

Comparing Care

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The care of the elderly in ten EU-countries

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The Netherlands Institute for Social Research / SCP
The Hague, November 2007

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Foreword

The way in which social care is organised has recently changed in the Netherlands. In 2007, home care services have been transformed from a nationally organised social provision for long-term care into a locally provided social service. Under the new system, personal and/or nursing care will remain part of the national provision. Home care will still be funded from national resources, but local authorities are legally required to compensate for disabilities of their citizens. Home care is one of the most important provisions in compensating for those disabilities and ensuring continuity of daily functioning. In most other countries, home care forms part of the locally organised long-term care arrangements. It is therefore interesting to look at a number of the countries surrounding the Netherlands and to learn how elderly persons with disabilities are supported there. In this report we have elected to adopt the perspective of the elderly themselves: their disabilities, their resources and the care they receive.

In April of this year, the SCP published a detailed report in Dutch on disabilities and the care provided in nine EU member states, based on the SHARE 1 dataset 2004 (excluding Belgium). SHARE is a cross-national database of microdata on the health, socio-economic status and social and family networks of individuals aged 50 years or over. This report both summarises and extends that report, as well as adding some new information. The extension and addition of new information have been made possible by the availability of an improved and extended dataset (SHARE 2), including Belgium. As a consequence, some of the results presented in this report may differ marginally from those presented in the original Dutch report. The dataset used in this report comprises the records of 26,500 respondents in ten EU countries.

We would naturally like to thank the SHARE organisation for making available the Survey of Health, Ageing and Retirement in Europe (<http://www.share-project.org/>). Edwin van Gameren is one of the authors of the Dutch report, and we thank him for his contribution to this report. However, the responsibility for the results and presentation is of course ours.

Prof. Paul Schnabel

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This report is an extended summary of the Dutch publication “Verschillen in verzorging”, but is based on release 2 rather than release 1 of SHARE 2004. There may therefore be some minor differences in the figures presented.

This report uses data from Release 2 of SHARE 2004. The SHARE data collection has been primarily funded by the European Commission through the 5th framework programme (project QLK6-CT-2001-00360 in the thematic programme Quality of Life). Additional funding came from the US National Institute on Aging (U01AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, Y1-AG-4553-01 and OGHA 04-064). Data collection in Austria (through the Austrian Science Foundation, FWF), Belgium (through the Belgian Science Policy Office) and Switzerland (through BBW/OFES/UFES) was nationally funded. The SHARE data collection in Israel was funded by the US National Institute on Aging (R21 AG025169), by the German-Israeli Foundation for Scientific Research and Development (G.I.F.), and by the National Insurance Institute of Israel. Further support by the European Commission through the 6th framework programme (projects SHARE-I3, RII-CT-2006-062193, and COMPARE, 028857) is gratefully acknowledged. The SHARE data set is introduced in Börsch-Supan et al. (2005); methodological details are contained in Börsch-Supan and Jürges (2005).

1 *Why compare care?*

Old age and disabilities go hand in hand. In the Netherlands, around 30% of people over the age of 65 suffer from physical disabilities that are serious enough to affect their daily functioning. This group comprises around 400,000 individuals with moderate physical disabilities and some 250,000 people with severe physical disabilities (SCP 2006). Many elderly people are thus sooner or later confronted with disabilities and require care. Responsibility for providing this care lies partly with the government and partly with individuals themselves. The government's main responsibility is to provide care when people are no longer able to provide it themselves.

The reform of the Dutch long-term care act (AWBZ) in 2000-2003 marks a radical change in the position of the Dutch government. This change manifests itself in several ways. The government now encourages people to continue living at home for as long as possible when they become limited in their daily functioning. This encouragement fits in with the desire by most people to remain in control of their own lives for as long as possible. Moreover, providing care in the home setting is less expensive than providing care in a nursing or residential care home. In addition, the government now plans to reimburse only the direct costs of care for people with disabilities via the AWBZ. In principle, housing costs are borne by the individual concerned and the costs of domestic help now fall outside the scope of the AWBZ. With regard to the provision of care at home, the concept of 'usual care' has been introduced. The introduction of this concept means that those closest to the person affected – in practice a partner where present and any children living at home – are expected to provide the necessary care. Only where the need for care is prolonged and there is a lack of informal resources are those affected eligible to apply for formal care (CIZ 2005). This means that the government is only responsible for the long-term care of people who are not able to find their own solutions. In other words, responsibility has been shifted away from the government and on to the citizen.

This report places care for the elderly in the Netherlands in an international perspective. The existing international comparative research on care for the elderly rarely addresses the actual disabilities and actual care provided, but is often more focused on the institutional framework, i.e. the prevailing care systems and the formal rights of the elderly. While not directly concerned with the institutional framework, this report does draw on its characteristics (enforceable rights and government responsibilities) to define more closely the level of care for people with disabilities as observed in practice.

An international comparative study of available care and care actually received can offer several starting points for policy. It can make clear whether there are particular groups who are missing out on the care they need. A shift from government to personal responsibility can mean that people with disabilities have to make greater demands of those closest to them. The study can also show how the Netherlands performs in a European perspective when it comes to providing care, both formal and informal, for elderly persons with disabilities.

The central question addressed in this report is: How do elderly persons in different countries resolve their health impairments? We answer this question using data from the Survey of Health, Ageing and Retirement in Europe (SHARE), which was conducted among people aged over 50 in several European countries (Börsch-Supan, A. et al. 2005). Ten countries are brought into the comparison in this report: the Netherlands, Belgium, Germany, Austria, Denmark, Sweden, France, Italy, Spain and Greece.

We subdivide the main research question into four constituent questions focusing respectively on the identified need for care, the available resources, the care provided and the relationship between formal and informal care:

- 1 What kinds of health impairments confront older persons in the various countries and how many people are involved?
- 2 How many people with health impairments have access to an informal network and how does this vary from country to country?
- 3 How much formal and informal care do people with health impairments receive and how does this vary from country to country?
- 4 How many people with health impairments are deprived of help, how can they be characterised and how does this vary from country to country?

The first question relates to the care needs of the over-50s in Europe. A smaller number of people in need of care in a given country logically implies that less care needs to be provided in that country. The degree of need is determined on the basis of people's disabilities. These may include physical disabilities, depressive symptoms as well as cognitive impairments which are related to the functioning of the memory and to elementary skills (language, arithmetic).

The second question is concerned with the availability of informal networks. Having a large informal network may be an indicator of the probability of receiving care from within or outside the household, and of the need to receive help via formal private or public provisions.

The extent to which people succeed in meeting this need is the subject of the third question, which compares the amount of informal and formal care actually received by elderly persons with disabilities in the ten countries studied. Formal care may be provided by both the public and private sector. Private care is paid or professional care that is not publicly funded (e.g. care provided by a 'cleaning lady' or 'paid help').

Public care incorporates the various forms of home care and institutional care in nursing homes in the countries studied, which may encompass both domestic help and personal care. Informal care is unpaid and may be provided by family, friends and neighbours.

Several individuals with health impairments and who are in need of care do not receive any care at all. In which countries does this happen and what are the characteristics of these elderly persons? The answers to the fourth question are intended to provide an insight into these situations. Is there a real problem or can specific circumstances provide an explanation?

In order to answer the research questions, data were drawn from the SHARE survey. However, while SHARE is a rich source of information, it has a number of limitations which affect the study performed here. The two main limitations are that elderly persons with disabilities were not asked who carries out the informal care tasks in the household, and that elderly persons with disabilities were not asked whether the formal help they received was provided publicly or privately. This means that, in this report, formal care may be provided either by a public-sector organisation or a paid private helper.

