

Summary and discussion

Unpaid help: who does what?

Extent, nature and characteristics of informal care and voluntary care and support in 2014

S1 Summary

Background

The Dutch care system is changing. Up to and including 2014, care for people with impairments and disabilities was funded and provided through two pieces of legislation: the Social Support Act (Wmo) for care provided through local authorities, and the Exceptional Medical Expenses Act (AWBZ) for centrally funded care. On 1 January 2015, a new Social Support Act was introduced (Wmo 2015) and the new Long-term Care Act (Wlz) came into force. People who require permanent supervision or 24-hour care can apply for provisions under the Wlz. The Wmo 2015 means that, from 1 January 2015, local authorities are responsible for providing a wide range of social support. The government's aim in introducing the Wmo 2015 is to strengthen the position of informal carers and volunteers. For example, informal carers must be involved in local authority assessments of applications for social support. A determination is then made of whether the client is able to contribute to the provision of their care themselves, and what support they need. The government believes the reforms are necessary in order to meet the changing demands that people place on quality of life, to increase their engagement in society and to ensure the financial sustainability of the care system.

The number of people in the Netherlands aged over 65 (a group who relatively often use unpaid help) has increased in recent years, while the number of 18-64 year-olds (who relatively often provide unpaid help) has remained roughly unchanged. Changes in the care system and demographic trends mean that the figures on unpaid care are outdated: the last large-scale study of informal care dates from 2007. Research on care volunteers is predominantly small-scale and descriptive in nature.

Box S.1 What is unpaid help?

Unpaid help is 'all help provided to people with diverse health problems which is not provided by a professional helper'. This includes both help that people provide to each other because of their mutual relationship (informal care) and voluntary work in the area of care and support. It thus includes all support provided, including to fellow-household members, because of impairments/disabilities, chronic mental health or psychosocial problems and which is not provided by care professionals. Examples include emotional support, help with making appointments or applying for support, transport, help with the household, personal care or administrative help.

At the request of the Dutch Ministry of Health, Welfare and Sport, the Netherlands Institute for Social Research¹SCP carried out a new study in order to form a recent picture of unpaid help. Prior to the study, SCP carried out a literature review on unpaid help (De Boer & De Klerk 2013), as well as a qualitative study of the scope and limitations of unpaid help. A central focus of this latter study was also to identify pointers for making better use of the potential of unpaid helpers and what role support might play here (De Klerk et al. 2014). In this third phase of the study, the focus is on the current status of informal help in the Netherlands and people's willingness to provide help. The central questions addressed are:

- What kind of unpaid help is given, and how much?
- Which groups are more willing than others to provide (more or different) unpaid help?
- Which characteristics are associated with giving help and the willingness and ability to do so?
- What are the consequences of giving unpaid help, for example in terms of perceived stress and quality?

New study: large-scale population survey

This publication is based on the findings of a survey of 7,311 Dutch independent community-dwelling adults (aged 18 and over) carried out in the period September-December 2014. The survey used a representative sample drawn from the Municipal Personal Records Database (GBA). The survey was partly web-based partly a telephone survey. As it was conducted in the Dutch language only and the response rate among non-Western migrants was low, the data on non-Western migrants need to be interpreted with some caution. The study design is different from earlier data collections on informal care (see Chapter 2), rendering comparisons over time with earlier studies impossible. The next survey scheduled for the end of 2016 as part of the evaluation of the reform of long-term care, and will be carried out by SCP at the request of the Dutch Ministry of Health, Welfare and Sport.

Lots of people provide unpaid help

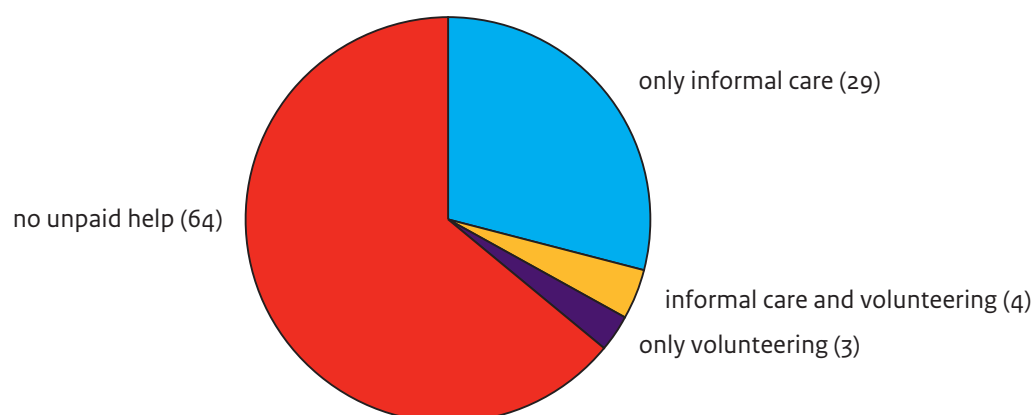
It is estimated that in 2014 over four million people (33% of Dutch adults) had provided some form of informal care in the year preceding the survey. Informal care is interpreted broadly here, and includes things such as providing emotional support or helping with transport (see Box S.1). 10% of informal carers provide help only with emotional support or companionship. Many people help long-term (longer than three months) but not intensively (maximum eight hours per week). Roughly one in six informal carers provide help for more than eight hours a week. Over 600,000 people provide help for more than three months and more than eight hours per week. These figures exclude the 'usual help' which household members are expected to provide to each other.

