professionals for 15 people with dementia and 15 carers) in community centres in the neighbourhood, hence the name the Meeting Centres Support Programme.

Outcomes

Various evaluations of the MCSP have been undertaken over the years. A multi-centre evaluation examined the effects for carers of participating in the MCSP (Dröes *et al.*, 2006). Ninety-four carers in the MCSP in eight meeting centres and 34 carers of dementia patients who frequented regular psychogeriatric day care (PDC) in three nursing homes took part in the study. The results showed:

- a majority of MCSP carers (82.1 per cent) reported lower felt burdens and more professional support
- the integrated MCSP proved more effective than PDC in decreasing psychological and psychosomatic symptoms in lonely carers
- participants appreciated that the Programme was both aimed at patients and carers, and valued the case management approach of the staff
- in the MCSP only four per cent of the people with dementia were institutionalised as compared to 29 per cent of patients using PDC in the control group.

Potential transferability

The MCSP has been successfully implemented, with small cultural adaptations, in a meeting centre for Surinam people with dementia and their carers in Amsterdam. This adaptation indicates there is a potential for transferability across (at least some) EU member states.

6.3.2 Carer Support Workers in GP surgeries, England

(Evidence rating 4: Acceptable Practice)

Description

During 2001 and 2002, Carer Support Workers based in 15 GP surgeries in the south of England offered a range of services to carers, including: information about

services; support/liason with other services; advocacy; counselling; referral to carers' groups; referral to specialist provider; referral to practice staff.

Outcomes

Torbay Council commissioned an independent evaluation of the Carer Support Worker service. The General Health Questionnaire (GHQ) was used with 68 randomly selected carers who had had contact with a Carer Support Worker. The sample of carers had a range of difficulties and experienced high levels of need. The evaluation found that Carer Support Workers had a substantial impact on carer well-being:

- Carers' overall distress was almost halved after an average of nine months receipt of the Carer Support Worker service.
- Symptoms particularly associated with stress were also significantly reduced. These included concentration problems, sleeplessness and depression.
- The service was generally extremely well received by carers. The majority (70 per cent) reported high levels of satisfaction; 56 per cent of carers felt that the service had made 'very much' of a difference to their situation.

Potential transferability

There are similar examples of Carer Support Workers based in GP surgeries in different localities in England, suggesting the model can be implemented in countries with similar primary health care arrangements. For further information about, and examples of, good practice for carers in primary care in England, see *Action Guide for Primary Care* produced by The Princess Royal Trust for Carers and the Royal College of GPs available at www.carers.org/professionals. See also the report *Access to Health Care for Carers: Intervention Evaluations* (Arksey, 2003a).

6.3.3 Preventive support programs for carers of mental health patients (schizophrenia, depression, borderline disorders), the Netherlands (Evaluation of programme for carers of people with schizophrenia Evidence rating 4: Acceptable Practice)

Description

The LSP (National Centre for Prevention and Brief Intervention) of the Trimbos Institute for Mental Health and Addiction has developed three standardised educative programmes for carers of people with mental health problems: schizophrenia, depression and borderline disorders. The courses are based on scientific research into the different disorders and on interventions that enhance the coping strategies of carers of these groups of people. The LSP trains prevention workers in mental health institutions to offer the course to carers of mental health patients. The programmes consist of psycho-education to help carers of patients with mental health problems

cope with the symptoms of the illness and the potentially disruptive behaviour of the patient. The aim is to help carers feel more competent and less burdened.

Outcomes

The course for carers of schizophrenia patients was evaluated (Bransen and van Mierlo, 2007; Cuijpers, 1999), with the following results:

- The burdens perceived by carers were significantly lower and their feelings of well-being were significantly higher at three and six months after following the programme.
- Participants scored the course at 8 (range 0-10, with 10 being 'perfect').
- The programmes are widely implemented. For example, the programmes for carers of schizophrenia patients are implemented in 92 per cent of the relevant mental health institutions.

There are plans to evaluate the programmes for carers of people with borderline disorder and for people with depression.

Potential transferability

The programme for carers of schizophrenia has proved to be effective and is widely implemented in mental health institutions in the Netherlands. The other programmes are also widely implemented. There may be potential for transferability across (some) EU member states.

6.3.4 ACTION (frail older people and their carers), England, Northern Ireland, Portugal, Republic of Ireland, Sweden (Evidence rating 4: Acceptable Practice)

Description

ACTION was a three-year project involving England, Northern Ireland, Portugal, Republic of Ireland and Sweden that ran from 1997 to 2000. The ACTION system was located in formal care settings and also the homes of some carers; it comprised video-telephones and multimedia to provide direct support and information to carers and care recipients. The video-telephones permitted direct contact with professionals, other carers and the research site. The multimedia programmes were accessible through video or computer and covered a wide range of topics, including lifting and handling; information about respite services; and coping skills for carers. Internet and e-mail facilities were made available to some carers.

Outcomes

ACTION had two demonstration and evaluation phases, covering benefits, acceptability and cost-effectiveness (Magnusson *et al.*, 2002). There was evidence to show that:

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- ACTION helped carers to increase their competence in their caring role because it helped to develop their knowledge and skills
 - with education and support, carers aged 65 and over were able to use the information and communication technology effectively
 - ACTION reduced carers' sense of isolation because it helped them feel that they were not on their own
 - older people and their relatives developed informal support networks with other families more readily and with greater ease
 - whilst there were cost savings for municipalities, at the same time there were improvements in the quality of life of both carers and care recipients.

Potential transferability

ACTION was initially piloted in a number of European countries. Since then, it has been implemented in Australia, New Zealand and North America. This diffusion indicates there is a high likelihood that the programme could be successfully implemented across EU member states.

6.3.5 Stroke Awareness for Carers programme (for carers of stroke patients aged under 65), Ireland (Evidence rating 5: Emerging Practice)

Description

The Stroke Awareness for Carers programme was developed at the National Rehabilitation Hospital (NRH) in Dublin, Ireland, in response to the need for families to have access to education regarding the impact of a stroke. The NRH programme was designed to be interactive and to help carers/family members to support one another. There is a strong emphasis on empowering families through information and peer support, as well as on enhancing coping skills to deal with a life-changing event.

The programme uses a number of approaches including crisis intervention (mobilising circles of support; managing stress and strong emotions); group work/facilitation; family systems; solution-focused therapy (enhancing current coping skills); and grief and loss counselling. Core features are an interdisciplinary approach that is family-centred. Participants are encouraged to focus on their own needs and feelings, in contrast to the usual focus of rehabilitation on the person with stroke.

Outcomes

In-house evaluations are carried out after each course about the content and methods used and the program is adapted or customised as appropriate. If, for example, a large number of participants have relatives with aphasia, extra teaching is provided on this aspect of stroke for that particular programme. Feedback from participants is reported to be very positive.

Potential transferability

There is no reason why this programme for carers of stroke patients could not be implemented in other EU member states.

6.3.6 Siblings: an organisation for brothers and sisters of children and adults with learning disabilities, Italy

(Evidence rating: unable to classify, no evaluation available to research team)

Description

The 'Siblings' organisation (<http://www.siblings.it/english/index.htm>), established in Rome in 1997, targets brothers and sisters of people with learning disabilities.

Siblings' aims are to:

- establish self-help groups where brothers and sisters of people with learning disabilities (mostly people with Down's syndrome) can share experiences and knowledge
- improve the skills and competences of brothers and sisters to care for the disabled person
- sustain scientific research on disabilities and disseminating of results.

Brothers and sisters can keep in touch and exchange opinions, experiences and information through self help groups, meetings and congresses and a mailing list.

Outcomes

The Siblings initiative has been evaluated as 'good practice' by the National Observatory on Families (<http://www.osservatorionazionalefamiglie.it>), a technical and scientific organisation established by the Ministry of Family in 2007. Personal testimonies on the Siblings website (see URL above) attest to the value of the group to its members.