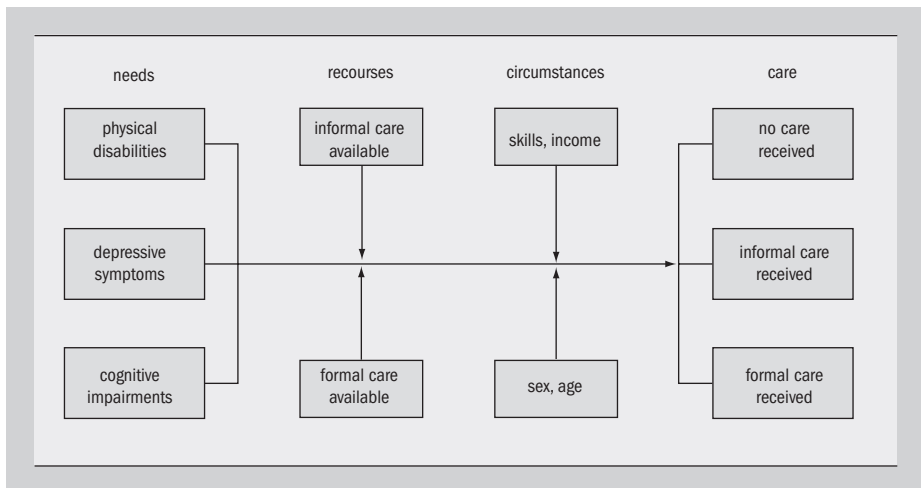
Country codes

BE	Belgium	GR	Greece	IT	Italy	SE	Sweden
DK	Denmark	ES	Spain	NL	Netherlands		
DE	Germany	FR	France	AT	Austria		

2 Care models

According to Anderson and Newman (1973), we have to distinguish three components in order to construct a model of care utilisation: needs, resources and predisposing circumstances (figure 1). Of course, needs are the most important precondition and determinant of care utilisation. Needs are related to health problems; we distinguish three kinds of health problems: physical disabilities, depressive symptoms and cognitive impairments. Next, we distinguish two kinds of means of responding to needs: the availability of care resources (family members, public services) and social circumstances. Social circumstances can be subdivided into predisposed characteristics (age, sex) and achieved characteristics (education, income). This distinction is of interest because achieved characteristics are within the scope of influence of personal decisions and public policy. Some characteristics are situated between predisposed and achieved, such as the urban or rural character of the place of residence.

Figure 1
A global model of care



Broadly speaking, a person with a health problem can choose between three options: no care, informal care or formal care. There are several views on the relationship between formal and informal care, which can be expressed in country typologies. In these different typologies, primary responsibility for meeting care needs may lie with the individual (Scandinavian model), the nuclear family (Continental model) or the extended family (Mediterranean model). The more the responsibility lies with the individual and not with their family, the bigger the role played by the govern-

ment. In addition to this public ‘responsibility model’, there is also the ‘task-specificity model’ (Litwak 1985), in which the family of the elderly person concerned performs light domestic work while professional carers carry out the more demanding caring and nursing tasks. Thirdly, there is the ‘hierarchical model’ (Cantor & Little 1985), in which the family is the main provider of care and the formal care system only comes into play when the family is no longer able to continue. Most studies show that informal care will not disappear but the character of informal care changes (Oasis 2003). Where formal help is available, the family takes a step back, in the sense that they switch to performing lighter and more social tasks, leaving more of the intensive and long-term help to the formal care network.

In Mediterranean countries the family has a legal duty to support relatives up to the third remove. In Greece, there is in fact almost a total lack of public support, so even in situations where relatives are not available, someone in need of help almost always lacks formal care, too. In Italy, only the person with the need can enforce the right to receive care, but in Spain the government can also enforce this right. Public services are only available for individuals lacking informal resources. Moreover, in Spain and especially in Italy the government buys off the duty to provide care by paying cash benefits where no relatives are present. These cash benefits are need-based and mostly¹ means-tested. Means-tests are not restricted to the persons in need but also apply to their relatives. A recent development in Mediterranean countries is the deployment of (female) immigrants. They help preserve the familial regime against societal developments, because the family remains responsible. These societal developments involve increasing female labour market participation, less extended families and weakening family ties.

In continental countries the family is the primary caring unit, but persons with more serious health problems have a legal entitlement to public services. This right to claim public services may be based on a public insurance system (Germany) or a public provision (Austria). In Belgium and France, both public systems are in operation. Cash benefits prevail in Austria, and are predominant in Germany and France, but are absent in Belgium. Cash benefits are entirely managed by local authorities in France and primarily so in Germany. Both cash benefits and benefits in kind depend on the level of dependency (all countries) and the level of family income (France). In Germany, Austria and France, many immigrants provide private care, though to a lesser extent than in the Mediterranean countries.

In Scandinavian countries and the Netherlands, the public sector has primary responsibility for persons in need for care. In Sweden and the Netherlands, the public sector does not have a legal duty to provide care when a partner of a person in need is available (a concept referred to as ‘usual care’). Children living at home are not responsible for taking care of their parents. In Denmark, families have no legal duty to care for elderly family members and help given is considered additional to

public services (Colmorten et al, 2003). No cash benefits are provided in these countries (with the exception of some managed benefits in the Netherlands). Owing to the fairly generous level of public care, hardly any immigrants provide private care.

In general, therefore, three types of care regimes are distinguished: a family type (Mediterranean), a mixed type (Continental) and a public type (Scandinavian). However, the classification of countries into care regime types can vary because the performance of countries is not always in line with theoretical expectations. For example, Leitner (2003) classifies the Netherlands as a Mediterranean type of care regime. Her classification of 'ideal care types' is based on two dimensions of public support: support provided directly by public provisions (home help services, nursing homes) and indirect support provided by offering relief to families in their caring functions (through care leave facilities, care transfers). However, the classification of the Netherlands as a Mediterranean type of care regime is based on doubtful figures on home help services and care allowances. The other countries are classified as expected, although the classifications are sometimes dubious on empirical grounds: the Scandinavian type (direct and indirect support), the Continental type (mainly indirect support) and the Mediterranean type (low levels of direct and indirect support). Bettio and Plantenga (2004) classify Ireland as a Mediterranean type, Austria and Germany as typical Continental regimes. Their classification is based on the level of formal and informal care in different countries. In their analysis, the Netherlands also shows some affinity with the Mediterranean type and France and Belgium with the Scandinavian type of care regime. Scandinavian countries (Denmark, Finland, Sweden) and Mediterranean countries (Italy, Greece, Spain, Portugal) are classified as theoretically expected.

Diagram 1 summarises the types of care regimes according to primary responsibility (state or family), kind of provision (in kind or cash) and financial accessibility (universal or means-tested). There is a fairly strong correlation between primary responsibility and financial accessibility. In Scandinavian countries, Austria and Germany, accessibility to public care is universal if needs are met by national or local eligibility criteria. In Mediterranean countries, elderly persons in need of care are means-tested on the basis of income.

Only a weak correlation is found between primary responsibility and type of provision. However, there is no theoretical reason to expect such a correlation. Cash transfers can be divided into supply-driven and demand-driven transfers. Supply-driven transfers are bound by spending rules in public legislation. In France, for example, the National Dependency Allowance (APA) is established on the basis of a 'help plan' and excludes informal carers. Comparable supply-driven transfers exist in Belgium, except that here in-kind provision dominates. On the other hand, in Austria and Italy care transfers can be spent as the recipient sees fit (demand-driven) and can be paid to informal carers. In Germany and the Netherlands both systems exist, although in Germany more cash transfers are allocated and in the Netherlands

there are more in-kind provisions. In Denmark, Sweden and Spain (nearly) all care is provided on an in-kind basis.

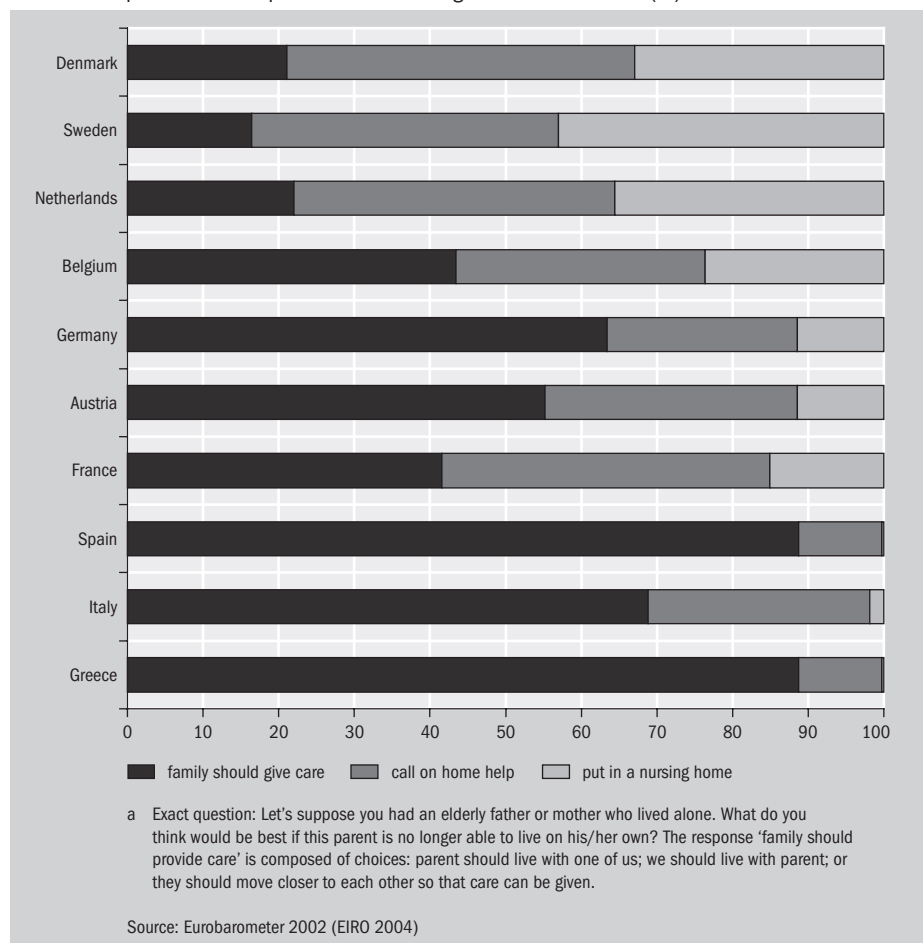
Diagram 1

Global classification of countries by primary responsibility, type of provision and public accessibility

	primary responsibility		type of provision		means-testing	
	State	DK, SW	In kind	DK, SW, SP, GR	Universal	DK, SW, AT, GE
		NL		NL, BE		NL, BE, FR
	↓	BE, FR, GE, AT	↓	GE, FR, IT	↓	IT
	Family	GR, IT, SP	Cash	AT	Means-tested	SP, GR

Figure 2

Who should provide care if parent could no longer live on their own (%)^a



The responsibility for providing care and the responsibility for paying for care is not only reflected in the legal system but also in the minds of the population. The Eurobarometer 2002 survey contained a number of questions about these responsibilities.