Almost a million people (7.5% of the population) had been active as volunteers in the care sector in the year prior to the survey, roughly two-thirds of them via a voluntary organisation. This includes (unspecified) occasional help and help not provided through an organisation. Some 630,000 people (5% of the population) engaged in volunteering regularly. A high proportion of volunteers (more than half) are also active as informal carers.

In total, 36% of Dutch adults provide informal help (as informal carers and/or volunteers).

Figure S1

Unpaid helpers, 2014 (in percentages)



Source: CBS/SCP (IZG'14)

Lots of people know someone who needs help

A majority of Dutch citizens (57%) knew someone who needed help in the year preceding the survey. This is common among 45-64 year-olds, who relatively often have parents needing help. People with a partner relatively often know someone who needs help because they have parents-in-law.

Not everyone who knows someone who needs help provides help. The reasons cited for not doing so are that other (professional or informal) help is available (54%), poor health, advanced age, no time or living too far away.

Diversity: different kinds of helpers

There is a tendency to think that it is mainly women who provide unpaid help, and this image is correct to some extent. Women provide help more often than men (58% of informal carers and 65% of care volunteers are women), but there are also many men providing help. There may be various reasons why women provide help more often. One key factor appears to be 'time': women have more time to help because they less often have a job for at least 12 hours per week. The converse is also possible, namely that women less often work for at least 12 hours per week because they more often provide informal help (De Boer et al. 2015). But men and women also appear to have different attitudes towards providing help. Women say more often than men that they know someone who needs help and that they sense when help is needed. Differing expectations regarding the roles of men and women may also play a role. Women more often say than men that the person needing help would prefer to receive it from them. A parallel can be drawn here with caring for children, another area where women are often thought to be more suitable carers than men (Van der Sman et al. 2014; Portegijs & Cloin 2012).

There are few differences between male and female informal carers. They provide the same number of hours of help on average, though men relatively often help their partner

while women provide help to a broader group of recipients. Men help slightly more with administration and transport, while women more often provide accompaniment for visits to the doctor and help with things such as making appointments and personal care. It is striking that women more often experience helping as a burden than men, even allowing for the intensity of the help. This echoes findings in earlier research (Broese van Groenou & De Boer 2009).

People in the 45-64 age group provide a relatively large amount of informal care, and the over-55s (and especially 65-74 year-olds) do a lot of volunteering in the care sector. There are also very young or elderly people who provide informal care, though the number of young informal carers in our study is relatively small (8% of all informal carers are aged under 24). We have no picture of very young informal carers because our study focused on people aged over 18. Care professionals describe young informal carers as a group who warrant extra attention (De Klerk et al. 2014). People aged over 75, who relatively often help their partner, also warrant attention because they often provide intensive help and have health impairments themselves. There are also wide age differences among volunteers, with young people relatively often doing occasional voluntary work whereas the more 'structural' volunteers are relatively often aged over 55. People who regularly attend church are more often active as volunteers in the care sector than non-churchgoers.¹ The diversity is also evident from the combination of work and care tasks. A quarter of volunteers in the care sector combine their volunteering with a job of 32 hours per week or more, and the same applies for almost half of informal carers aged 18-64 years. Workers and non-workers provide help equally frequently, but workers are less often the central carer than non-workers and less often provide intensive help.

51.1 Informal carers

Informal carers often help close family

Four out of five informal carers provide help to a relative, often a parent/parent-in-law (45% of informal carers) or a partner (14%). More than one in five informal carers provide help to friends (16%) or neighbours (6%). Although this help is relatively light in nature, it can be essential for the quality of life of the person receiving it. Roughly one in five helpers support a fellow-household member, usually a partner or child.

The recipients are people who need help and support with living independently and participating in society. The reason for needing help varies widely, from physical problems to dementia, intellectual impairments, advanced age, mental health or psychosocial disorders and psychosocial problems to terminal illness. The care intensity can be high: roughly one in fifteen informal carers provide help to someone assessed as eligible for admission to an institution. Around one in ten of those needing help are no longer able to be left on their own for longer than half an hour. The intensity of help provided to child recipients is relatively high, while that provided to friends, neighbours or acquaintances is relatively low. Most people help because they enjoy doing it or consider it natural and therefore have an intrinsic motivation. However, some provide help because they believe no one else is avail-

able, because that is what the recipient wants, or in order to defer or avoid having to call in professional carers.