Potential transferability

Siblings Australia (<http://www.siblingsaustralia.org.au/>) is a similar national organisation committed to enhancing the wellbeing of siblings of children and adults with special needs, including disabilities, chronic illness and mental health issues. This suggests that Siblings project could be replicated across EU member states, since sibling carers face similar problems in every country. A similar generic model could be adopted, but adjusted accordingly to suit local cultural requirements.

6.3.7 Co-operation Initiatives in Home Care (Samenwerkings Initiatieven in de Thuiszorg [SITs]), Belgium (Flanders)

(Evidence rating: unable to classify, no evaluation available to research team)

Description

Co-operation Initiatives in Home Care (Samenwerkings Initiatieven Thuiszorg (SITs)) have two main aims: (a) providing a forum for consultation and cooperation in home care; (b) managing care planning for patients. The SITs are local organisations in which every discipline can participate. In managing care plans, case managers (zorgbemiddelaars) in the SITs work together with informal carers and other formal carers. A care plan contains information on the tasks and roles of the persons involved in care-giving, and can be changed according to the needs of the situation. The care plan aims to enhance a patient's capacity for self-care and provide proper support for informal carers. The care manager informs the patient and informal carers of services available. SITs are targeted at patients with high care needs.

Outcomes

According to Breda and Verlinden (2001), two out of three carers think their situation has improved after the care manager became involved. Most carers feel that their opinion has been taken into account in the process of arranging care. De Lepeleire *et al.* (2007) found that 90 per cent of carers were satisfied with the arrangements in the care plan; 80 per cent thought the care plan provided support for them and they felt better able to cope with care-giving; about 80 per cent also felt more confident about who to contact for help. However, the availability of a care plan did not make a difference for the burdens experienced by caregivers in this study.

Potential transferability

The potential for case management systems to be introduced in other European member states is likely to reflect the existing social services structures in place.

6.3.8 Practical Home Care Skills training programme, Ireland

(Evidence rating: unable to classify – no evaluation has been undertaken as yet)

Description

Launched in 2008, *Practical Home Care Skills* is a comprehensive 14-week training programme (three hours per week) designed to provide course participants with the practical skills and knowledge required to deliver high quality home care while also gaining a recognised FETAC Level 5 qualification. It has been designed specifically with the following people in mind: family carers; home helps; respite workers; care assistants; individuals wishing to pursue a career in the care sector. The *Practical Home Care Skills* programme comprises four units: Unit 1 – Communication and

Listening Skills; Unit 2 – Safe Caring; Unit 3 – Practical Care Skills; Unit 4 – Care Support.

Outcomes

No formal evaluation has been undertaken of the *Practical Home Care Skills* training programme as yet. Intended learning outcomes for people who successfully complete the training are to:

- develop good communication skills relevant to the care role
- understand the personal care needs of the person being looked after
- understand the importance of maintaining a safe, healthy and hygienic environment for the person being cared for
- acquire the practical skills that maintain the best quality of life for the person being looked after
- identify the needs and supports that are available to carers providing practical care.

Potential transferability

The *Practical Home Care Skills* training module is recognised within the National Framework for Qualifications – a European-wide framework that sets consistent standards in education and training; the promotion of quality; increasing training access, transfer and progression opportunities; and improving international recognition of basic qualifications. The *Practical Home Care Skills* training module model could therefore be easily replicated within other EU member states.

6.3.9 ‘All Round Care at Home’ project (Rund um die Pflege daheim), Austria (Evidence rating: unable to classify – no evaluation available to research team)

Description

This project involves local groups, services, presentations, events and support for carers. Some local groups focus on carers of people with specific illnesses such as dementia or multiple sclerosis. Groups are organised regularly (at least once a month for two hours) in different localities and venues of the region (Vorarlberg), in collaboration with adult education institutes, GP surgeries or local associations. Specific aims are to:

- organise events, provide information, publications and presentations about care, for carers, by carers, with carers in the region (Vorarlberg)
- facilitate the exchange of experiences and information between carers locally
- provide an opportunity for carers to have some time for themselves in a protected and supportive environment.

Outcomes

No evaluation is available and no examples of outcomes have been provided. However, it is reasonable to assume that carers attending these groups are likely to be better informed about available services, support and benefits, and that they stand to benefit from sharing experiences with other people in a similar situation in a 'safe' environment. There is also the possibility of carers extending their social networks so they are at less risk of isolation.

Potential transferability

A holistic approach to carers' support, reaching from general information, public events and the organisation of carer groups to specific services and support in a local context is certainly worth considering if the average 'career' of carers is more than eight years. Different needs of individual carers have to be addressed and/or met within the local context; this also requires that such activities are coordinated at a regional level.

6.3.10 Time off for Family Carers (ANNA – Angehörige nehmen Auszeit), Upper Austria

(Evidence rating: unable to classify – no evaluation available to research team)

Description

This service, which is provided by the Upper Austrian branch of the Public Health Insurance, goes beyond the usual services of health insurance by organising a service that allows carers to take a necessary cure at a health resort, if the carer has been diagnosed as suffering from care-related health problems such as back pain, depression or psycho-somatic illness. As well as the usual therapies, counselling about problems and solutions related to the care-giving situation is also provided during the carer's stay at the health resort. Services are organised to replace the family carer for a period of three weeks. About 400 Upper Austrian carers take up this service per year. For further information, see <http://www.oegkk.at/portal/index.html> and search 'ANNA'.

Outcomes

No evaluation is available about this service, but it can be hypothesised that carers would benefit from a stay at a health resort and the opportunity to focus on their own health needs.

Potential transferability

In principle, there would be scope for introducing this service in other EU member states. Its cost can be justified as a preventive measure to sustain the pivotal role of carers in community care and avoid additional expenditure on treating carers who develop serious health problems of their own through lack of a break.

6.3.11 Pay slip campaign, Scotland

(Evidence rating: unable to classify – no evaluation available to research team)

Description

Some information sources for working carers can be exclusive; for example employees without access to work-based computers are unable to benefit from digital information available to colleagues with access to a PC. The 'pay slip campaign' in East Ayrshire, Scotland aims to identify and inform all working carers. Information provided by the local carer's centre is included in the pay slips of all employees of large local companies.

Outcomes

No evaluation is available, but it should be a low cost measure with the potential to benefit employed people with care-giving responsibilities who might otherwise not know about local support services. Other methods would of course be needed to direct information to self-employed carers.

Potential transferability

Transferability depends on whether information about monthly wages is automatically sent to all employees. Costs are minimal given that information is added to existing regular mailings to employees.

6.3.12 Carers Emergency Alert Card, England

(Evidence rating: unable to classify – no evaluation available to research team)

Description

Many carers are anxious about what happens to the person they care for should they be involved in an accident or taken ill. Many English local authorities have introduced a confidential carers emergency alert card scheme. The card contains an emergency call centre phone number; the call centre keeps all the information needed for appropriate help to be sent to the cared-for person. Carers registering with the scheme complete a form detailing the action to be taken in the event of an emergency. There is also a similar card for care recipients, which is especially useful for people with memory problems or learning disabilities. There is no charge for the scheme and the service is confidential – no personal details are included on the card.

Outcomes

No evaluation is available. The intended benefits of the carers emergency alert card are that carers:

- have emergency cover 24 hours a day

- can be less anxious about going out or leaving the person they care for alone for a short time.

Potential transferability

Transferability depends on there being a local health call centre, with appropriate database systems. It has already been introduced in many local authorities in England.

6.3.13 Cinema Exhibitors' Association (CEA) Card, UK

(Evidence rating: unable to classify – no evaluation available to research team)

Description

The CEA Card is a national concessionary card developed by the Cinema Exhibitors' Association for UK cinemas that allows disabled people to obtain one free ticket for a person accompanying them to the cinema. There is a small charge to cover the administrative costs of the scheme. The card is issued to the person who requires assistance, so that they can be accompanied by a family carer or care worker. The aim of the CEA Card is to provide a consistent national approach to the provision of complimentary tickets for people with disabilities – previously this was available on a site-by-site basis. Around 90 per cent of UK cinemas support the scheme. Individuals applying for the card need to be in receipt of a specified disability benefit or be registered blind. For further information, see: <http://www.cinemauk.org.uk/ceacard/>.

