Summary

Background

The picture of the care provided to sick relatives and friends as portrayed in the press and in policy plans is a somewhat ambivalent one. The majority of articles and policy documents express a one-sided view: the willingness to provide informal care is declining; and if people do provide this help, it is not out of free choice and they experience the giving of care as a burden. They are portrayed almost as Cinderella figures, who are forced into service by the wicked stepmother of social norms. The other side of providing care rarely receives any attention, and where it does it is often encapsulated in abstractions such as 'informal care on a human scale', or 'people's independence is fostered by informal care', or 'informal care as an example of solidarity'.

The cliché image of informal carer is that of a daughter aged between 35 and 54 years old, who is in paid employment and cares both for her children and her elderly, needy parents, and who is overburdened as a result. This report takes a closer look at this image.

This general picture is found to be too one-sided; there is a whole range of different types of informal carers. In addition, we examine a number of the assumptions expressed in the press and in policy documents. Is the willingness to provide care really declining? If so, is this related to the fact that family members live further apart or less frequently share care tasks? Do older persons move in with their children more often as a consequence? How accurate is the image of the informal carer as a Cinderella figure? What is the position as regards the burden and the costs of providing care, and does the carer receive assistance from their social network or from support services?

Changes in informal care, 1991-2003

People often believe that the availability of informal care is declining because of the growing labour market participation of women. It has been demonstrated that this image does not apply for the population as a whole: both in 2003 and 1991, more than 12% of the population provided informal care. This is a striking finding given the decline in the availability of state care provisions for the elderly over the same period and the rise in the number of people in need of help, partly due to the ageing of the population.

A breakdown by age categories reveals that women are providing less informal care because they are more often in employment, is too simple. While it is true that (relatively) young women aged 18-44 years go out to work more and provide less informal care, it is also true that most of these women work part-time, and that the difference

in the provision of informal care given by non-workers and part-time workers is very small. Moreover, women in the older age groups (45-64 years) also go out to work more often, but no decline in informal care provision is observed here.

The profile of informal carers has altered over the last 15 years, with more and more of them being older and being in work. In the older age categories, many will be providing care to partners. Earlier research has shown that it is precisely those who are providing care to their partners who are at risk of becoming overburdened. The fact that the proportion of people combining informal care provision with paid employment is rising implies that a growing number are having to combine work and informal care and that schemes designed to facilitate this are becoming increasingly important.

Estimated extent of informal care, 2000-2020
For this report, estimates were made of the demand for and supply of informal care (population simulation model). These estimates suggest only a modest increase in the demand for informal care: the number of users in 2020 will be only 5% higher than in 2000. This is because the largest group of people who receive no help other than informal care increases to such a small extent (3% in 20 years). Earlier estimates suggest that people who need help increasingly use self-paid help, especially private domestic help. The better socioeconomic position of older persons in particular makes this possible, and means that help provided by children is no longer needed.

The increase in the supply of informal care is also unspectacular, though at 15% is still considerably higher than the rise in demand. The supply of long-term care increases to an even greater extent, rising by 20% in 20 years. Here again the improved socioeconomic position of the population plays a key role, since the better that position is, the lower the demand for informal care but the greater the propensity to offer it.

These estimates are based on assumptions which – some more than others – are open to discussion. The first of these assumptions is that the supply of professional help will be able to keep pace with the demand for it. Major changes in that professional supply or in the government-funded entitlement to it will lead to an increase in demand which will easily outstrip the predicted increase in the supply of informal care.

The second assumption is that there will be some growth in prosperity up to the year 2020 and that groups consuming large amounts of care, such as older persons, will share proportionately in that prosperity growth. If the financial position of these groups were to fall a long way short of expectations, this could push up the demand for informal care considerably (because the consumption of paid private

care will then be lower). It is doubtful whether the supply would then be able to meet the demand, especially if the government continues to cut back on publicly funded care provisions. In short, demand for informal care could be substantially higher than estimated. Based on the supply estimates it is reasonable to assume that some increase in demand could be accommodated, but that the margins will rapidly become too small in the event of major shifts. Nonetheless, there is no reason to assume that informal care will become a disappearing phenomenon.