How do informal carers combine work and care?

Five out of six informal carers aged 18-64 years are in paid work. Almost three-quarters of male and more than a quarter of female informal carers combine their care tasks with a job for 32 hours per week or more. These gender differences are comparable with the labour participation rate of all 18-64 year-olds.

Four out of ten working informal carers frequently provide help on days that they also work; 11% have to interrupt their work on a daily or weekly basis in order to provide help. This applies especially for those providing care to someone with a terminal illness or to a partner, and those providing intensive help. Flexible working hours can then be important in enabling them to combine work and care tasks. However, one in five working informal carers cannot take a day off without warning, and more than a third cannot set their own working hours.

Working informal carers tend to take time off rather than using formal care leave

Three out of ten working informal carers took one or more days off in 2014 in order to provide informal care. Most of them had a job for 12 hours per week or more, were providing intensive help and were helping partners or children. Relatively little use is made of formal leave arrangements (5% use unpaid leave and 7% paid leave). Around 10% (roughly 275,000 informal carers) have temporarily or permanently reduced their working hours or stopped work because of their informal care tasks. This is more common among those helping partners and children, intensive helpers and people who often have to interrupt their work to provide help.

Informal care not always open for discussion at work

Over half of working informal carers have told their manager that they are providing informal care. The main reason for not telling them is that there is no reason to do so. Intensive helpers also give as a reason that their manager is not open to it. Roughly three-quarters of those who have spoken about it at work receive an understanding response from their manager – which means that a quarter do not. One in seven have made arrangements with their manager in relation to providing informal care, for example on flexible working hours, taking more time off or working from home more often. Working informal carers report that they benefit most from flexible working hours and understanding from their manager are the biggest help in combining informal care and work.

Many informal carers living outside the home share the help tasks with informal or formal carers

Among informal carers who help someone outside their own household (82%), almost all share the help with others: 7% of informal carers provide the help alone, 26% in an informal network shared only with informal carers, 26% in a mixed network containing both

informal carers and professionals and 8% in a network of care professionals.² The remaining 15% provide help to someone living in a care institution and therefore always share the help.

The type of network is closely associated with the nature of the illness or disability: mixed networks are found most commonly where the recipient has a terminal illness, and the chance that an informal carer will be providing help alone is then the lowest. Informal carers providing help to someone with dementia or an intellectual disability often share that help with professionals and relatively often help someone living in an institution. Informal carers helping someone with a mental health or psychosocial problem relatively often have to do so alone. Helping a parent or other family member is often carried out by a mixed network.

Cooperation with professional carers not yet optimum

The majority of informal carers who share the help with home care or community nursing professionals feel that they can go to them with questions and be taken seriously. They are less satisfied about their ability to participate in decisions and about sharing help: almost half feel they play little part in decisions about the care or are not able to share it satisfactorily. More than half feel that home care or community nursing professionals take too little account of the welfare of the informal carer. Informal carers of people with mental health or psychosocial problems are the least satisfied with the cooperation.

One in three informal carers are afraid, unable or unwilling to ask for help

Not sharing informal care with others may be linked to all kinds of inhibitions about asking for help. It may be that carers are afraid or unwilling to ask family or friends for help (or a combination of both), that they do not know enough people whom they could ask for help or that the recipient does not wish to be helped by anyone else. In total, 18% of informal carers have two or more reasons for feeling unwilling or unable to ask for help. Those who find it difficult to ask others for help are more often (over)stressed. Informal carers of people with mental health or psychosocial problems say there is often no one available, because people with mental health or psychosocial problems often have a small network. They also do not want to receive help from others. It may be that they do not want others to know about their problems, or that they regard more help as unnecessary.

Roughly a fifth of informal carers use support

Informal carers can apply for support under the Wmo, for example in the form of respite care (during the daytime or overnight), information, advice or financial support.

Around a quarter of informal carers make use of respite care. The need for and use of this care is difficult to establish, because a sizeable group of carers do not know. Among those who do know about it, 20% use respite care and 14% have an unfulfilled wish to do so.³

Daycare services are particularly well used, but are also cited as a provision for which there is (more) demand. The use of and need for support is related mainly to the nature of the care need. For example, respite care is frequently used or desired where the recipient has a

terminal illness, dementia, a mental health or psychosocial problem or an intellectual disability.

Roughly one in five make use of different forms of support, such as information and advice, following a course or training programme, contact with fellow-carers or material help. Information or advice is most commonly used. A quarter of informal carers have a need for (more or more frequent) support of a different kind, mainly information and advice (15%), but also material help and help in applying for provisions. More than half the informal carers who have a need for this are unaware of any of the direct forms of support.