Outcomes

No evaluation of the CEA card by disabled people and their carers is available. However, as the card can be used in the majority of cinemas and as carers and disabled people can be disadvantaged financially, the CEA offers carers the opportunity to enjoy movies free of charge.

Potential transferability

The financial cost to cinemas is likely to be small as without the CEA card disabled people and carers, both often on low incomes, would not have been able to buy two tickets. The involvement of all major UK cinema chains suggests that other national associations may be amenable.

6.3.14. Carers Leisure Pass, England

(Evidence rating: unable to classify – no evaluation available to research team)

Description

A voluntary organisation Carers Centre in the north of England is piloting a Carers Leisure Pass, which gives carers unlimited access to local authority swimming, gym and leisure facilities (PRTC and Crossroads – Caring for Carers, 2009). Use of the card is monitored. If it is not used for a continuous period of two months, then the carers centre is informed. They then contact the carer to check if they: are unwell; are having difficulty using the Leisure Pass; or no longer want the Pass, in which case it is withdrawn and issued to another carer.

Outcomes

No evaluation is available. However, there is potential for it to improve health outcomes and reduce carers' use of health services.

Potential transferability

There is potential for the scheme to be implemented in other areas, depending on administrative and resource issues. The statutory responsibilities of English municipalities to promote the well-being of local people may have helped secure municipal commitment. The scheme has the indirect benefit of alerting the organisation running the scheme to possible problems the carer may be facing.

6.4 Employment and workplace-related measures

The interventions described below are designed to support carers sustain paid work, or return to work after or during a period of care-giving.

6.4.1 People into Employment, England

(Evidence rating 4: Acceptable Practice)

Description

People into Employment (PIE) was established in north-east England in 2000 to assist carers and people with disabilities return to paid employment. Initially, PIE was a small project managed by a multi-agency steering group but is now part of a not-for-profit training company. It retains strong links with partner training and employment organisations. PIE provides information about training and employment opportunities; offers basic training, including confidence-building; directs carers to other organisations for training in specific skills; accompanies clients to job interviews; and offers on-going support to carers through the process of re-entry to work.

Outcomes

PIE's modest costs have meant it has been sustainable. It has supported carers and former carers to find, and stay in, paid work; others do voluntary work in preparation for paid employment. An independent evaluation found that key factors in PIE's success included: job search activities and training specifically tailored to each client's abilities and strengths; and a timetable for training and job searching appropriate to individuals' circumstances (Arksey, 2003b).

Potential transferability

This support initiative has modest costs and is managed by a not-for-profit company. Partnership working – with mainstream services; agencies with direct contact with carers and/or who can help with financial advice, obtain packages of care and so on; employers; training and employment agencies – is an important success factor.

6.4.2 Suite of work-related support services, England

(Evidence rating: unable to classify – no evaluation available to research team)

Description

As part of the international ACE2 (Action for Carers and Employment) partnership, one local authority in south-east England developed a package of tailored services to help working carers or carers wanting to work to explore employment options, calculate potential income and gain protection in the workplace (see Yeandle and Starr, 2007 for details of this and other employment related services; see also Yeandle *et al.*, 2007). The services include:

- pre-career guidance to help carers consider all options including retraining and volunteering
- money advice to help carers calculate their likely income, including the impact on benefits and cost of additional services to replace their care-giving role
- opportunities for carers to access courses at local colleges
- agreements between carers and work-place managers to safeguard any special work arrangements (for example, flexi-time) that accommodate carers' needs.

Outcomes

There is no evaluation of the effectiveness or cost-effectiveness of these measures. However, the project has enabled the local authority to maintain resources and tailored services to meet (working) carers' needs (Yeandle *et al.*, 2007).

Potential transferability

The scheme brings together existing sources of information and support for other similarly disadvantaged groups such as the long-term sick and unemployed, and targets these specifically at carers. According to Carers UK, a large national carers

organisation, this package of employment support services has potential to be transferable across EU member states.

6.4.3 Right to paid work leave arrangements, the Netherlands

(Evidence rating: unable to classify – no evaluation available to research team)

Description

Employed carers in the Netherlands are helped to stay in work because of relatively generous leave arrangements. Under the Work and Care Act 2001, carers can take advantage of different types of care leave, including: two days paid ‘calamity’ leave to deal with an emergency situation; short-term unpaid leave for up to ten days per year; and long-term unpaid leave to look after a relative with a life-threatening disease for up to six weeks full-time or 12 weeks part-time. Another option is the Life Course saving scheme, whereby employees can ‘bank’ time or wages, which they can later exchange for educational leave, sabbatical leave, care leave or early retirement.

Outcomes

Statistical data suggest that Dutch people providing care rarely make use of long-term care leave (CBS, 2007). As far as the Life Course scheme is concerned, women are more likely than men to take advantage of the facility. Those caring for a partner and those with a full-time job (28-plus hours per week) use such arrangements more often than those caring for a parent or child or carers working part-time. Carers in public sector employment also use the arrangements more than others (de Boer *et al.*, 2009). However, many women – especially those in low income groups – face difficulty in banking enough time because of part-time work, discontinuities in paid employment, and having previously used up any savings for parental leave (SCP, 2004).

Potential transferability

In principle, there is scope for implementing similar forms of employment leave to help carers provide work and care at critical times in care-giving situations, although there are potential resource implications for employers and/or the state. Other countries, including Finland, England, Sweden, Australia and Canada, have also introduced legislation giving employees with care-giving responsibilities the right to limited amounts of paid or unpaid leave. Canada’s (Employment Insurance) Compassionate Care Benefit scheme is particularly generous. It gives eligible employees who are absent from work to provide care for a gravely ill family member the right to six weeks of compassionate care benefits (up to 55 per cent of average insured earnings) without putting their jobs or income at risk (Williams *et al.*, 2006).

6.4.4 Right to request flexible working arrangements, England

(Evidence rating: unable to classify – no evaluation available to research team)

Description

In England since April 2007 carers of disabled adults or older people have had a legal right to request flexible working such as altering arrival and leaving time, compressed working hours, job sharing or part-time working and working at home. Employers can refuse such requests, but must demonstrate clearly why. Parents of disabled children have had this right for some time and experience shows that about 80 per cent of their requests are granted.

Outcomes

Flexible working arrangements are critically important in enabling carers to combine work and care (Arksey *et al.*, 2005). It can therefore be assumed that flexible working helps carers continue in work when they might otherwise have to leave paid employment altogether, with all the negative financial and health consequences. Creating a legislative right for carers to request flexible working may reduce any stigma or negative attitudes that carers face in the workplace.

Potential transferability

Other countries have also introduced legislation around flexible working, suggesting considerable scope for transferability. In the Netherlands, employees can ask for flexible working arrangements four months ahead (Labour Hours Act 1995, later incorporated within the Work and Care Act 2001). Employers are asked to deal with such requests 'in a reasonable way' but have the right to refuse in the interests of the organisation.

6.5 Conclusions

- There are different models of financial support for informal care. Some models direct resources at the person needing care, who uses these resources to employ or provide financial support for the carer; the carer has no independent income of their own and may become financially dependent on the person receiving care. Other models of financial support provide low level replacement incomes for carers who cannot earn because of their care responsibilities; however these are usually means-tested and very low in value. In the Netherlands, the Carers Compliment is one of the few European examples aimed purely at recognising and appreciating carers' efforts.
- Different models of financial support for carers have implications for carers' ability both to undertake other remunerative work and to access formal services that substitute for family care and therefore provide a break from care-giving. Most

restrictive in these respects are models of financial support that assume informal care-giving to be a full-time role and which is therefore incompatible with mainstream labour market participation and also assumed to reduce demand for formal services.