Family responsibility is felt most keenly in Mediterranean countries and least in Scandinavian countries (figure 2). The Netherlands fits more the individualistic Scandinavian type while Germany and Austria are more like the familial Mediterranean type. Calling on home help services is the preferred option in France, the Netherlands and Denmark. Swedish respondents are most in favour of nursing or care homes in the event of care problems, but in the Mediterranean countries nursing and care homes are not really considered.

Family responsibility on the part of children is also reflected in the views on paying for care. If EU citizens are asked who should have primary responsibility for paying for the care of an elderly parent (the parents themselves, their children or the public authorities), the North-South contrast emerges clearly. In Scandinavian countries fewer than 5% of the adult population expect their children to be mainly responsible for paying for their parents' care; in Continental countries the figure is about 15% and in Mediterranean countries around 30% (EIRO 2004). The Netherlands approaches the Scandinavian position. The only striking exception is the Austrian population, which fully shares the Mediterranean view that children should mainly pay for taking care of their parents.

The views of the population are of course reflected in countries' care systems and care policies. It is difficult to make causal inferences about the relationship between institutions (policy) and cultural values (opinions). Obviously, where public provisions are scarce, family care becomes important; but this may be an expression of cultural values (children should take care of their parents) rather than a consequence of inadequate supply or contrastive policy (children have to take care of their parents). In general, the care system reflects public opinion. For instance, in Scandinavian countries elderly people stress the importance of their autonomy and independence, reflecting the individualistic perspective (Larsson, 2004).

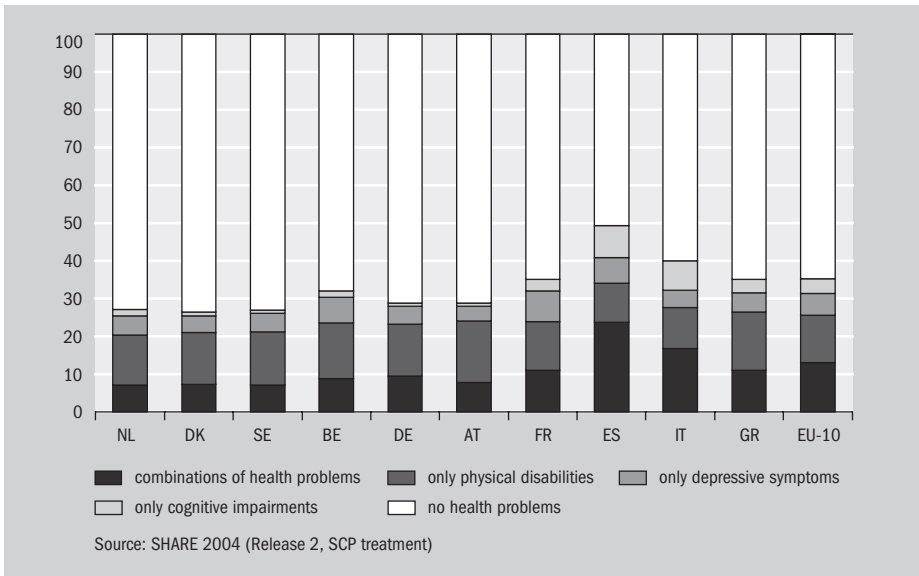
3 Health and care problems

The approach chosen in this report is to follow the path from care needs to care provision. First, we try to identify how many and which elderly persons experience impairments. Next we describe the informal networks to which people have access and which may be important in meeting their care needs. Finally, we investigate the actual take-up of care by people with disabilities. Broadly, three situations are distinguished: no help, informal help and formal help.

What are the health problems faced by elderly persons in the different countries, how many people are affected and which type of people are mainly affected? To answer this question, a ‘disability scale’ was constructed, consisting of three underlying measures of health problems: physical disabilities, depressive symptoms and cognitive impairments. This indicator made it possible to determine how many over-50s experience disabilities and how serious they are. We define a needy elderly person as being someone who suffers moderate or severe health problems because of physical disabilities, depressive symptoms or cognitive impairments.

Figure 3

Type of health problem by country of people aged over 50 years (%)



Physical disabilities impose restrictions on traditional household (cleaning, cooking, laundry) and personal care (toileting, bathing, dressing) activities. It is assumed that below a certain level of physical health, personal help is needed for cleaning and personal care. Of course, the formal eligibility criteria for receiving help differ between countries, but in this report we use the same yardstick for all persons in need. Depressive symptoms restrict the psychological functioning and symptoms of dementia impair cognitive functioning.

On average, 65% of the population aged over 50 years have no serious health problems. However, around 35% of the over-50s in the ten European countries studied suffer from a physical, mental or cognitive problem. The proportion of people with physical disabilities is 25%; roughly 15% of the over-50s suffer depression-related problems and 12% suffer from cognitive impairments. A good deal of overlap can be observed in the disability scale: more than 60% of people with a depressive symptom or cognitive impairment also suffer from a physical disability. The converse does not hold, because there are considerably more people with physical disabilities than with depressive symptoms or cognitive impairments. On average, 13% of the over-50s suffer a combination of a physical disability, a depressive symptom or cognitive impairment.² 13% of the over-50s thus suffer only from physical disabilities, 6% only from depressive symptoms and 4% only from cognitive impairments.

People in southern countries suffer relatively more often from cognitive impairments. In Spain and Italy, especially, more older persons face serious memory, reading or writing problems. Since they also suffer from more physical disabilities, more combinations of health problems are found in these countries.

The proportion of people with disabilities is relatively high in the southern countries, and relatively low in the Netherlands and the other northern countries (figure 3). In Spain, for example, according to the scale used, there are almost twice as many people with disabilities as in the Netherlands (49% versus 27%). This largely has to do with underlying factors which influence the likelihood that someone will suffer from disabilities. For example, the chance of physical disabilities increases with advancing age, and a low education level increases the probability of cognitive impairments. The distribution of these factors in different countries largely determines the number of individuals with disabilities. If allowance is made for the degree to which factors such as these play a role in the various countries, the country differences are found to be considerably smaller; for the Netherlands, for example, 30% of people would be expected to have health problems on the basis of underlying factors, while the figure for Spain would be 44% (figure 4). Only Sweden (lower) and Spain (higher) achieve scores that are significantly different from what might be expected on the basis of the available explanatory factors.