Finally, it is striking that over a third of informal carers do not know what might help them the most. Lack of knowledge about what is available may play a role here, but so may the fact that informal carers did not have a (conscious) need for support at the time of the survey.

Positive experiences with giving help

Although providing help can be a heavy task for some people, it also definitely has a positive side. More than 80% of informal carers say they enjoy the good moments and derive positive feelings from giving help. People volunteer in the care sector primarily because they enjoy doing something meaningful for others and because they find it an enjoyable and useful way to spend their time.

Informal carers of people with an intellectual disability often find providing the help to be a positive experience. This also applies for informal carers of people who show their appreciation for the help. Those providing intensive help have less positive experiences.

It is striking that people who are providing help to a friend, colleague or other relative are more positive than those helping a partner, parent or child. This may be because they are providing less intensive help or because they are more able to choose for themselves whether or not to provide help. An alternative explanation is that the positive feelings created by helping someone 'at a distance' can improve the relationship, whereas helping someone close at hand can put a strain on the relationship.

Almost one in ten helpers experience severe strain

Among the negative consequences of providing help are being – or feeling – unable to let go of the predicament of the recipient, or becoming ill or overstressed as a result of providing help. The more people experience these feelings, the more severe the strain of providing help is. Roughly one in ten informal carers (approx. 400,000 people) feel they are under severe strain. They are relatively often women and main carers. A demanding care situation is associated with heavy strain: a care recipient with incontinence or who demands a great deal of attention; not being able to plan help properly; or helping someone with a mental health/psychosocial problem or a terminal illness. Carers who work, provide lots of hours of help, give help in order to put off calling in professional help or because they feel there is no one else, also often experience helping as a heavy burden. Those helping family

members other than a partner, parent or child, and those helping a friend, report relatively low levels of strain.

It is sometimes difficult not to lose patience

One in three informal carers admit that they sometimes lose patience when caring for someone, and 9% admit that this can lead to screaming or rough treatment of the care recipient. Informal carers who are under heavy strain, performing lots of tasks or helping someone who can show aggressive behaviour or who does not show their appreciation, are more likely to lose their patience. The same applies for informal carers who feel that no one else is available to provide the care.

51.2 Volunteers in the care sector

A third of volunteers in the care sector are independent

Two-thirds of volunteers in the care and support sector do their volunteering through an organisation, and two-thirds do so on a structural basis. Almost half always work through an organisation. Around one in three volunteers help a group of people, while two-thirds provide help on a one-to-one basis. Volunteers often offer companionship or emotional support (61%), provide support with activities or provide transport. Women more often offer companionship and men more often transport; lower-educated volunteers more often provide meals and help in the household, while more highly educated volunteers more often help with administration. Volunteers often help someone with long-term physical disabilities (over 40%), but also help people with dementia, an intellectual disability or mental health or psychosocial problems. Some 13% of care volunteers find volunteering (too) stressful.⁴ This is more common among permanent volunteers aged between 35 and 44 years, those aged over 75 and those whose daily functioning is impaired.

Volunteers more positive about contact with professionals than with informal carers

Just under half (46%) of volunteers sometimes work alongside professionals (in an institution or a home setting). They are generally satisfied with this contact. More than four out of ten volunteers sometimes have contact with informal carers. A quarter of these volunteers say they are rarely or never able to coordinate the help with the informal carer.

Tasks of volunteers not always clear

A sixth of volunteers say they have sometimes performed tasks which they afterwards thought should have been carried out by professionals (such as accompanying clients to hospital). They feel they lack the necessary training to provide care and nursing services, for example. Most volunteers in the care sector are clear about what their tasks are; 17% find this unclear.

Almost one in ten volunteers would like more support

36% of volunteers working through an organisation say they receive no assistance or support from the organisation – though the caveat applies here that not all volunteers feel they need it. Over a third of all care volunteers feel they receive inadequate travel or out-of-pocket expenses, while one in six feel there are insufficient opportunities to follow training or courses. A substantial minority have no opinion about the adequacy or inadequacy of their liability insurance, training opportunities and travel or out-of-pocket expenses, and 14% say they do not know where they can go if they need advice, information or support. Almost one in ten of the volunteers active at the time of the study reported that they would like more support, such as a course or training programme, a listening ear or reimbursement of expenses.

5.3 Help potential

Men and older people often find it difficult to offer help

People vary in how easy they find it to offer help. Women report more often than men that they find it easy when help is needed, do not find it difficult to offer help and less often give help only when asked. Older people relatively often find it difficult to offer help, putting men and older people in the same bracket of ‘reticence to act’.