- All of the models of financial support for informal care offer only very low levels of financial reward in comparison to the actual level of care provided. Even where hourly payment rates are at or above the minimum wage, the total volume of care provided usually far exceeds the hours that are actually paid for. Income replacement benefits for carers wholly unable to work are typically means-tested and paid at very low levels. The low levels of financial payments for informal care are likely to reinforce existing gender inequalities and unlikely to change the gender distribution of caring work. 'An unequal distribution of caring work contributes to income inequality, inequalities in retirement incomes and in participation in social life' (Jenson and Jacobzone, 2000: 34).
- Existing models of financial support also do little to bridge the boundaries between informal care and formal labour market participation, for example by explicitly encouraging carers to retain contact with the labour market while caring. There is also no evidence of measures to formalise the skills acquired in informal care-giving as potential assets for future employment (Fujisawa and Colombo, 2009), even where carers have previously been employed by care recipients holding a personal budget. Some workplace-based measures do offer carers leave for an extended period with their jobs protected, but long-term paid leave is unusual.
- Examples of good practice measures from EU member states to relieve carer burden which have been rigorously evaluated are very limited in number. Thus even though many initiatives are developed to support carers, there is little scientific evidence available on what works, why it works, for whom and what the short- and longer-term impact on the carer and/or the person they care for might be. Some examples of good practice are multi-component interventions; with these it is even more difficult to identify what particular elements of these intervention are effective and why.
- Based on the evidence from the range of initiatives described here, factors that contribute to effective support for carers include:
 - a 'package' of complementary interventions or combination of different approaches that provide synergy; for example, day care for the care recipient combined with psychosocial support and practical help for carers
 - tailoring the package to meet the needs of specific categories or groups of carers and care recipients, such as people with dementia, or other mental health problems, and their carers
 - acknowledging the common concerns of carers and care recipients, as well as their separate needs

- embedding the intervention within existing networks, linked to existing professions
- being easily accessible.

Chapter 7 Summary, Discussion and Recommendations

7.1 Aims and methods of the study

7.1.1 Aims of the study

This project, carried out at the request of the European Commission (DG EMPL), aimed to identify and collate evidence on the prevalence and socio-economic impacts of informal and family care-giving, with a focus on those with the heaviest care obligations or burdens. The project aimed to gather evidence on:

- The prevalence of family care-giving in EU countries, including recent and anticipated trends; and the provision of long-term (informal) care within a family setting to dependent family members or relatives.
- The socio-economic impact of care-giving on the households of family carers. The review was to focus on the most vulnerable carers, paying particular attention to gender inequalities in care-giving and their consequences.
- Measures aimed at alleviating burdens on family carers by:
 - supporting them in the provision of care, and/or
 - compensating for the adverse socio-economic consequences of care-giving.

Ideally, the study aimed to identify EU-wide evidence on the prevalence and impacts of informal and family care, including numbers of vulnerable carers with particularly heavy care-giving responsibilities. Again ideally, information on the social and economic impacts of care-giving would focus on those carers with the heaviest responsibilities as measured, for example, in the number of hours per week spent on caring tasks; and would compare this data with information on the situations of non-carers.

7.1.2 Challenges in conducting the study

The study depended on utilising easily accessible and comparable information. It quickly became apparent, however, that the necessary data was scarce, both at EU level and also within member countries. There is currently no substantial, EU-wide body of data on the current and projected numbers of carers, whether with lighter or heavier care responsibilities; or on different groups of carers, such as carers of older people, young carers or carers of people with psychiatric problems.

Reflecting concerns about demographic trends, it was not surprising that the study found the most extensive evidence to be available on the informal care of older people (Chapter 3). However, even the 23 National Background reports produced for

the ground-breaking FP5 Eurofamcare project, which again relied on secondary data sources, sometimes lacked consistency in the definitions and terms used.

Problems of consistency were even greater when trying to collate information from across individual member states. Some national data sources focused only on carers of older people; other sources included carers of people of all ages. Few data sources identified 'heavily burdened' carers – those with the most intensive involvement in care-giving; those distinctions that were used, such as the number of hours per week spent caring, were rarely comparable. It was not always clear whether national data included help given to people who were only temporarily sick; some countries did not appear always to exclude care of non-disabled children from their data on carers.

Furthermore, the concepts of 'burden' or obligation are complex; available published research uses both objective and subjective dimensions and these may not always co-vary. Thus someone with relatively light responsibilities may experience a heavy burden, while someone with many intensive obligations may feel not burdened at all. Both subjective and objective dimensions are likely to be affected by wider cultural expectations about the respective responsibilities of families and the state; and by the levels of support from extended families and formal services that are actually available locally and are acceptable to carers and those needing care.

The 'socio-economic impacts' of informal care are also potentially wide-ranging. The review aimed to identify evidence on the employment, financial, social, health and other aspects of carers' situations, if possible compared against similar individuals and households currently without care-giving responsibilities. However, such data were not readily available; moreover evidence on the health, employment or financial consequences of care-giving is rarely compared with relevant population norms. The methodological challenges and shortcomings of the available data are discussed in detail in Chapter 2.

The study aimed to identify initiatives aimed at alleviating the socio-economic burdens experienced by those carers with the heaviest burdens (Chapter 6). Financial measures to support informal care are commonly embedded within, and reflect, the welfare systems, institutional arrangements and assumptions about family and gender responsibilities of individual countries. They are therefore not always easily transferrable.

There is a wide array of potential service initiatives to support carers. Some are mainstream and widely available in some countries or local areas; others are pilot, experimental initiatives, dependent on short-term funding. Moreover, good practice measures within one welfare system or local context may be difficult to adapt and transfer to other settings. Most seriously, relatively few appear to have been subject to rigorous evaluation.

7.1.3 Amendments to the original study design

The team originally planned to examine cross-national research datasets, particularly on family care for older people collected for the Eurofamcare study; and to supplement this with data on carers of other groups of disabled people, from between six and eight EU countries that, between them, represented a range of welfare regimes. However, as summarised above and described in detail in Chapter 2, serious challenges in implementing this design soon became apparent:

- There was a lack of comprehensive, up-to-date data on carers of older people other than available in the Eurofamcare study.
- There was even less data concerning carers of people other than older people.
- There was a lack of consistency in the definitions used by a wide range of research studies in estimating numbers of carers. There were also inconsistencies in the criteria used to identify carers with ‘heavy burdens’ of care; some data sources did not identify these carers at all.
- Concepts like ‘heavy care obligation’ or ‘burden’ are mostly used as dependent variables – the outcomes of care-giving – rather than as independent variables that would allow us to identify the consequences for this particular group of carers.
- Assumptions about the numbers and roles of carers was sometimes derived from data on older people and other people with care needs, rather than from primary data gathered on carers themselves. Other data on carers was derived from studies of people receiving particular disability- or care-related benefits and was therefore restricted by the eligibility criteria and take-up of the benefit.

These challenges led to an adjustment of the original study design:

- The study was extended to include a wider range of EU-wide datasets than originally planned (Chapter 5).
- Expert informants from a small number of countries, where it was believed that possibly relevant data were available, were asked to supply data specifically on carers of non-elderly people (Chapter 4).
- Both members of Eurocarers and expert informants were asked for examples of ‘good practice’ in supporting carers and/or alleviating the adverse socio-economic impacts of care-giving, with a focus on examples that had been independently evaluated to establish clear evidence of their effectiveness (Chapter 6).

The project was carried out by an English-Dutch team. This meant that gathered data needed to be available in languages readable to the team. As both the Netherlands and England/the UK also have long-established and extensive traditions of research on informal and family care, it is possible that this report is biased towards evidence from these countries. However, these long-established traditions mean that research

and policies from these two countries may have particular relevance for the future research activities of other advanced European welfare states.