Take-up of support by informal carers
In 2001 a quarter of informal carers reported that they were fairly severely overburdened, very severely overburdened or simply overburdened. Around 7%, or roughly 260,000 persons, feel overburdened or very severely overburdened. A third of informal carers make use of advisory services; 17% use in-home respite care services and in 10% of cases the person requiring help uses daycare services. Informal carers who experience a heavy burden are overrepresented among those who use advisory and in-home respite care services. This is not the case for daycare services, which are used to an equal extent by people receiving help from burdened and unburdened informal carers.

In-home respite care and advisory services are forms of support which help to reduce the burden of informal carers, as evidenced by the fact that informal carers who provide many hours of help receive such support more often. Home care and support are also provided simultaneously, probably because home care organisations either offer this support themselves or refer informal carers to such facilities. This suggests that once people have taken the step to seek help, the need is high; this results in cumulative take-up of support and professional care.

Informal carers encounter all manner of barriers to the actual take-up of support. Non-users with a need for support frequently cite lack of familiarity with support or with the precise services available; this is especially true for advisory services. The informal carers surveyed appeared to be more familiar with respite services. In addition, more than one in ten informal carers state that the difficulty in accessing advisory services played a role in their non-take-up; they did not know how to access this support. These findings suggest that the availability of support services needs to be made much more widely known.

Sharing care
Adult children often work together in providing care for their elderly father or mother. In 60% of families the children share the care tasks; in roughly half of these cases the tasks are shared equally, while in the other half the child with the primary care task is supported by one or more brothers or sisters. Of all children providing care (n = 521 in our survey), only 40 were caring for their father or mother on their own. The general picture is thus that in most families the provision of care by adult children is a matter of cooperation and sharing of tasks with brothers and/or sisters.

The size and composition of the family is a key determinant of how many children provide care and how they divide the care tasks. In small(er) families with only sons, there is a strong chance that these sons will share the tasks equally or that they will not provide any care at all. Sons thus act less frequently as primary caregivers.

In small(er) families with only daughters it is much more common for one of them to take on the care task, with her sister(s) providing no care at all. In a fifth of these families, the daughters share the tasks equally, but in only 13% of cases does one sister act as the primary carer and her sibling(s) as secondary carer(s). 'Either alone or shared equally' appears to be the credo of women with only sisters, and it may be that sisters are more inclined to discuss the situation and coordinate the care tasks; in many cases this then results in the sister who lives closest becoming the caregiver. It is also possible that this sister regards it as natural that she should provide the care and is not particularly inclined to mobilise her sister(s). Substitution patterns in the task division between children appear to occur most commonly in these 'female families'.

In large(r) mixed families we relatively frequently find cooperation between the children, with an unequal division of tasks (primary and secondary carers). The motto in large families is: 'the more my brothers and sisters do, the more I will do'. These findings underscore the importance of family size for the provision of care by children. However, this study also makes clear which solutions are open to children in small families. Whether they become primary carers or share the tasks with their brothers and/or sisters depends on the composition of the family, but also on their individual situation and that of their siblings.

Geographical characteristics and informal care

There is a common view that informal care comes under threat if those in need of care live a long way from the members of their network. The probability that people will provide care is indeed greatest when the distance between the potential caregiver and the recipient is no more than 5 km; between 5 and 40 km the probability declines sharply, but after that it remains constant. This latter finding suggests that the role of distance should not be overestimated: even when family and friends live further away, they are prepared to cover long distances in order to offer help.

No correlation is found between degree of urbanicity and the provision of informal care, though people living in the southern Dutch provinces of Zeeland, Noord-Brabant and Limburg do provide informal care to their parents and siblings more often than those living in other parts of the country. This finding is not attributable to active church membership or network size, and may indicate that the family ties in the south are somewhat stronger than in other parts of the country.

Geographical characteristics play a lesser role in the receipt of informal care. There is no demonstrable correlation between receipt of informal care and distance to network

members, nor with degree of urbanicity and geographical region. By contrast, age has a considerable effect: 18-39 year-olds receive help from parents and parents-in-law more frequently than 40-79 year-olds. The quality of the contact between the potential giver and receiver of care is also a crucial factor; it is not the presence of family members but the strength of the ties between those involved which correlates with more informal care.

Mobility of the informal carer
Travelling informal carers are often females, visiting their parents or parents-in-law in order to offer help. They provide an average of 12 hours' help per week, mainly domestic help and psychosocial support, and are less likely to provide personal care.