Figure 4
 Difference between observed and expected number of persons aged over 50 with health problems (%)

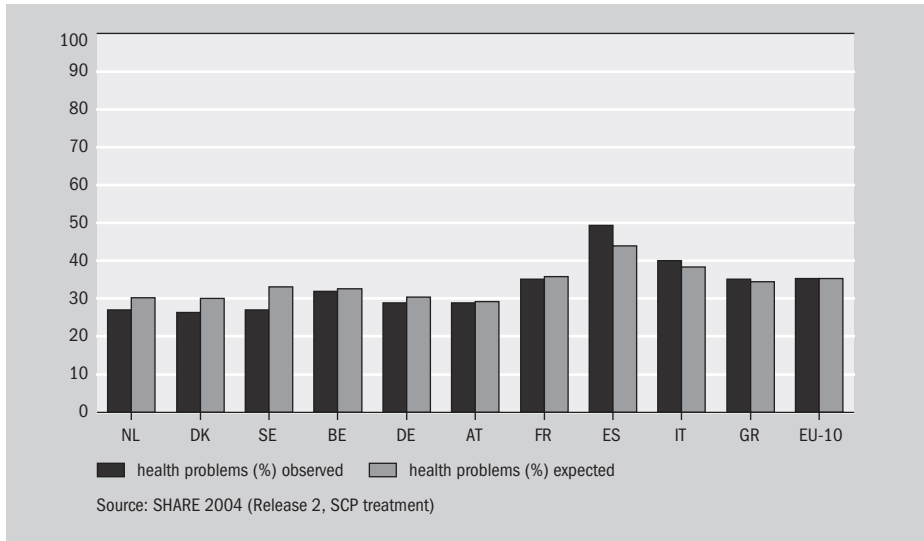
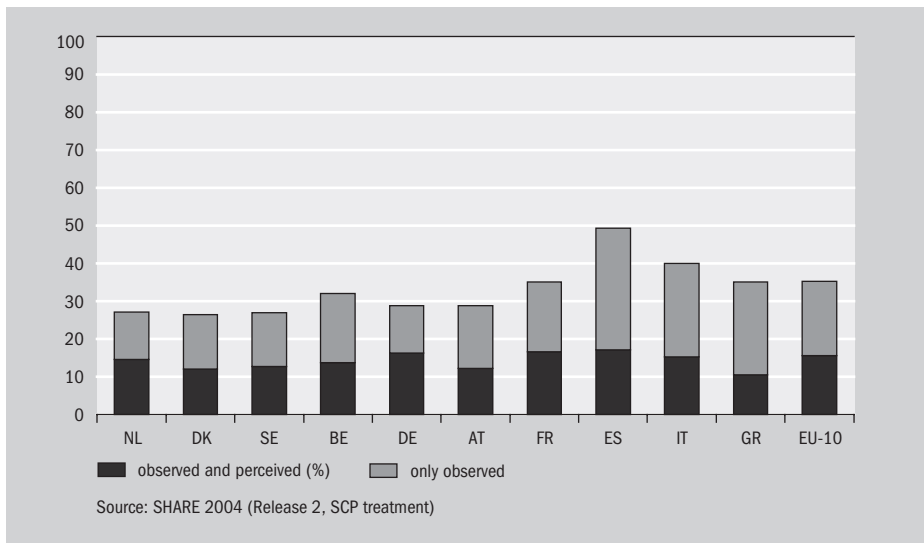


Figure 5
 Observed and perceived health problems of the over-50s (%)



The observed physical, psychological and cognitive health problems are not always perceived by those affected as a hindrance to their daily functioning. This applies particularly in the southern countries (figure 5). On average, just under 45% of the over-50s with health problems regard their problems as a hindrance to their daily functioning. This proportion is lower in the southern countries (35%) than in the northern countries, including the Netherlands (49%). To take account of this, a care problem approach for disabilities is also incorporated in this report, in which people experience impairments in both an objective and subjective sense. The proportion of over-50s with impairments then falls from an average of 35% to an average of 16%.

Observed health problems which are perceived as health problems are called 'care problems'. They are expected to reduce daily functioning seriously. On average, therefore, 35% of the over-50s are confronted with health problems and 16% with care problems. The differences between individual countries are much smaller with the care problem approach (ranging from 11% to 17%) than with the health problem approach (26% to 49%).

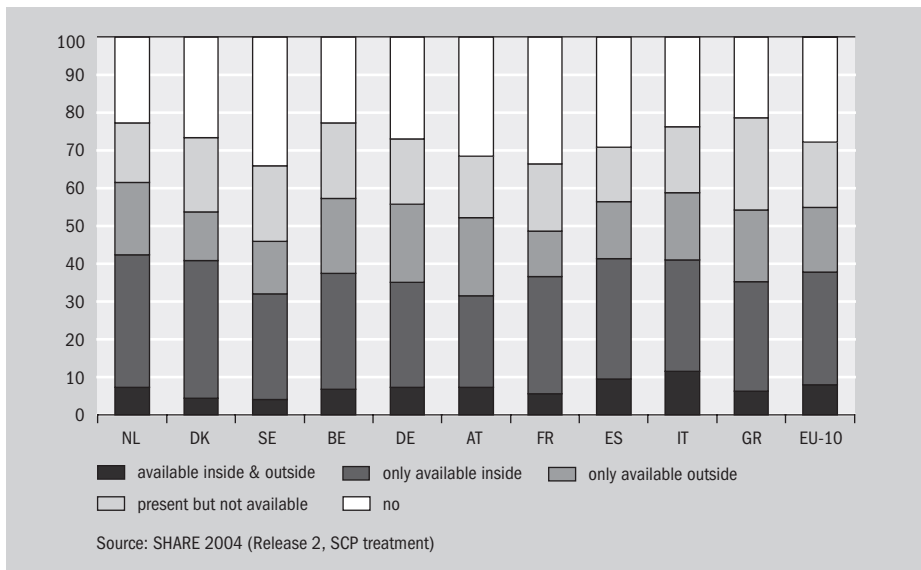
We can conclude that in the Mediterranean countries a relatively high proportion of elderly people report disabilities, while in the Scandinavian countries and the Netherlands, by contrast, a relatively low number of elderly people are affected by disabilities. The presence of chronic diseases has a major impact on limiting daily functioning. However, people of advanced age, people with a lower education level and women are also at higher risk of impairments in their daily functioning. If allowance is made for these explanatory factors, differences are still found between countries, though they are considerably smaller than if no account is taken of these factors. One reason for this may be differences between the objective and subjective disability scales. The subjective scale is determined by perceived impairments. The specific effect of the southern countries disappears if the analysis is repeated on a group of over-50s who suffer impairments both objectively and in their own perception. In other words, the southern countries have an overrepresentation of people with disabilities, but those disabilities are perceived as such to a lesser extent in everyday practice.

4 Available care

Roughly 80% of the population aged over 50 in the selected countries potentially have access to an informal network. Only nuclear and extended family members are included in the informal network here; although neighbours and friends can provide informal care, these are not traditionally counted as being part of the informal network because they cannot be called upon to provide informal care. Moreover, they rarely do provide care in practice (De Boer, 2007).³ Family members with disabilities are excluded from the informal network, since it is assumed that they generally can not or hardly provide informal care. Children living more than 25 km away from their parent(s) are also excluded from the network. If we consider only people with disabilities, the availability of an informal network falls to 72% (figure 6). This is because of the greater age of these people and consequently the smaller chance that there will be a partner (figure 7).

A striking phenomenon is the combination of a low presence of partners and a high presence of children in some countries, such as Austria, Italy and Spain. Elderly persons with care problems are most likely to have a partner in Denmark, the Netherlands, Belgium and France, and least likely in Spain and Austria. Children living with their elderly parents is a familiar phenomenon in southern countries such as Italy and Spain, where extended families still exist, although the number of older people living with younger relatives is declining (Da Roit 2007).

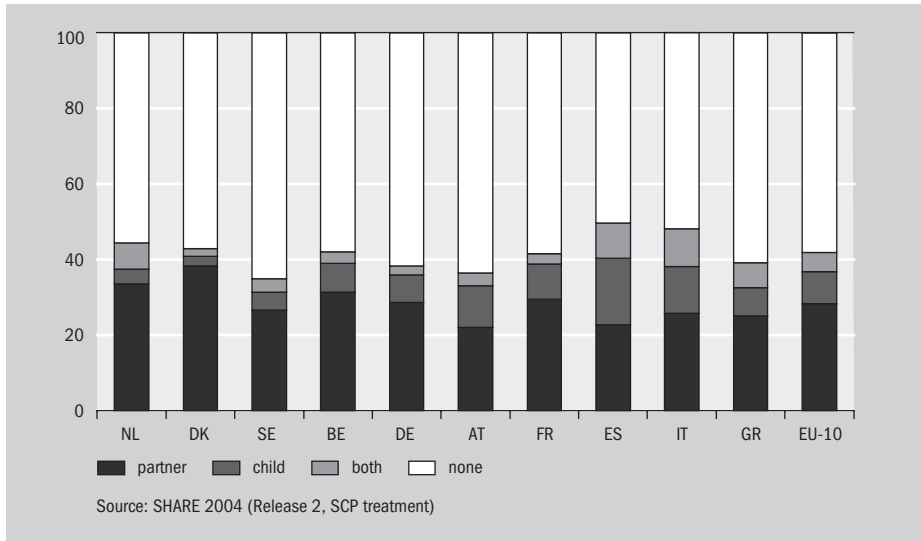
Figure 6
Access to an informal network inside or outside the household of persons with care problems (%)



Elderly persons in Sweden and France achieve the lowest mean score on availability of an informal network (figure 7). By contrast, elderly persons in the Netherlands, Greece, Belgium and Italy have access to a relatively large informal network in our SHARE sample.

Not all potential informal help is actually available in practice, because relatives may themselves suffer from disabilities or may have a full-time job. In total, these limitations apply to a quarter of the potentially available help. This reduces the availability of the informal network from an average of 72% to 55%. The Netherlands occupies a relatively favourable position on informal networks, partly because of the high proportion of part-time workers, especially woman (part-time working family members are part of the available network). The same applies to a lesser degree to Germany (OECD, 2006).