7.2 Main findings of the study and issues for discussion

7.2.1 Numbers of carers in the EU

Estimates of the numbers of carers in the EU vary according to the definitions of the EU and of carers that are used, and the methods used to identify carers in EU-wide data, in particular, reflects the process of enlargement that has taken place since 2003; sometimes it is restricted to the original 15 member states and sometimes includes new member states as well. However, the significant differences in patterns of family obligation and formal welfare services between the older and newer member states (see Chapter 5) mean that figures from the EU15 cannot simply be scaled up to reflect current EU membership; the prevalence and consequences of informal care in the older and newer member states appear to be very different.

Some national and international studies identify carers indirectly, through the older or disabled person needing help, but this risks under-estimating the numbers of carers if it is assumed that each older or disabled person has only one carer. Many studies focus only on carers of older people, or people caring for elderly parents, again leading to potential under-estimates. In some countries, informal carers are identified with reference to administrative categories, such as those receiving a specific service or benefit, or those supporting elderly or disabled recipients of a specific service or benefit, thus excluding eligible non-applicants. Some criteria used to identify carers do not specify a minimum length of time and so risk including those caring for a sick person on a temporary basis.

Alber and Köhler (2005) estimated there are about 100 million carers in Europe in 2003 – about a quarter of what was then considered the total European population. However, this was derived from the European Quality of Life Survey; it did not specify any minimum number of hours per week or duration of care-giving episode and is likely to include many people with only very light care commitments.

Grammenos (2005) used an operational definition of carers as those providing at least 20 hours a week help, in order to exclude those with very light care commitments. He estimated that in 2005 there were around 19 million carers over the age of 25 in the EU. Of these, around 9.6 million could be considered very 'heavily burdened', in that they were caring for at least 35 hours per week. However, again this is only a rough estimate based on data from only 11 countries, plus additional UK and other data. In addition, using data from England and Australia, it is estimated that between two per cent and four per cent of all children and young people have additional care responsibilities, usually arising from the chronic illness or disability of

a parent. All these estimates may also need adjusting, given different patterns of family responsibilities, employment and other key variables in newer EU member states.

Grammenos (2005) also estimated that the numbers of carers aged 25-plus would increase by 13 per cent by 2030, to 21.5 million (providing at least 20 hours a week care) and 10.9 million (providing at least 35 hours a week care), with a marked increase in numbers of older carers.

Further calculations carried out by the study team, combining findings from the Second European Quality of Life Survey with Eurostat population statistics, concluded that 32 million people are actively caring on a daily basis across the EU27. However, the available data does not allow any more detailed estimates, for example of the numbers caring for more than 20 hours a week.

All the national and cross-national data accessed by the study team shows a markedly higher prevalence of care-giving among women compared to men – it is estimated that between 60 per cent and 80 per cent of all carers are women. Moreover, when caring becomes more intense, women are also more likely to bear the main responsibilities.

Despite these findings (and particularly the extensive evidence generated by the Eurofamcare study) there are still major gaps in the available evidence. Estimates of the numbers of carers, of those with the heaviest responsibilities and details of the impact of these responsibilities on carers all remain very tentative. As noted earlier, these shortcomings are underpinned by the absence of a common definition of ‘carer’ and of common criteria identifying those with the heaviest care responsibilities. Attempts to derive EU-wide estimates have also been affected by the shifting boundaries of the EU during the recent process of EU enlargement.

7.2.2 Variations within and between EU countries

Patterns of informal care, societal attitudes towards informal and family care, and the roles of the state in supporting families in their responsibilities for family care-giving, vary widely across the EU.

There are clear indications of regional differences in attitudes towards carers and/or in (public) long-term care regimes; depending on the dominant regime, more or less responsibility is placed on the shoulders of carers and potential carers. In countries where families are assumed to be primarily responsible for the care of older and disabled people, fewer resources are available for formal services (EPC and European Commission, 2006; Lamura *et al.*, 2007), thus placing greater burdens on informal carers and often taking their input for granted (Kröger, 2003), despite the

opportunity and other costs incurred. These costs are reflected in a lower quality of life among carers in the Mediterranean countries compared with carers in countries like the UK and Sweden (Mestheneos and Triantafillou, 2005b). Alber and Köhler (2005) identify an East-West divide, with Eastern EU countries placing greater pressures on carers; more care provided within the same household, especially by people over 60; and with a higher incidence of carers who also have responsibility for dependent children. According to Eurofamcare, inter-country differences in patterns of care for older people also reflect different employment patterns, particularly among women; and differences in the prevalence of extended, multi-generational family households (Mestheneos and Triantafillou, 2005a). Furthermore, Kröger (2003) found that in Southern European countries time to care for one's children appeared to be sacrificed to care for an elderly relative, whereas in Northern European countries childcare responsibilities reduced the care given to older relatives.

The SHARE study (Bonsang, 2006) also suggests that family care co-varies with socio-economic status; lower socio-economic status tends to be associated with the provision and receipt of informal or family care (although the evidence is not extensive). However, causal relationships between socio-economic status, poor health leading to needs for care and the prevalence of care-giving are complex. Are lower socio-economic groups or individuals more likely to provide more informal care because the opportunity costs of reduced labour market participation are less pronounced; or does extensive informal care-giving lead to reduced social mobility; or do both reflect the impact of a third, underlying variable such as the poor health status of both carers and people needing care?

It is also reasonable to assume that the prevalence and nature of informal care will differ between rural and urban areas within any member state, because of the difficulty of providing extensive formal services in sparsely populated rural areas and their poverty compared to urban areas.

7.2.3

Carers of older people

The most extensive data on carers focuses on carers of older people or carers supporting elderly parents. The Eurofamcare study found that:

- Seventy-six per cent of main carers of older people were women.
- Carers' mean age was 55.
- Nearly 50 per cent of carers were children of the older person.
- The median number of hours of caring was 24 hours a week, the mean was 45.6 hours a week.
- The average caring episode lasted for five years.
- Forty-one per cent of carers were also in paid work.

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- About one in four carers lived further away from the older person they were supporting than ten minutes by car or public transport.
 - Caring involved meeting health needs (sometimes including nursing and medical care); providing emotional and psychological support; helping with mobility and transport; helping with domestic tasks; providing emotional, psychological and social support; managing finances; dealing with welfare agencies; and organising formal care services.
 - Caring, although rewarding for many, often had adverse physical and psychological consequences, as well as additional financial costs and/or loss of income. Depression and exhaustion were common, especially among those caring for more hours per week, over a long period and/or without (social) support.
 - A key motive for caring was love, reciprocity and/or 'wanting to do something in return'.
 - For half of carers, a perceived absence of alternative options was a key reason for providing care.

The Eurostat study (2007) on health care and long-term care provides – so far unique – EU(30)-wide data on those who cared for their parent(s) during the last year.

- Carers performed – on average – three caring activities (not counting visits).
- Almost every carer provided personal care (IADL) such as help with getting dressed, feeding, washing or bathing or going to the toilet.
- Half of the carers also helped with finances, administration and liaising with professional services.

7.2.4 Carers of non-elderly disabled and chronically ill people

The study also sought evidence on carers of other groups of (non-elderly) people from expert informants in five countries (England, Netherlands, Belgium, Austria and Italy). The majority of carers of non-elderly people in the five countries were aged 45 and over (but some data sources included carers of older people as well, which may have increased the age distribution). The majority of carers were women. Most carers lived with the person they cared for – an indicator of more intensive care-giving and a reflection of the relative prevalence of care for spouses and for disabled children among this group. In addition, up to ten per cent of carers were looking after two or more disabled people (one of these may have been an older person). Less burdensome care-giving – help with practical and domestic tasks – was more prevalent than more onerous personal care such as bathing and dressing.