High proportion of non-carers unable or unwilling to offer help

People not providing help were asked whether they would be able and willing to do so. Roughly two-thirds said they would be willing to provide help. Just under half said they would only be willing to do so occasionally. Older people (who are already relatively often providing intensive help) are less willing to help than others. Forty percent of those not providing help said they had the time to do so, especially those not in work, people without children and younger people. In total, 35% would be both able and willing to provide help. These are intentions: whether people would actually provide help in practice would depend on the circumstances. Churchgoers are more often able and willing to help than others, while those who work many hours are less likely to do so.

Scope for providing (more) help

Around a third of current informal carers say they could do more if needed, while roughly a fifth say they would definitely not be able to do more. The largest group say it would depend on the situation, for example the type of help, intensity of help and whether they were able to combine giving help with work.

Volunteers in the care sector are reticent when asked if they could do more. The number who say they plan to do (slightly) more in the future is roughly the same as the number who say they intend to do less in the future. Around 70% think they will continue giving the same amount of help.

A majority (61%) of non-helpers are willing and able to provide half a day of help per week long term to a parent; 28% say it would depend, and 11% say they would definitely not be

willing or able to help. Of those not providing informal care, 41% would be willing to help pay for domestic help for a parent – a smaller proportion than those who would be willing to care for a parent. The willingness to provide long-term voluntary care (helping someone for two hours per week for an extended period) is low (15%). For many people (36%), the willingness to volunteer depends on the situation; for example, some say they are only willing to help someone they get on with, or who is someone they know. People also need to have the time to volunteer, and it makes a difference precisely what they are asked to do.

The finding that 35% of non-helpers would be willing and able to do something for a loved one appears to suggest that there is a potential of help. Evelien Tonkens refers in this context to the ‘altruistic surplus’. Yet this potential should not be overstated. Whether people would actually provide informal help in practice depends among other things on the social relationship, what kind of help is needed and whether people have time to give it in their daily lives. On the other hand, it is known that people do more and more when their help is actually requested (Timmermans et al. 2005). This applies for informal carers, but also for volunteers, who are often asked to do voluntary work by word-of-mouth (Schyns & De Boer 2014).

S2 Discussion

In this section we look more closely at the significance of the findings. In doing so, we look at those who provide help (micro-level), organisations involved in the provision of informal help, employers and local authorities (meso-level) and national policy (macro-level). First, however, we look briefly at the design of the study, which was conducted in 2014, shortly before the new legislation setting out the reforms in the care system came into force.

Rich information source, but incomplete: missing perspectives

This publication describes informal help from the perspective of those who provide it. This means that the experiences of a number of key stakeholders are left out of the picture. For example, we do not know how recipients experience the informal help they receive. Do they value it? Do they consider it to be of sufficient quality? The perspective of professional carers, voluntary organisations or local authorities is also absent: how do they view informal helpers and how do they experience the cooperation and support? Notwithstanding these shortcomings, this study provides us with a wealth of information.

Informal help: a diffuse concept

The definition of informal help as ‘all help provided to people with diverse health problems which is not provided by a professional helper’ seems clear, but that is not always so. One reason for this is that ‘help’ is a diffuse concept: most people will regard personal care as help, but perhaps not emotional support or assistance in applying for provisions. The inclusion of as many specific examples as possible in the survey questions means there

is little risk that we have underestimated the number of helpers, but there are always people who take the help offered so much for granted that they do not themselves describe it as help. In addition, a more specific definition can be necessary for policy, for example to determine precisely who is eligible for support. This might for example be based on a minimum number of hours of help or the provision of certain types of help.

The boundary between informal care and volunteering is not clear to everyone – someone who has at some point volunteered as a buddy can later become good friends with the recipient. The fact that people are unsure whether they are classed as informal carers or volunteers in policy terms is evident in our study from the fact that some respondents describe the help they give as both. There is also an increasing number of hybrid forms of help; for example, informal care is in principle unpaid, but there are also informal carers who receive payment from the care recipient's personal budget. When it comes to volunteering, there are independent volunteers who do not fall within the official definition of voluntary work, and 'managed' volunteers who can be 'ordered' to differing degrees to perform voluntary work, for example in return for social assistance benefit. Some people wonder whether this can be genuinely described as volunteering (see e.g. Hetem 2013). The fact that citizens, informal helpers, researchers and policymakers use terms such as informal help and informal care interchangeably can also be confusing. People do not always recognise themselves in those terms, seeing themselves as the care recipient's daughter, for example, rather than as their informal carer (Linders et al. 2013). One side-effect of this can be that they sometimes do not realise that they may be eligible for support.

Attention for partner-helpers and intensive helpers

Partner-helpers and intensive helpers (more than eight hours' help per week) may be vulnerable. They are partially overlapping groups: people who are providing help to their partner or child relatively often provide intensive help (eight hours per week or more), which they are moreover not always able to plan in advance. They interrupt their work to provide help more than others. They also take more time off to provide informal care and more often temporarily or permanently reduce their working hours or stop working in order to provide help. They relatively often provide help because they feel it falls to them to do so ('the person in question wants it to be me who helps') or 'no one else was available'). Partner-helpers (who include a relatively large number of over-75s) and those providing intensive help regularly feel under heavy strain and more often lose patience. This may be a group who need extra support.