Figure 7
Presence of a partner or a child within the households of persons with care problems (%)

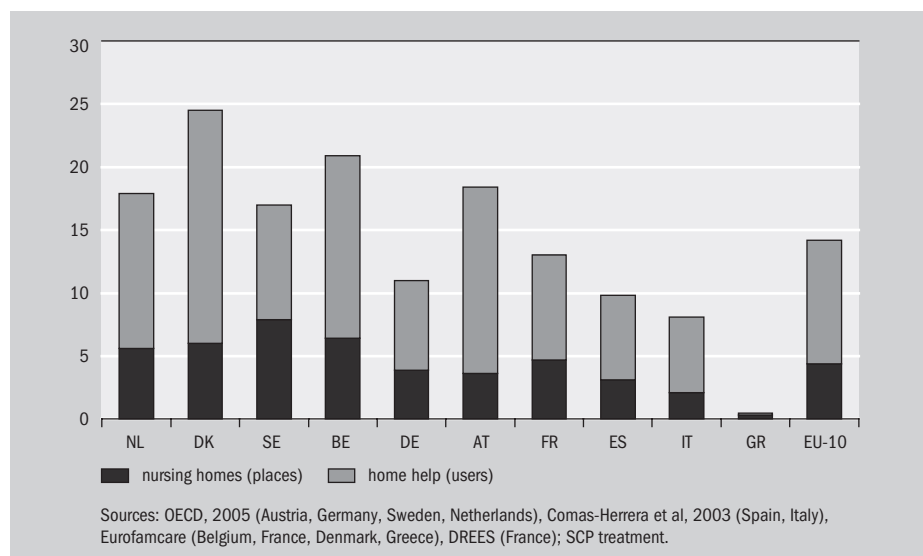


If we break down the total availability of informal care into availability within and outside the household, we find that older persons in Sweden have access to less informal care both within and outside the household. In Austria there is less informal care available within the household and in Denmark and France there is less informal care available outside the household. Elderly persons with health problems in the Netherlands, Italy and Spain have the most extensive informal networks. Italian and Spanish elderly persons mainly have larger extended families, while in the Netherlands elderly partners tend to attain a relatively high age together. Within the southern cluster, people in Greece have a relatively small network, partly

because of the high percentage of women who work full-time (OECD, 2006). There is virtually no correlation between availability of informal care within and outside the household. It seems plausible to assume that in the southern countries, where the availability of care within the household is greater because of children living at home, there will be fewer children able to provide care outside the home. However, in practice there is virtually no evidence to support this negative correlation.

The availability of formal care (paid private care or subsidised public care) varies widely between countries. In some countries, especially the Mediterranean countries, private care is an important part of the care supply. In particular, older migrant women from less affluent societies provide care in the private homes of elderly people in a live-in working arrangement (Escrivà & Skinner, 2006). In Greece, with hardly any formal care, the family would probably hire an immigrant worker if the family were no longer able to cope. Little financial assistance would be available (Blackman, 2000). However, different modalities of care supply emerge between public professional care and unpaid family care, which are difficult to classify into formal and informal care. For instance, in countries with unconditional cash transfers to persons in need of care (Austria and to some extent in Germany and Italy), those transfers can be spent on private care (a ‘cleaning lady’) but also on family care (a ‘cleaning daughter’). Consequently, informal care acquires some of the characteristics of formal care, although in a sense these transfers can be viewed as symbolic payments, adding purchasing power to the family (Hammer & Österle, 2003). In this report, therefore, cash transfers are treated as formal care.

Figure 8
Supply/use of formal (public and private) care per 100 elderly persons (65+), 2000



Owing to the limited representativeness of the SHARE dataset with regard to nursing and care homes, information about the supply of care is also drawn from other records too (figure 8). Nursing home care is fairly extensive in Scandinavian and some Continental countries (Netherlands, Belgium) and virtually absent in Greece. Home care is frequently used in Denmark, Austria, Belgium and the Netherlands, and again hardly at all in Greece. Germany, Italy and Spain have moderate levels of home care facilities.

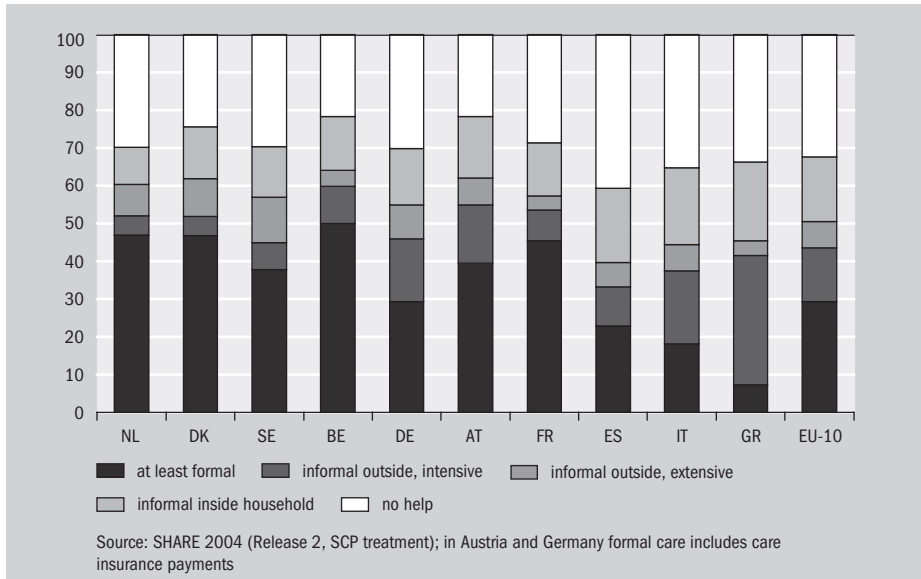
We can conclude that on average, just over a quarter of people with disabilities have no access to an informal network. There is also a clear difference in the care available between the Continental and Mediterranean countries (with the exception of Greece and the Netherlands), with people in the southern countries having access to a larger informal network within or outside the household. In the southern cluster, people in Greece have a relatively small network, while among the northern group the Dutch have a relatively large network. A number of factors emerge when we try to explain why some people with a disability have access to an informal network while others do not. The availability of informal care in a person's own household decreases as they grow older (loss of a partner); in addition, people living in urban areas have less access to informal networks.

5 *Care received*

Almost 45% of older people with health problems and almost 60% of older people with care problems receive informal care, sometimes in addition to formal care (see figure 9). Just under 30% of older people with health problems and almost 40% of older people with care problems receive only informal care. Four countries stand out: in Belgium, France, the Netherlands and Denmark a relatively high proportion of older persons with disabilities receive at least formal care (figure 9). Greece is characterised by a particularly low level of formal care, though the amount of formal care is also limited in Italy and Spain. The Netherlands and Denmark have high levels of both home care (especially domestic services) and institutional care, while in France a large number of older persons receive home care (especially nursing services). In all three countries, older persons receive large amounts of both domestic care and personal and nursing care compared with the other countries. According to Viitanen (2007), formal care substitutes informal care that is given outside the carer's own household but not that which is provided within the household. Informal and formal care tend to complement each other when it comes to providing household services and substitute each other for nursing and personal services. The Netherlands forms an exception when it comes to household care, with a high level of formal care and a low level of informal care. This fits in with the findings of Timmermans et al. (2003). Evidently the task-specificity model operates in the Netherlands, in which the family performs light household tasks and leaves the more demanding care and nursing tasks to the professionals.

There are striking differences between the availability and take-up of care for people with disabilities. The availability of informal care is greatest in the Netherlands and lowest in Sweden. However, the take-up of informal care appears to show little correlation with this, being highest in Greece and lowest in the Netherlands. High availability therefore does not necessarily translate into greater use of informal care, as is well illustrated by the Netherlands, where as stated the relatively high availability of informal care is accompanied by a relatively low take-up. The intensity of care also varies considerably. In the southern countries, in particular, partners or children often provide daily or weekly care to needy relatives (called 'intensive' in figure 9); in the northern countries and the Netherlands this is much less the case. These conclusions retain their validity if allowance is made for differences in the age profile of the various countries, differences in the numbers of people with disabilities and differences in the available networks.

Figure 9
Care received by persons with care problems (%)



The availability of informal care does however tend to depress the amount of formal care received; governments evidently respond to the availability of an informal network.

If we categorise countries by the actual take-up of formal and informal care by people with disabilities, a rather complex picture emerges (figure 10). In this picture, the very low levels of formal and informal care (less than once a week or one hour a week) are excluded. The Netherlands, together with Denmark and Sweden, then represents the individualistic Scandinavian model (a high level of formal care and a low level of informal care). The same calculations show that greater use is made of professional care in the Netherlands than in many other countries in comparable circumstances.