Research on carers of non-elderly people in all five countries found negative impacts on their physical health and emotional well-being. There was also clear evidence of negative effects on carers' labour market participation, especially for people caring over 20 hours per week. People caring for partners (among the most 'heavily burdened' carers) were particularly likely to reduce the number of hours worked. There was evidence of differential employment effects according to gender; women were more likely than men to work part-time or stop work altogether. Carers' financial situation was therefore detrimentally affected by care-giving; the longer the duration of the period of care-giving and/or the higher the number of hours of care provided, the larger the negative impact on carers' earnings. Reflecting their potential for higher earnings, male carers tended to experience more extensive financial effects than female carers, particularly when co-resident with the care recipient.

Across Europe, between two and four per cent of children and young people are also likely to be caring for a disabled or ill relative. Their education and training are likely to be affected, which means that in turn it can be difficult for them to find and sustain paid work.

Parent carers of disabled children have substantial and long-term care-giving responsibilities, with subsequent marked negative impacts including poor health, reduced labour market participation and long-term adverse career prospects.

Overall, the available evidence on carers of non-elderly people was sparse and fragmented. Some national data sets did not differentiate between carers of older people and those caring for working age disabled or chronically ill people or disabled children. Differences in sample sources and definitions made comparisons between countries impossible. Some countries appeared to collect no data on carers of non-elderly people themselves but estimated prevalence rates and care tasks from surveys of the households of disabled people, or from surveys of people receiving specific benefits.

These shortcomings in available data are important, as carers of non-elderly people are likely to be more diverse than carers of older people; they are also more likely to be of working age themselves and thus more vulnerable to adverse effects on their employment and income.

7.2.5 Older carers

Reflecting the prevalence of older people as the recipients of care and the roles of adult children in providing that care, there is a concentration of carers in the 50-64 age group. This is confirmed by a wide range of data sources including Grammenos (2005), Eurofamcare, SHARE, Eurostat (2007), Alber and Köhler (2005) and Anderson *et al.* (2009).

Although the EU is currently primarily interested in the relationship between care obligations and labour market activities, the prevalence of older carers will become increasingly important in future, as more spouses or partners of elderly people become carers (Grammenos, 2005). There is currently very little evidence on the circumstances of carers who are themselves elderly.

As the European population ages, the age of carers will increase as well. Moreover, as carers grow older, the intensity of care-giving increases, with economically inactive people aged 70-plus spending on average 25 hours a week caring (Schultz 2004). Older spouse carers are likely to have very substantial care burdens; they are more likely to be co-resident carers; to have health problems of their own; and also more likely to be caring for a partner with a deteriorating and stressful cognitive condition such as dementia. Evidence is needed of measures that are effective in supporting older carers. Without these, older carers may be at greater risk of breakdown, with consequent implications for younger generation family members and/or increased risks of admission to expensive institutional care.

Moreover, the European Employment Strategy is encouraging the extension of working life. Research into the growing care responsibilities of older people, as well as those of current working age, will therefore be needed to inform policy measures aimed at helping people stay in work for longer.

7.2.6 Carers with multiple caring responsibilities

Many working age carers have simultaneous multiple responsibilities, for non-disabled dependent children as well as for older or disabled relatives. The Eurofamcare study estimated that one in three carers support more than one person with a care need, albeit with major differences between countries (Chapter 3). We found similar evidence for carers of non-elderly people in Austria, Italy and the UK (Chapter 4). Australian research suggests higher rates of depression and worse mental health for parallel carers (Edwards *et al.*, 2008). However, more evidence is needed about the prevalence and experiences of people with multiple care responsibilities, and the policies and practices that are most effective in supporting them.

Even less information is available about the prevalence and experiences of 'serial caring', where carers take on one caring responsibility after another. These carers are likely to experience severe labour market and financial disadvantage as a result.

7.2.7 Carers from ethnic minorities

The study did not set out to identify research specifically on carers from ethnic minority backgrounds. However, it is likely that language and cultural traditions, including those relating to illness behaviours and care obligations, are different – it is not possible to say whether they result in more onerous care responsibilities. Carers are also likely to experience difficulties in accessing mainstream service provision – we found only one example of ‘good practice’ that had been adapted for a minority ethnic community (Chapter 6). There appear to be major gaps in research evidence across the EU on these carers.

7.2.8 Care and gender

Caring is gender-based; women take the brunt of caring and are also the majority of care receivers. This gender bias is even more marked when physically intimate and/or emotionally more demanding tasks are involved. The proportion of men caring is smaller; they care for fewer hours per week; and the tasks they undertake are less onerous and stressful. Broadly speaking, the pattern is very similar to that found in relation to housework and childcare; women are more likely to organise paid work around care, while men tend to organise care around work.

There is a complex interaction between local labour market opportunities for women and men, financial payments to informal carers and gender responsibilities for care. In all EU countries, part-time workers are more likely to provide care, and to provide higher levels of care, than full-time workers; and even in Nordic countries, women are more likely to work part-time than men. Nevertheless, even where full-time work for women is the norm and part-time opportunities are rarely available, as in many Eastern European countries and Portugal, women still predominate among care-givers. It has also been argued that the conditions of entitlement and low levels of many forms of financial support for carers do little to redress the gender imbalance in care.

As care is mainly a female activity, the consequences of caring have more impact on women than men. According to data found by this study, these effects include:

- not being able to (fully) participate in the labour market, associated opportunity costs and lower incomes both currently and in the future
- higher expenditure on care-related services
- emotional consequences, exhaustion and depression and other adverse health effects
- where direct payments, personal budgets or care allowances allow informal carers to be paid for (some of) the support they provide for a disabled or older person, this tends to reinforce women’s primary responsibility for care.

However, with population ageing and an anticipated increase in numbers of older carers, it is likely that more men will become carers in their own old age. The interactions of gender and age-related factors, and the appropriateness of existing services and support arrangements for older male carers will also need investigation in the future.

7.2.9 Indicators of carer burden

Direct evidence on the extent to which carers experience undue burdens as a result of their responsibilities is scarce and conclusions have to be inferred from data on, for example, carers' health and well-being. However, it is estimated that between ten and 25 per cent of carers of older people show signs of experiencing heavy burdens (de Boer *et al.*, 2003; Kröger, 2003). German data provided for Eurofamcare suggested even higher rates (41 per cent of carers of older people were carrying heavy burdens of care).

Although evidence on causality is lacking, caring (for an older person) is often linked to relatively poor health status and poor quality of life on the part of the carer. Half the carers of elderly people across Europe report feeling 'trapped' in the caring situation. Other problems reported by carers (of older people) include additional costs; juggling with time; attenuated social networks; and feelings of exhaustion and/or depression. Difficulties experienced by carers can impair the quality of care-giving. When care-giving is undertaken out of a 'sense of duty' because no alternative is perceived to be available, rather than as the result of motives such as love or affection, it is likely that the felt burden will be higher, all other factors being equal. However, religion may function as an antidote to negative feelings of depression or anxiety, as was reported in, for example, Malta and Poland among spouse carers.

According to Eurofamcare, the risks of adverse impacts on carers' health and well-being increase where:

- carers and people receiving care share the same household
- high levels of care are provided
- the older person has behavioural problems
- carers suffer from depression and low self esteem
- carers and care recipients have been in conflict in the past
- the carer does not feel supported by social services
- the carer has had to give up other areas of activity (especially employment).

Additional UK data (using a broader concept of 'carer') indicated that the physically tiring nature of caring was perceived as most stressful by carers, followed by

responding to the mobility and personal care needs of the person receiving care. Caring has a marked impact on carers' emotional health and sleep.

Although people caring for an elderly spouse are likely to have already retired, they are much more likely than other carers to suffer from health problems and chronic conditions themselves.

7.2.10 Caring and paid work

The relationship between caring and paid work is complex. Depending on the data source, more or less consistent evidence was found on the adverse impact of care on paid work. According to SHARE data (first wave), there appears to be a broadly inverse relationship between caring activities and active labour market participation among working-age women; the more intensive the care-giving, the lower the probability of active labour market participation among working-age women (Crespo, 2007). This probability is higher in Southern European countries than in the western European and Scandinavian countries.