Attention for informal carers of people with mental health or psychosocial impairments

Informal carers who are providing help to someone with mental health or psychosocial impairments seem to be a group who warrant specific attention. They often feel ill-equipped, which is understandable given that the problems are usually complex. They often provide help alone and relatively often say that there is no one to take over from them if they should become indisposed (see also Wittenberg et al. 2012). They relatively

often feel under heavy strain and more often lose their patience. Where these informal carers do share giving the help, they are less satisfied with the coordination of the help than others. Informal carers of people with mental health or psychosocial problems appear to warrant attention, particularly as regards their well-being. If providing the help becomes too much of a strain, other help (from volunteers or professionals) needs to be readily available.

Quality of help

It is difficult to obtain a good picture of the quality of informal help by asking informal helpers. This is a question that should preferably also be put to the care recipient or care professionals, but they were not included in this study. Care professionals in the past have indicated that informal carers are sometimes under too much strain and do not realise that they are no longer fit to care (De Klerk et al. 2014). The number of times that actual mistakes are made is limited according to the informal carers in our study: 4% of those providing nursing or personal care say that something has occasionally gone wrong with the care or the medication, and that on the odd occasion this due to their error.

Informal carers usually consider themselves skilled, although 8% consider themselves lacking in skills. People who provide help because no one else is available or who feel stressed out relatively often feel they lack the necessary skills. Some 28% of informal carers who also provide nursing or personal care think a professional would do this better. These helpers need more support in the form of either skills training or professionals to provide them with more support or take over tasks from them.

Almost one in ten informal carers say that they have become so impatient during the year preceding the survey that they screamed or subjected the care recipient to rough treatment. This makes clear that there are limits to what informal carers can cope with. If the pressure of helping is high and people receive little in return, this increases the risk that something will go wrong. Professionals need to know whether informal carers are still capable of providing care of sufficient quality. Not all informal carers are on the radar of professionals to an equal extent, however, for example because the home-care services are not involved. There may be a role here for neighbourhood social work teams or GPs in signalling problems. Investing in raising the profile and accessibility of approachable locations in the neighbourhood or municipality, where informal carers or care recipients can go for support and advice, remains important.

Need for support and appreciation

Many helpers manage perfectly well and have no need of support. When they do need support, this can take different forms. Informal carers who work mainly need more flexibility (especially flexible working hours), but also more time (in the form of days off or paid leave). However, support does not always lie in expensive solutions: over a quarter of working helpers say what they need above all is understanding.

As regards support from local authorities, around a quarter of informal carers need respite facilities such as daycare or help from a volunteer. There are several reasons why people do

not make use of support even though they need it. It is quite common for the care recipient, often someone with dementia or mental health complaints, not to want respite care, and it can be very difficult for informal carers to choose between their own wishes and needs and those of the care recipient. Second, good support is not always available or there may be waiting lists (see also Leder(in) 2015).

Helping a loved one who is vulnerable can be very stressful, and receiving understanding for their situation and a listening ear can be very greatly valued by informal carers. Appreciation is also very important – not just from the care recipient, which is sometimes forthcoming and sometimes not, but also from other helpers, the social network and the government (De Boer & Van Campen 2009).

Many volunteers manage perfectly well in their own voluntary work. Nonetheless, a minority would like more support in the form of courses and training programmes as well as a listening ear from the voluntary organisation. In addition, some are not fully aware of the support that is available.

What can the informal carer or social network do?

Before looking at the role of local authorities, home-care or voluntary organisations, employers and the national government, we will first look briefly at the helpers themselves. A proportion of them provide long-term and intensive help. Informal carers could more actively seek others at an earlier stage with whom they can share the help or their own concerns. This need not only be their family network, but could also include other networks in which they are active (Schothorst 2014).

What can local authorities do?

A key focus of the informal care policy of local authorities is to relieve the burden on informal helpers by offering them support and improving the coordination between formal and informal help. This study shows that most informal carers manage well: the vast majority do not feel stressed, or only to a limited extent, by providing the care. However, one in ten do experience providing care as a heavy burden. Good support and being able to share the help is important for them. The support available for informal carers needs to be both broad and focused on people with specific problems. It is difficult to say whether new support is needed, because informal carers themselves are not clear about what they need. Support services need to be as approachable and accessible as possible. For a helper with a heavy care task, having to go through complicated application procedures can be off-putting. Simplifying application procedure and offering support with making the application (from a volunteer, an informal carers' support centre, informal care broker or independent client support officer) could then offer a solution.