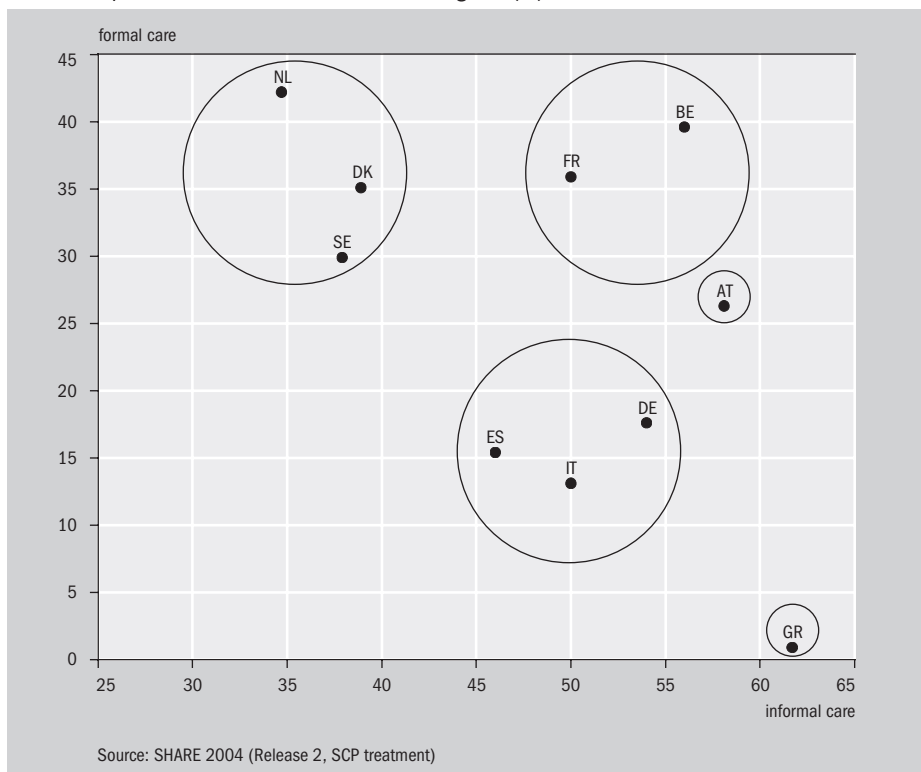
Although Sweden still represents the Scandinavian model, in the last twenty years the amount of home care has greatly reduced and been replaced by family care and private care. The balance between families and the state has thus shifted and Sweden is moving from the Scandinavian towards the Continental model of care (Sundström & Johansson, 2005).

Greece represents the archetype of the extended family-based Mediterranean model (a low level of formal care and a high level of informal care). Belgium and France, together with Austria, represent the nuclear family-oriented Continental model (relatively high levels of both formal and informal care), although Belgium seems to

score rather highly on both dimensions of care. Spain, Italy and Germany occupy a position between the extended family-based model represented by Greece and the individualistic Scandinavian model. Evidently, the reality on the ground is difficult to encapsulate in the 'ideal' cluster types outlined earlier, which are also reflected in the opinions expressed by the public.

The classification in figure 10 is roughly in line with Bettio and Plantenga (2004), based on the same criteria, although some differences can be observed. In our 'empirical' classification, Belgium and France have a higher level of formal care and the Netherlands a lower level of informal care. Moreover, Italy and Spain are shifting in our analysis from the extended family-based Mediterranean type towards the intermediate Continental type of care system.

Figure 10
Relationship between formal and informal care given (%)



6 Use and non-use of care

The findings of this report suggest that people with disabilities in Denmark, Belgium and Austria are in the best position in terms of care. Disabled persons in these countries have the best chance of receiving some form of care (figure 9). Belgium and Denmark score highly because of the high level of formal care, while in Austria high levels of both formal and informal care are provided. The Netherlands broadly follows the Danish pattern, with a high level of formal care and a modest level of informal care. People with disabilities are worst off in the Mediterranean countries: many receive no care at all, and if they do receive care it is generally informal in nature.

The question of how people with disabilities receive help is answered in three stages. First, factors are examined which determine the use or non-use of care. Second, when persons receive care, factors are examined which determine whether they use formal or informal care. Third, factors are examined which determine the use of informal care inside or outside the household.

The main factor determining the chance of receiving care is old age; but having a disability is also found to be related to the care provided. Table 1 presents the percentage of persons with physical disabilities by type of help received. In particular, persons receiving no help relatively often have less serious physical disabilities, irrespective of country of residence (varying from 25 % in the Netherlands to 34% in Germany). Persons in Mediterranean countries receiving formal care suffer from serious physical disabilities to a greater extent than in other countries, so that formal care in Mediterranean countries is mainly reserved for those with the greatest need. The high percentage (67%) of Swedish disabled people who receive informal care from outside the household is striking. In 1992 the Swedish government introduced a different care policy (ÅDEL reform) to reduce costs and to solve the 'bed-blockers' problem. The intention was that 'bed-blockers' in hospitals should receive home care. As a result, the coverage of home care halved for the elderly aged 65 and over (from 16% in around 1980 to 8% in around 2000) and the help given intensified. Elderly persons with extensive care needs had to fall back on their family (Trydegård 2003).

Table 1 shows that there is a relationship between care received and physical disabilities. However, personal and social factors and the extent to which elderly persons have access to informal networks are also determinants of the provision of care for people suffering from disabilities. Using an explanatory care-use model, the pathway from disabilities to provision of care was analysed further in order to obtain a more in-depth answer to the four study questions.

Table 1

Persons with physical disabilities by type of help received (%), subsample: over-50s with care problems^{a)}

	Nether- lands	Den- mark	Sweden	Belgium	Germany	Austria	France	Spain	Italy	Greece
none	25	28	30	29	34	30	26	33	33	28
informal, within	47	54	53	61	53	66	54	64	71	73
informal, low level, outside	37	43	44	25	38	42	36	38	43	65
informal, high level, outside	32	28	67	42	40	50	47	58	59	65
at least formal help	58	65	72	65	76	70	66	81	76	88

a) Weighted percentages; 3-4 disabilities is weighted by 0.25; 5-6 by 0.50; 7-8 by 0.75 and 9 or more by 1.00.

Source: SHARE 2004 (Release 2, SCP treatment)

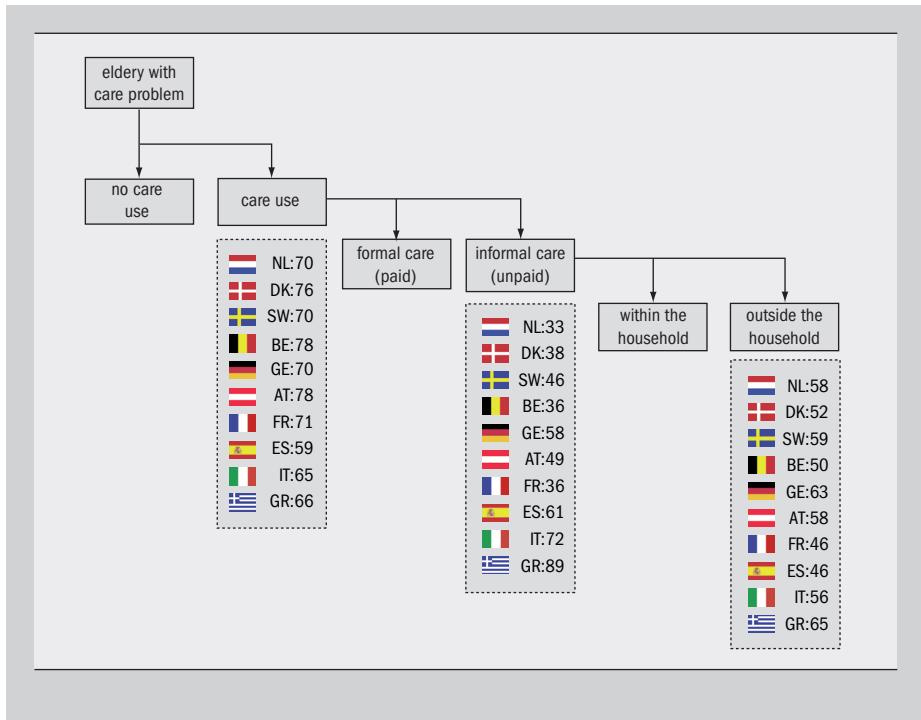
In our model (figure 11) the use of long-term care in ten European countries is analysed,⁴ starting with elderly persons with a care problem and ending with care provided. We distinguish four different categories, only one of which is chosen by each elderly person. The first category is one in which no long-term care is used. If the elderly person does use long-term care, it may be unpaid informal care provided by other household members, unpaid formal care provided from outside the household (by friends, relatives, neighbours) or formal care (publicly or privately financed).