Co-resident carers are more likely to undertake more extensive care tasks and may therefore be at greater risk of adverse health and socio-economic effects. Thus carers looking after a member of the same household are less likely to be employed than carers looking after someone living elsewhere (Schultz, 2004). However, age could be an intervening variable here, as many co-resident carers are older spouses who are already retired.

Although the overall patterns are the same, the extent to which care-giving is shown to be associated with reduced employment varies between different EU-wide data sources (Chapter 5), not least because opportunities to reduce working hours are not equally available in all countries. Specific studies of carers of older people (Chapter 3) and of non-elderly people (Chapter 4) confirm the following patterns:

- Many carers experience difficulty combining caring and employment; there is a clear probability that especially heavy caring reduces active labour market participation and therefore current and future incomes.
- Opportunities to work part-time are available for some carers (particularly women) and in some labour markets (particularly northern and western Europe). However, taking advantage of such opportunities can also have longer-term consequences for labour market positions and career prospects.
- Many working-age carers do not work. They either quit working because of caring or they take on care responsibilities because they are currently out of, or only marginally attached to, the labour market. However, these patterns vary significantly across the EU, depending on long-term care systems, culture and local labour market conditions.

- The number of hours per week spent caring by working carers differs markedly between European countries and by gender. For example, research shows that working Irish male carers spend 28 hours a week caring, but Norwegian and Swedish working men and women spend five hours each week caring.
- The consequences of reducing work hours last until after the caring period. UK-evidence shows that heavily involved carers are significantly less likely to be in paid work when care-giving ends. Not only do they take longer to return to work, but the proportion in paid work continues to decline beyond the caring episode.

7.2.11 Good practice examples

There are different models of financial support for informal care. All have advantages but also potential drawbacks. Some models direct resources at the person needing care, who uses these resources to employ or provide financial support for the carer. However, carers may have no independent income of their own and may become financially dependent on the person they are caring for. Other models of financial support provide replacement incomes for carers who cannot earn because of their care responsibilities. Although these models are usually means-tested and very low in value, they nevertheless recognise carers' rights to an independent income of their own and also acknowledge the impact of care on carers' labour market participation. Only in the Netherlands was there an example of limited financial compensation offered to carers simply as a token of recognition of their role.

Different models of financial support for carers have implications for carers' ability both to undertake other, paid work and to access formal services that substitute for family care and therefore offer a break from care-giving. Indeed, some models assume informal care to be a full-time role; they therefore restrict access to both paid work and substitute services and also inhibit the development of formal services that can benefit both carers and those they support.

These models may therefore contribute to increasing the risks of both stress and poverty experienced by carers. The low levels of financial support for informal care that characterise all models risk reinforcing existing gender inequalities and are unlikely to change the gender distribution of caring work. Existing models of financial support also do little to bridge the boundaries between informal care and formal labour market participation; financial and other measures to help informal carers combine care-giving with paid work also appear to be relatively undeveloped.

According to the evidence supplied by our expert informants, there appears to be a relative shortage of up-to-date 'good practice' measures to support carers in maintaining paid work while caring (Chapter 6). Some countries have rights to leave from work for short periods, for example to provide care for a terminally ill person, or

for longer periods on an unpaid basis. There is also a shortage of policy and practice measures to support carers in returning to work or in formally recognising the experiences and skills acquired in caring as a means of entering the paid care workforce.

Although there are many examples of good practice measures to support carers, very few have been rigorously evaluated. Many of the examples documented in Chapter 6 lacked thorough evaluation. An analytical model constructed by the University of Wollongong to assess the robustness of evaluations of carers' support measures therefore proved to be of only limited usefulness. There is therefore little robust evidence on what works, why it works, for which groups of carers and what the short- and longer term impacts are for the carer and/or the person they care for. Some examples of good practice are multi-component interventions; without rigorous evaluation, it is even more difficult to identify exactly which elements of these interventions are effective and why.

Moreover, it may be that some measures that have demonstrated benefits for carers within one welfare state context have limited transferability. This is not just because a measure is likely to be embedded in the organisational and administrative structures of one particular welfare regime. The experiences and expectations of carers themselves are also shaped by their perceptions of available welfare systems; carers in more developed welfare regimes may have higher expectations of supportive measures (Kröger, 2003).

Possible factors contributing to the success of service and practice interventions include:

- a 'package' of complementary interventions or combinations of different approaches that provide synergy; for example, day care, combined with psychosocial support and practical help for carers
- tailoring the support to meet the needs of specific categories or groups of carers and care recipients, such as people with dementia or other mental health problems, and their carers
- acknowledging the common concerns of carers and care recipients, as well as their separate needs
- embedding the intervention within existing networks, linked to existing professions
- being easily accessible to carers.

7.3 Recommendations for further research

7.3.1 Improving the consistency and comprehensiveness of EU-wide evidence on informal and family care

This study has revealed a serious lack of up-to-date national and cross-national research evidence specifically on carers. While the study gathered a wealth of material, particularly on the care and support needs of older people, it nevertheless found a lack of evidence on carers themselves. Moreover, where such data was available, it was subject to methodological shortcomings that made comparisons between countries and EU-wide conclusions impossible.

There appears to be a link between the availability of research on carers and the broader visibility and awareness of carers' roles and needs within individual countries. For example, there is extensive research evidence from the UK and the Netherlands, where carers' needs are also widely recognised in legislation and among service providers; but a marked lack of both research evidence and policy recognition in, say, Poland and Greece. Thus where the available evidence suggests there are the biggest pressures on carers, there are also the biggest gaps in knowledge.

At a European level, the Eurofamcare project is the only research project focusing on carers. However, much information in the Eurofamcare studies is older than 2004; some of the background data go back to the end of the 1980s or early 1990s, so its future relevance may be limited.

Given the social and economic relevance of carers to core EU policy domains, comprehensive and up-to-date research into carers' situations and needs is critically important. The FP5 CARMEN-project developed a research agenda for integrated care for older people that is relevant for at least some groups of carers (Nies, 2004). A wider research agenda should include more consistent and up-to-date data about the prevalence and situations of carers; the socio-economic consequences of care-giving; and information about particular groups of carers/carers supporting particular groups of people, such as older carers, spouse carers, those from ethnic minorities and those with multiple or serial care responsibilities. Comparisons are needed between carers and the general population (including former carers); research should also track changes over time.

Such research requires:

- Consistent definitions, including clear common thresholds for identifying carers – for example, those providing at least 20 hours a week care – and those with particularly 'heavy burdens' (say 35 hours a week care-giving).

- Clearer analyses of shorter and longer-term outcomes according to the time spent caring, gender and so on.
- Clearer evidence of causality (for example between care responsibilities and labour market participation).
- Robust evidence of what services and policy measures ‘work’, for which groups of carers, in what circumstances. This evidence should include details of the quality, efficiency, sustainability and transferability of measures aimed to support carers. It should be possible to require any application for funding for a new policy or service initiative to include plans for rigorous evaluation.

More robust evidence on these issues could also enable the EU and member states to develop macro-economic estimates of the opportunity costs of informal care; and to respond to carers’ wishes in developing policies to reduce these opportunity costs.

In addition, research into specific aspects of informal care is also recommended. Many of these have been detailed in Section 7.2.

7.3.2 Labour market effects and dynamics of care

Given the centrality of labour market participation to the EU’s Lisbon policy agenda, research into the interactions and dynamics of care and paid work for women and men in the context of different local and regional labour markets is a high priority. Studies are needed that compare the labour market histories, current patterns and future aspirations of current carers, former carers and those who have never had substantial care responsibilities, across different welfare regimes and labour markets. Smaller scale, qualitative research is also needed to understand the dynamics and outcomes of carers’ decisions about paid work and care within different labour market settings and family care cultures. Both quantitative and qualitative studies should adopt a longitudinal perspective, tracking carers’ movements into more intensive care-giving and beyond, and identifying the options and choices available at different points in the care-giving ‘career’.