It often seems that support only comes into the picture when people are already stressed out. Those who need support are insufficiently aware that it is available and will sometimes need to be approached more proactively by those who are in contact with them, for example neighbourhood (social work) teams and those who conduct home interviews, GPs, geriatric specialists, nurses, home-care workers, front-desk staff, volunteers, and so

on.⁵ Local authorities should focus more on ensuring a good interplay between formal and informal care, for example by challenging the institutions from which they buy care. Informal carers say that what they most need are understanding and appreciation. They want to be seen by policymakers and professionals and to be recognised for their experiential expertise. The appreciation of informal carers has been on the policy agenda for some time. Up to 2015 there was the national ‘informal care compliment’, and the introduction of the new Social Support Act (Wmo) has placed responsibility for appreciating helpers with local authorities. They can determine for themselves how this is given form so as to tailor it to the local situation and local needs (NHM 2015). Other wishes expressed by informal carers relate to financial support or a personal budget, help with applying for provisions and other material help.

What can home care organisations do?

Many informal carers share the help they give with others. Good coordination and cooperation (joining up formal and informal care) is then important. Informal carers who work together with home-care or community nursing professionals are by no means always positive about the relationship. Almost one in three informal carers (29%) say they are rarely or never allowed to take part in decisions about the care of their loved one. More than a third of informal carers feel that home-care workers or community nurses rarely or never take account of them. It would seem that there is still a great deal to be gained on this point. One improvement could be that home-care organisations give their staff the explicit task (in terms of both time and expertise) of working with and supporting informal carers. The booklet on ‘caring together’ (*Dossier samenredzaamheid*) published by the Dutch Nursing and Carers’ Association (v&vn) is an example of efforts to improve the cooperation with informal carers. However, it takes time to translate this into procedures and into practice. Particularly where informal carers do not share a household with the care recipient, it is difficult to establish contact between professionals and informal carers. Digital communication can help here, but is not yet widely used (Van Wieringen et al. 2014).

Informal carers helping someone with mental health or psychosocial problems are relatively often dissatisfied about the cooperation with professionals. The care recipient can themselves play a role here, for example if they do not want the informal carer to be involved in discussions with a professional. Lack of expertise on the part of the professional can also play a role. A generalist home-care worker who provides personal or domestic care to someone with a mental health/psychosocial disorder and who has little experience in this specific area may find it difficult to deal with the client or may not interpret signals correctly.

The increasingly community-based care provided by the Dutch mental healthcare (GGZ) is likely to lead to an increase in the number of people with mental health or psychosocial disorders living independently. This group, and probably also those requiring dementia care, demand a high degree of professionalism: good communication skills, professionals who can deal with conflicting interests and who take both clients and their informal carers seriously. It is thus important that organisations invest in home-care workers, in terms of

time and training, in order to enable them to work with these groups of clients. Some groups (GGZ clients, psychogeriatric clients or clients with intellectual disabilities) may require specialist home-care or family care.

Home-care workers can also play a role in promoting the expertise of informal carers. Roughly one in ten informal carers feel insufficiently equipped to provide the help their loved one needs. Learning skills from home-care workers, whether personal care or nursing skills or learning how to support a client, is not something that always happens automatically (at least at the time of our study). The caveat does need to be applied here that it is sometimes not good practice for an informal carer to perform certain actions (e.g. nursing tasks). Consideration will have to be given on a case-by-case basis to whether it is possible or desirable for informal carers to learn a particular activity or skill.

What can voluntary organisations do?

Voluntary organisations are faced with a rapidly changing environment. The diversity of volunteers is increasing. For example, there is a large group (roughly a third) – and according to Verhoeven (2010) a growing group – who volunteer on an occasional basis, and there are people with mental health impairments themselves supporting others with similar problems (Schyns & De Boer 2014). New forms of volunteering are also developing, such as volunteering in return for social security benefits or as part of a reintegration programme (Ranshuijsen 2013). The content of voluntary work is also changing, with volunteers increasingly providing companionship and support to older and disabled people, and the intensity of care needs is also increasing (Van Tillaart 2010).

All this is placing ever more demands on volunteer support organisations. Finding a good match between volunteer and client, and providing good support to volunteers when needed, is of crucial importance (Elferink & Scholten 2013; Nienhuis et al. 2011; Schyns & De Boer 2014). That support also includes clarity about liability insurance and travel expenses. Some volunteers say they would like more contact with others (e.g. in peer review meetings) and that they would like to receive training (Elferink & Scholten 2013; Nienhuis et al. 2011).

Voluntary organisations also have an important role to play in the cooperation with care professionals and informal carers. They can for example oversee the sharing of tasks between professionals and volunteers (Van Bochove et al. 2013; Nienhuis et al. 2011) and support the coordination between informal carers and volunteers.

A small proportion of volunteers find volunteering (too) stressful. Voluntary organisations could help them by spotting this early and offering support where possible.

What can employers do?