Figure 11 shows large differences between countries. On average 30% of the elderly with physical disabilities in the European countries studied do not receive any care. In the southern countries relatively many elderly persons receive no care; in Denmark, Austria and Belgium relatively few do so. Half of the elderly people who receive care receive only unpaid care; the remaining half receive paid care (possibly in addition to unpaid care). The differences between countries are striking. Three countries stand out: in Belgium, the Netherlands and Denmark a relatively high proportion of older persons receive paid care. Greece is characterised by a particularly low level of paid care, though the amount of paid care is also limited in Italy. Of the elderly people receiving care, 50% receive solely informal care and no formal care. About 55% of informal care is provided by someone outside the household, the figure being highest in Greece and Germany and lowest in France and Spain.

Can we attribute the differences between countries in care shown in figure 11 to observable differences in needs, resources and circumstances? The coefficients in our care-use model (table 2) show that having severe physical disabilities, in particular, increases the probability of receiving care and, conditional on that, also raises the probability of receiving paid care and unpaid care from relatives inside

the household. In line with the reasoning in figure 11 we observe in general that the choice between care and no care is dominated by differences in needs and age; the choice between formal and informal care by differences in country and age, and finally the choice between informal care from inside or outside the household by differences in available resources.

Figure 11
A formalised model of care: the care-use model (use in %)



More specifically, having a partner or children who are able to provide care, because they are not impaired and do not work full-time (having an informal network inside one's own household) increases the probability of receiving care and also the probability of receiving informal care from inside the household. The existence of an informal network inside the household does not play no role in the 'choice' between formal and informal care, while living alone does. Having an informal network outside the household (only children) increases the probability of receiving care, but this in turn decreases the probability of receiving formal care and informal care from within the household. Age appears to have a positive effect on receiving care, as it does on receiving formal care and informal care from relatives inside the household.

Table 2

Nested logit estimates of use of care by the over-50s with care problems^{a)}

	care/no care		formal/informal (care users)		inside/outside (informal care users)	
needs						
severe physical impairments	1.9	***	1.0	**	1.0	***
having had a stroke	0.4	**	0.4	**	-0.2	
resources						
single-person household	0.7	***	0.8	***	n/a	
informal network inside	0.3	***	0.1		1.4	***
informal network outside	0.2	***	-0.5	***	-1.1	***
circumstances						
age 50-64 (reference age)	0		0		0	
age 65-74	0.4	***	0.6	***	0.7	***
age 75-84	1.1	***	0.9	***	0.3	
age 85+	1.9	***	2.0	***	0.3	
gender: female	0.1		-0.0		-0.4	**
Country-specific effects						
Netherlands (reference country)	0		0		0	
Denmark	0.2		-0.2		0.3	
Sweden	-0.6	**	-1.3	***	0.1	
Belgium	0.1		-0,1		0.7	*
Austria	-0.5	**	-1,3	***	0.3	
Germany	-0.0		-1.0	***	0.5	
France	-0.1		-0,2		0.7	
Spain	-1.2	***	-1,6	***	0.8	*
Italy	-1.0	***	-2,0	***	0.5	
Greece	-1.1	***	-3,9	***	0.1	
R ²	0.19		0.22		0.32	

*** significant at the 1% level, ** significant at the 5% level, * significant at the 10% level.

a) The variables gender, level of education, degree of urbanisation, income distribution, long-term illness, ill-health symptoms, diabetes and being an alcoholic are not statistically significant at the 10% level and are not presented.

Source: SHARE 2004 (Release 2, SCP treatment)

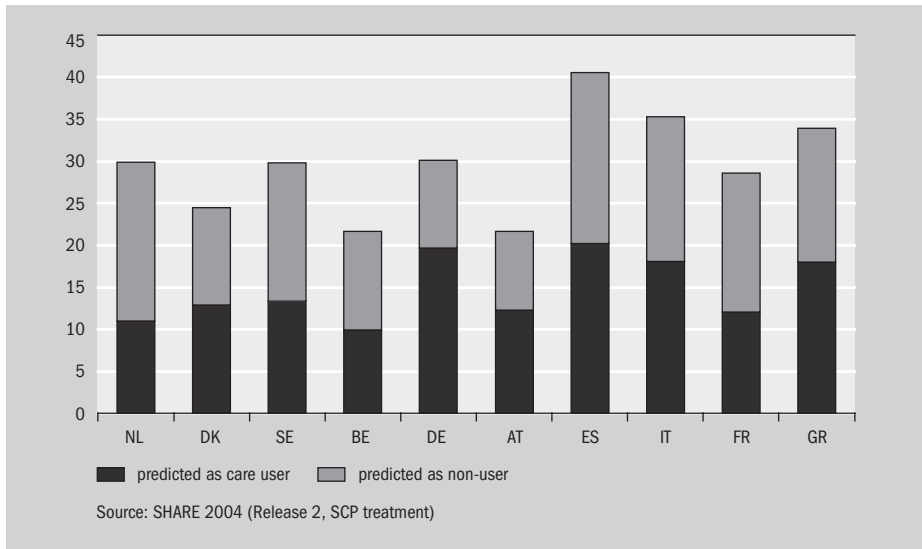
Even after correcting for differences in the distribution of needs, resources and circumstances, we find country-specific differences between the share of elderly persons receiving care. A part of the differences between countries can thus be attributed to the aforementioned observable differences between countries, while

a further part can be ascribed to observed country-specific factors that were not observed. A dichotomy emerges between the Netherlands, Denmark, Belgium, Germany and France, with a high probability of care, and Sweden, Austria and the southern countries with a low probability of care. With the exception of Germany, the probability that those in receipt of care will be receiving formal care is also higher for the same countries. If an elderly person receives informal care, the probability of receiving care from persons inside the household is higher in Belgium and in Spain than in all other countries.

On average 30% of elderly people with care problems in the selected countries do not receive any care. The differences between the countries are wide, however. Who are these elderly who have a care problem but who are not receiving care? Using the care-use model we divide elderly persons with a care problem into two groups: the potential care users, namely those whose characteristics would lead one to expect (based on the model) that they would be receiving care, and the predicted non-users, i.e. those whose characteristics are such that we would not expect them to be receiving care. Figure 11 shows the division of elderly people with care problems who do not receive care into potential care users (the group at risk of not receiving the level of care they really need) and predicted non-users.

Figure 12

Non-users of care divided into predicted non-users and potential users (%), subsample: over-50s with care problems



The countries with the highest proportion of elderly people with a care problem who are not receiving care are also those with the highest proportion of potential

care users among the non-users. This implies that in these countries (Spain, Italy, Greece and Germany) elderly people who are genuinely in need of care but who are not receiving it are at risk. Their daily functioning probably leaves a lot to be desired. On average, half of this high-risk group live alone.

On average, the potential care users among the non-users are almost ten years older than the predicted non-users among the actual non-users. More of them suffer from long-term illnesses or have serious physical disabilities. Almost half the potential care users among the non-users live alone, and relatively few have an informal network available. Once again this is a signal that this group is at risk of getting into serious difficulties. Of the predicted non-users among the actual non-users, only 15% live alone, and almost all have a partner or children living in the household to care for them.

There are considerable differences between the countries in the composition of the potential care receivers among the non-users. In both the Netherlands and Germany, for example, 30% of elderly people with care needs do not receive care. However, in Germany the proportion of potential care users is almost twice as high. The potential care users in Germany are almost six years older; most are female, living alone and have severe physical disabilities. All this could mean that the risk that poorly functioning elderly people who are genuinely in need of care but do not receive care, is greater in Germany than in the Netherlands.

7 Concluding remarks

The questions addressed in this report are concerned with health problems, need for care, available resources and care provided to people aged over 50 in ten Western European countries. Table 3 recaps the main results based on the SHARE sample, dividing the countries into three main clusters: the Scandinavian, the Continental and the Mediterranean types. In the Scandinavian group, individuals by and large carry primary responsibility for their own care provision, with the government stepping in when the individual experiences health problems. In the Continental model the nuclear family is primarily responsible in the event of health problems, while in the Mediterranean model this role is fulfilled by the extended family (including relatives outside the nuclear family). It should be borne in mind that this is no more than a broad categorisation; the Netherlands, with the recent introduction of the concept of 'usual care' (fellow household members should care for family members), has for example moved towards the Continental model.