Evidence is required on the incentive effects of financial measures to support care-giving and on current and future labour market participation. The effectiveness of care leave and other workplace-related measures in enabling carers to maintain contact with the labour market in the short and longer-terms also require evaluation. Research is needed into the interactions between extending working lives and the growing prevalence of care responsibilities among older people, including measures such as personal budgets (see Section 6.2.1) that might attract newly retired older people into care.

More broadly, a more integrated knowledge base on all human resources in long-term care is needed. This should provide a comprehensive picture, from specialised medical help to informal family care; and also develop projections of changes in the balance of human resources as a consequence of demographic, technological and economic pressures. This recommendation echoes a recent OECD report, which deplores the dearth of information on the factors that might contribute to a quality and sustainable long-term care workforce (Fujisawa and Colombo, 2009).

7.4 Policy recommendations

7.4.1 The EU and carers

The EU has no formal competencies or policy instruments relating to carers. Nevertheless, as discussed in Chapter 1, there are many policy domains where the EU and member states could develop measures that would indirectly benefit carers or that could support carers. Supporting carers is essential because they are central to the sustainability of long-term social and health care; carers also constitute a significant sector of the potential and actual labour supply in all EU member states (Chapter 1). Moreover, the critical role played by carers, at the intersections of long-term care and employment policies, will increase with population ageing and with the growing financial pressures on the economies of member states.

The contributions of carers are rarely included in calculations of the costs of long-term care systems; however, this does not mean these contributions are budget-neutral (European Commission, 2008: 31). The opportunity costs for carers may be substantial (Jenson and Jacobzone, 2000), including:

- foregone earnings and leisure
- displaced household expenditure
- poor health and relationship breakdown
- a redistribution of employment, health and future opportunities for well-being between women and men.

The EU could therefore play an active role in encouraging member states to make visible the roles played by carers; their current contributions to the sustainability of long-term care arrangements; and the actual and hidden costs of these contributions, both for carers themselves and for other welfare services and sectors such as health and income maintenance. The EU could also encourage member states to develop longer-term strategies and consider the roles that family carers could play in meeting growing demands for a long-term care workforce. Such strategies could in turn be linked to policies aimed at reducing the current challenges experienced by many carers in remaining in or re-entering paid work.

These developments could be facilitated through the OMC Social Protection process. Future rounds should focus explicitly on carers and aim to disseminate information on policies and other measures to support carers, including details of the target groups, coverage, effectiveness, sustainability and cost-effectiveness of such measures. Proper independent evaluations of projects and initiatives to support carers are also required and these should also be widely disseminated.

7.4.2 Family policies and intergenerational solidarity

In many EU countries, family care for disabled and older people is still taken for granted. This report provides ample evidence that this can no longer remain an option. European policies relating to the reconciliation of work and family life have traditionally focused on child care. The SOCCARE project (Kröger, 2003) however, concluded that child care involves different patterns and requires different infrastructures from those for the care of an older person (Kröger, 2003). Policies aimed at reconciling child care with employment will therefore have only limited relevance for carers.

However, in view of the SOCCARE findings, policies on reconciling work and informal care appear to require at least as high a priority as measures to combine paid work and child care. Family and employment policies therefore need to extend their focus to the informal care of disabled and older people, including those caring for children with disabilities, illnesses or other special needs.

The linked issue of intergenerational solidarity often focuses on the roles of grandparents in child minding and on so-called 'hard solidarity' - economic transfers in order to fund the anticipated higher levels of GDP expenditure on long-term care. What is often less recognised in discussions of intergenerational solidarity is the enormous transfer of child-to-parent care, as has been highlighted in this report. 2012 will be European Year of Intergenerational Solidarity; this would provide an ideal opportunity to highlight, through research and wider public activities, the role of adult children in supporting elderly people.

7.4.3 Demographic ageing, caring and employment policies

Tensions exist between the increasing demand for informal carers because of the demographic ageing of member states on the one hand, and the European employment strategy on the other. With demographic ageing, these tensions will increase.

European debates about demography focus on encouraging higher birth rates; increasing employment rates and extending working lives; and combining family life

(responsibility for dependent children) with paid work (European Commission, 2007, especially pages 161 and 164). In these debates, currently very little attention is paid to carers. An example is a recent European study on ageing and work, which made no reference to the need for some working age people to care (Warwick Institute for Employment Research, 2006). Moreover, so far as the provision of informal care is recognised, this is restricted to combining working while caring, which – as we have seen – is only a part of the debate.

7.4.4 The interactions between formal and informal care and the implications for public expenditure

Discussions about long-term care and ageing tend to treat public expenditure on formal service provision, problems of supply in the professional paid care workforce, and the future supply of informal care as relatively discrete topics (see for example Tsovala and Mortensen, 2006). However, we suggest that closer links are required between policies on informal care and paid professional care, so that both are treated as parts of an integrated long-term care workforce (see Fujisawa and Colombo, 2009). Moreover, as this study has shown, informal care risks major adverse impacts on carers' health, well-being and socio-economic status, in both the shorter and longer terms. Assumptions about the availability of unpaid informal care at home as a free resource (in contrast to formal domiciliary services or institutional care) will almost certainly under-estimate the additional public expenditure costs that arise from unsupported informal care. Carers are likely to require additional health care and care situations may be at greater risk of breakdown and the eventual use of resource-intensive institutional care. These public expenditure implications will arise on top of the loss of revenue from the taxation and wealth generated by employed carers.

These risks are acknowledged in the 2009 Ageing Report, that points to a growing gap between the numbers of older people requiring support and the actual supply of formal care services. At the same time, however, the future supply of informal care may also be constrained by changes in family structure and the growing participation of women in the labour market.

Well-evaluated innovative policies and practices for supporting carers in paid work while care-giving, enabling former carers to return to work after caring or allowing carers to retain contact with the labour market during a period of leave, are scarce. This is also reflected in working patterns across the EU; there are still many countries where a (temporary) reduction or alteration of working hours in order to accommodate care responsibilities is not an option. There is an important role for the EU in drawing member states' attention to these problems and in encouraging the development of statutory rights for carers to, for example, request flexible working

patterns or take periods of leave without jeopardising their job security (see Chapter 6).

Additional measures could also harness the skills and expertise that many carers develop through their experience of caring and formalise these into recognised, transferrable qualifications. Such measures could both help carers remain in or return to the labour market and also address shortfalls in the supply of formal care workers.

7.4.5 The role of carer NGOs

Discussion of carers' issues at both EU and member state levels requires the full involvement of carers themselves and/or their representatives. In some countries there are organisations that represent the interests of all carers, but in other countries these organisations represent only a minority of carers, for example those of people with Alzheimer's Disease. Moreover, in many countries carers' organisations suffer from a lack of funding and stability. This hinders their role in articulating carers' needs and contributes to the continuing lack of professional and policy awareness of carers.

Representation of carers at a European level is also limited. Currently, for instance Alzheimer Europe, EUFAMI, COFACE and Eurocarers, FERPA and AGE all play some role in representing carers' interests. EUFAMI, Eurocarers and COFACE represent carers across the EU. However, the fragility of these organisations limits their ability to play a full-blown role as partners in a context where multiple policy issues may be relevant. More support is needed, both within member states and at EU level, for organisations that can represent and advocate for carers.

7.4.6 Concluding remarks

Although the above policy discussion is focused primarily at EU level, it is also highly relevant to the national governments of member states. While there are major differences between countries in the stages of economic and welfare state development, they share common issues relating to demographic change, the development of sustainable long-term care systems and the role of family carers within these. While there may be reluctance to invest in new research on the care work carried out within families or to provide additional financial or service support for carers, both are essential. Informal care is the foundation of every long-term care system. Without appropriate policies and practice, informed by rigorous research evidence, the public expenditure costs will inevitably be much higher in the longer term.

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