The government drive on more participation in paid work requires better facilitation of the combination of work and care tasks. This study shows how important it is that people are able to take a day off unexpectedly or to set their own working hours to some extent.

The Flexible Employment Act (*Wet 'flexibel werken'*) which comes into force on 1 January 2016 offers employees more scope to set their own working hours. This will of course be easier

to do in some jobs than others. Understanding from colleagues and managers is also important.

Little use is still made of special leave arrangements: many employees prefer to use up holidays when they need time off. When this study was carried out, long-term leave arrangements existed only for a partner, parent or child. The new arrangements – extending short-term and long-term care leave – which came into force on 1 July 2015 offers more scope for workers to provide help to relatives in the second degree, fellow-household members and other members of their social network. In contrast to short-term care leave, however, long-term care leave is generally unpaid.

A minority of informal carers have reduced their working hours or stopped working altogether because of their care tasks. A rough estimate suggests that the figure in 2014 was 275,000 people, often caring for a partner or child. The fact that working informal carers take such radical steps could indicate that their ability to tailor their work in a way that enables them to perform their care tasks is inadequate.

Finally, employers could encourage volunteering by giving their employees the opportunity to do so, for example spending a day volunteering with the company or team.

What can the national government do?

Although supporting informal helpers is a responsibility of local authorities under the Wmo, there are also steps that the national government can take, for example to make it easier to combine work and care tasks. Measures such as this will become more important as the number of people combining work and care increases (see e.g. Josten & De Boer 2015), a likely development given that people will be working for longer now that the state retirement age is being raised, and the need for help (including informal help) will increase due to the changing composition of the population. Tax breaks are another option for the government.

Another task for central government is to offer training and education. An example is the volunteer support programme *Vrijwillig Dichtbij*, which aims among other things at the upskilling and support of volunteers who are dealing with complex problems.

Could the government increase the engagement of citizens? Among the suggestions put forward by respondents when asked what the government could do to increase the supply of informal help were tax and other measures and leave arrangements. Some respondents used this question to argue that the government could do more to strengthen professional care, or that it is not the task of government to promote informal help. Yet others felt that the government ought to be promoting an awareness that citizens need to engage with each other, as long as people are not left feeling that they must provide informal help. Although the State Secretary for Health, Welfare and Sport, Martin van Rijn, has stated that providing informal help must not be an obligation, people sometimes do feel a moral imperative to help. This is evident among other things from the fact that informal carers sometimes help because no one else is available. It continues to be important to explain why the care system has been radically reformed.

Policymakers and researchers warn about the implications for the quality of care that are associated with the shift towards informal care. Some informal carers do not feel sufficiently competent, and some occasionally lose patience when performing care tasks. The latter can of course also happen with professional helpers, but is less likely because they are further removed from the client. This begs the question of whether we wish to apply quality standards to informal care to eliminate safety risks, or whether we are prepared to accept certain risks.

Conclusion

This study shows that many citizens in the Netherlands are giving informal help, but also that there are limits. Those limits are related to the number of hours informal carers have available, their expertise and, for example, their ability to seek help in time if they are no longer able to cope. A substantial proportion of the Dutch population say they would be able or willing to do more. Whether they actually do so will depend greatly on who needs what help and when. It is uncertain what role the government could play here. The realisation that the welfare state is changing, that some support can be less taken for granted and that people are expected to do more for themselves, is something that takes time to sink in.

The most important thing for people who are providing help is that support is available when they need it. If they feel that they have to help because no one else is available, this can impact on the quality of the help and cause them to experience giving help as a burden. It is important that people are appreciated for the help they give (for example by professionals, but also by the local and national government), that there is good cooperation and coordination with other helpers and that people can count on support and receive help in obtaining that support. Various bodies could play a role on this latter aspect: local authorities, employers, care institutions, neighbourhood social work teams, stakeholder groups, voluntary organisations, etc. These organisations will need to engage in regular dialogue at local level with informal helpers and/or their representatives in order to ensure that wishes and capabilities can be matched (see also Linders & Feringa 2014).

Notes

- 1 The term 'church' is used as a collective term for all forms of religiously inspired gatherings, and can therefore also referred to a mosque or prayer meeting .
- 2 A small proportion (also) share the care with care volunteers. They are included among the professionals/mixed networks here.
- 3 If we treat 'don't know' answers as a sign of use and need, 24% of informal carers make use of respite care and 26% have a need for it. If we treat 'don't know' as a sign of not using or needing respite care, 19% use respite care and 12% have a need for it.
- 4 This was established in a different way from the stress felt by informal carers and is therefore not comparable.
- 5 The Wmo 2015, which came into force on 1 January 2015 (and was therefore not in force at the time of the study), aims for an integrated approach: when examining a reported need for social support, local authorities must henceforth also explicitly take account of the situation of the informal carer (their capabilities, need for support and ability to cope).