The division into country clusters is most clear-cut when it comes to the preference of children for the care provided to their parents: who bears primary responsibility when parents need help? The opinion that this responsibility lies primarily with the children themselves is least strongly represented in the Scandinavian countries (Sweden: 16%), and most strongly felt in the Mediterranean countries (Greece: 89%). In practice, however, this distinction is less easy to find. The informal care received by people with disabilities varies from 25% (Netherlands) to 59% (Greece). The notion that the family should take responsibility does not always readily lead to the provision of informal care in practice. This brings the danger that needy elderly persons will be deprived of help. For example, 41% of people needing help in Spain and 35% in Italy do not receive the help they need, compared with about 23% of older persons needing help in Belgium, Austria and Denmark. The Netherlands is not in a favourable position here, partly because of the limited use of informal care. This is not caused by limited availability; on the contrary, there are relatively few households in the Netherlands where no informal care network is available, partly because of the high proportion of women working part-time (full-time workers are regarded as unavailable for providing informal care).

The position of the Netherlands in a European perspective is a topical subject. Does the Netherlands score better or worse on the care provided to people with disabilities than its neighbouring countries, and should it mirror itself on the countries where the levels of care are lower? The empirical findings point to something of a two-way split, in which the total amount of care received in the Mediterranean countries is significantly lower than in the rest of the countries studied. The reasons for this have to be sought in the lower availability and lower take-up of formal care; extended

families in Mediterranean countries are (or feel) responsible for providing care to their close relatives, and this is reflected in reduced availability of public provisions.

Table 3

Key figures for the over-50s: from disabilities to care provided (in percentages)

country cluster	who has to provide care ^a			with health problems ^b			with informal network ^c		help received ^d			total	
	own family	home care	institutional	perceived & observed	only observed	none/light	inside & outside	inside or outside	no help	informal	formal		
Scandinavian													
Sweden	16	41	44	13	14	73	4	42	54	30	32	38	100
Denmark	21	46	33	12	14	74	5	49	46	24	29	47	100
Netherlands													
	22	43	36	15	13	73	7	54	38	30	23	47	100
Continental													
Belgium	43	33	24	14	18	68	7	50	43	22	28	50	100
France	42	43	15	17	19	65	6	43	51	29	26	45	100
Austria	55	33	11	12	17	71	7	45	48	22	38	40	100
Germany	63	25	11	16	12	71	7	48	44	30	41	29	100
Mediterranean													
Italy	69	29	2	15	25	60	12	47	41	35	47	18	100
Spain	84	11	5	17	32	51	10	47	43	41	36	23	100
Greece	89	11	0	11	24	65	6	48	46	34	59	7	100

a Question put to children about care for their own parents (Eurobarometer).

b The health problem variant relates to people with moderate or severe disabilities; the care problem variant relates to people who also perceive this to be so, none/light (SHARE).

c Family members, within or outside household of people with disabilities (health problem variant); the figures for the care problem variant are virtually identical (SHARE).

d People with disabilities (care problem variant, SHARE). People receiving formal care may also receive informal care. Austria and Germany includes care transfers

Source: Eurobarometer 2002 and SHARE 2004 (Release 2)

Less use is made in the Netherlands than in other countries of informal help with household tasks provided by people outside the household. In addition, there is a greater readiness in the Netherlands to use formal public care services for help with daily living tasks. The responsibility of individual citizens has however recently been increased, with the introduction of the assumption that family members will provide 'usual care', especially with domestic tasks.

The European countries included in this report differ from the Netherlands on a number of points. To some extent these differences can be explained by country-

specific differences in age distribution, disabilities faced by the elderly, household composition and education level. However, country-specific differences remain even after allowing for these factors, which we did not specify further. What explanations can we offer for this? Differences in household composition between countries partly explain differences in informal care. In Southern Europe, people live together in larger families, often covering several generations. This has to do not only with cultural differences, but also with more practical matters. In Italy, for example, it is difficult for young couples to find an affordable home of their own. In addition, increasing prosperity leads to a reduction in the birth rate, and the smaller number of children in turn leads to a reduction in the availability of informal care. At the same time, friends and neighbours in the social network are becoming increasingly important as potential providers of informal care.

In addition, a number of differences between countries can be identified which could not be considered in this report due to measurement problems, but which do influence care. These include the employment rate, the social distance between parents and children, the wishes of the older person and institutional differences. A person's labour market position has an influence on the informal care they may or may not provide; the more time people spend at home, either willingly (by choosing part-time work or choosing not to work) or unwillingly (high unemployment rate), the more opportunity they have to provide informal care. In Denmark and Sweden people spend a great deal of time in paid work, which may explain the lower amount of informal care provided in those countries. In the Netherlands and the Mediterranean countries, the employment rate of women has risen sharply in the last twenty years (OECD 2004), putting further pressure on the availability of informal care.

In this report, the physical distance between parents and children plays a role, but not the social distance between them. It is logical that partners are willing to care for each other, but we do not know how and whether children and neighbours are also inclined to provide care. The report *Old Age and Autonomy* (Oasis 2003) characterises countries by the way in which family relationships function, ranging from 'close' to 'distant'. No clear country picture emerges, and in particular not the anticipated picture that Mediterranean countries more often fall into the first category and Scandinavians more often into the second. What does become apparent is that many ambivalent relationships arise when parents and children 'negotiate' with each other on the dividing line between autonomy and dependence.

The wishes of the elderly persons concerned are a very important factor in the provision of informal care. Much depends on whether an elderly person wants to receive help from their family or prefers formal care. It may also be that the elderly person wishes to continue doing as much as possible for themselves. This desire can perhaps be supported by the provision of aids such as a wheelchair or home adaptations. Research suggests that older persons wish to continue living independently

for as long as possible and limit the help provided by family if alternatives are available (Oasis 2003). These findings fit with the notion of the citizenship paradigm: citizens continue to play a normal part in society for as long as possible and wish to receive support in doing so for as long as possible; that support may be found in the form of medical and other aids and in the social network (Van Gennip 1997).

Institutional factors mainly affect the provision of formal care. These factors include things such as legislation and regulations, social norms and public provisions. The legislation in all countries has a residual and generic character: the government is expected to provide the services that people with disabilities need and which they and their close relatives are unable to provide. However, this principle can be interpreted in either a flexible or a strict sense. For example, the Mediterranean countries tend towards a strict interpretation (the extended family bears responsibility, unless this is not a real option), while the Scandinavian countries adopt a more flexible interpretation (the government is responsible, unless the family is still able to meet the need).

The strong focus on the family in providing care for the elderly has been under great pressure in recent years, especially in the Mediterranean countries. It is not only demographic factors that are responsible for this (fewer families with children and fewer children per family); geographical factors (increasing physical distance) and economic factors (rising female employment rate) also play a role. The familial support principle is sustained to a large extent by the large-scale hiring of migrants from Eastern European and non-European regions. This provision of care by immigrants has become very popular in recent years in countries such as Spain, Italy and Greece. In Italy, for example, the number of domestic carers has quadrupled in the last fifteen years and the proportion of foreign carers – due in part to the introduction of the personal budget to be spent as people see fit and to the low wages paid to immigrants – has risen from around 15% in 1990 to approximately 85% in 2005 (Lamura et al. 2006). Although the marked increase in the provision of domestic help by immigrants has clear advantages (meeting a need, low costs), there are also clear disadvantages, relating among other things to the position of immigrants and the sustainability of the migration model. This kind of substitution is not yet an issue in the Dutch context, partly because the government already goes a long way towards meeting the need for formal care.

The findings also reveal another picture. Of the total number of people with moderate and severe disabilities, a third receive no help whatsoever, either formal or informal. The Netherlands occupies an average position here among the ten European countries studied. This picture is perhaps less rosy than expected, including in the light of future developments. The social networks of older people are increasingly reliant on friends and neighbours and less and less on family. Older persons in the Netherlands contribute to this trend themselves because of their preference for

a greater degree of independence. The contributions payable by the clients of public services are increasing, especially in situations which the government does not see as its primary responsibility. This applies in particular for provisions falling outside the realm of direct care (housing and transport provisions which enable older people to retain their independence for longer). A shift is taking place from a providing government (the government is responsible unless the family is still well able to provide the care) towards a supporting government (the family is responsible, unless this is genuinely no longer possible). Given the problems outlined earlier in the Mediterranean countries, a further shift towards the Mediterranean familial model does not seem likely. The way in which the present situation evolves in practice should make clear whether the recent shift towards the more nuclear family-oriented Continental model will be enough to enable people with disabilities to meet their needs for care.

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Notes

- 1 In Italy, the national allowance is not means-tested.
- 2 About 95% of the combinations are with physical disabilities.
- 3 We also know that personal and domestic care is predominantly undertaken by female spouses and daughters (Walker and Malthby, 1997).
- 4 We have estimated a sequential nested logit model (McFadden (1978)) in STATA. In the nested logit model, the set of alternatives is partitioned into subsets (called nests) such that IIA holds within each subset, and does not hold for alternatives in other subsets. For our choice set, the tree diagram in figure 11 depicts the natural substitution patterns.