For most informal carers, the time travelled is short; half of them do not have to travel more than a quarter of an hour, while for three-quarters of them the journey is no more than half an hour. The car is the most widely used means of transport, especially for journey times of more than a quarter of an hour. This travelling costs money: informal carers who have to travel for less than a quarter of an hour spent an average of EUR 4 per month on travel, but with longer journeys the costs can quickly become burdensome, reaching almost EUR 100 per month for a helper who travels for more than an hour, for example. An estimated 90,000 informal carers were confronted with high travel costs in 2001 (more than EUR 160 per year, the top 25% of travel costs) combined with a relatively low income (less than EUR 15,000 per year, the bottom quartile of the income distribution of informal carers).

As might be expected, informal carers who face long journeys provide different care from carers with short journey times. They visit less frequently and provide more psychosocial help than carers who live close to the care recipient. Domestic help or personal care are provided less frequently as the journey time of the informal carer increases. Informal carers with long journey times spend just as many hours providing care as carers who do not have to travel so far; they visit less often but stay longer, so that the average number of hours spent per week is roughly the same as that of carers with shorter journey times.

Older persons in multiple-generation households
Reference is not uncommonly made to a situation where children take in their needy parents in order to look after them at home. This report suggests that this image bears little relation to present-day reality. Although a large number of the over-65s do live with their children, in almost half the approximately 100,000 households of these parents the children are still young and are often dependent on their parents rather than vice versa. Multiple-generation elderly households of this kind continue to exist only until the last child becomes independent, and will therefore not have a long life.

A few tens of thousands of parents live in with their children, and the number of needy older persons sharing a home with their children is of the same order. The situation where needy parents move in with their children is therefore uncommon – so uncommon that it is difficult to determine their number accurately, though at most it will be a few thousand. Finally, needy older persons in multiple-generation households are found to receive care from outside the household just as often as other needy older persons living together. Older persons who are cared for by their children and who share the household with them are found to be a marginal phenomenon numerically.

In rural areas and in the east and south of the Netherlands the proportion of older persons sharing a home with their children is around 30% above the average. This is most marked in the eastern province of Overijssel, where the proportion is 90% higher than for the Netherlands as a whole. This is the only province where the proportion exceeds 10%, but even here the share of needy older persons living in multiple-generation households is no higher than 3%. Even in regions where these households are traditionally more common, therefore, they are by no means the norm. Catholic older persons do not live with their children any more often than their non-Catholic counterparts.

Vulnerability of the children appears to provide little reason for staying with or moving in with parents. The strong overrepresentation of persons who have never married suggests that most children in multiple-generation households have stayed living with their parents because they have not found a partner with whom they could form their own household. For older persons, by contrast, the theory of vulnerability as a factor does appear to hold water: 9% of older persons with severe limitations live with their children compared with an average of 6.4% for the population as a whole. However, it is apparent that even for vulnerable older persons, only a fraction live in multiple-generation households.

A few conclusions

In this research a number of persistent images about informal care are presented and confronted with objective data from research. This enables the erroneous view that people are less and less willing to provide informal care to be corrected – at any rate, during the last 15 years the proportion of persons aged over 18 who provide care to sick relatives and friends has remained stable. This is striking given the decline in professional care and the increase in the labour market participation of women in this period. The image that one child within the family takes on the task of caring for a needy parent or parents is also distorted. In many cases the care tasks are equally divided among the children or they cooperate in providing the care (with one providing more/more frequent help than the other(s)). The idea that informal carers must live close by the care recipient can also be qualified: half of all informal carers have to travel for more than a quarter of an hour and one in ten face a journey of more than 60 minutes.

This report shows yet again that informal care occurs in many forms. For example, there are many men who provide informal care; adult children who share the care for their needy parents and regularly travel back and forth to do so; informal carers of people with psychiatric disorders or of a child with physical limitations; informal carers looking after a chronically ill friend or neighbour; and parents who live with their adult children or children-in-law and can therefore easily exchange care tasks.

Although the image of the informal carer as a Cinderella figure is one-sided, it is still the case that there are providers of informal care who have taken on too great a burden and run the risk of being overwhelmed by it. This report indicates which groups are vulnerable in this regard: people with a low income and high travel expenses, informal carers who have to provide all the care themselves (sometimes without home care services), carers who need support but do not access it. In addition, certain categories of care recipients deserve extra attention because they primarily need professional help. Examples include people with only distant relatives, people who do not have good contacts with their children (e.g. because of divorce), or families with only male children.