Summary

There for each other?

Unpaid help in 2016: a review

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Summary and discussion

S.1 Summary

The Netherlands Institute for Social Research (SCP) is charged with evaluating the reform of long-term care in the Netherlands on behalf of the Ministry of Health, Welfare and Sport. This study, which reviews the status of unpaid help, comprising informal help provision and care volunteering, forms part of this evaluation.

The central question addressed in this study is as follows: *What is the current situation as regards the extent, nature and consequences of providing unpaid help in 2016, and what differences can be discerned between 2014 and 2016?*

The background to this question is the reform of long-term care in the Netherlands: since 1 January 2015, people needing care can apply for support funded through the Social Support Act 2015 (Wmo 2015), the Health Insurance Act (Zvw) or the Long-term Care Act (Wlz). The Exceptional Medical Expenses Act (AWBZ) and the 2007 Social Support Act (Wmo 2007) have been repealed. The Wmo 2015 places greater emphasis on citizens' own responsibility, but also on support provided by informal helpers (see also Chapter 1).

Quantitative studies were carried out at the end of 2014 and the end of 2016 (using online and telephone surveys) among more than 7,000 Dutch citizens (including people with a non-Western migration background, rural dwellers, urban dwellers, young people, older people) to ascertain who provides unpaid help. Those who were active as informal helpers or care volunteers were then asked about the help they provide and about their experiences in doing so. Those not providing help were asked about their willingness to do so.

Comparing the outcomes of the two surveys makes it possible to identify changes for the adult population in the Netherlands between 2014 and 2016. It is not possible on the basis of these two surveys to determine whether there is a trend or whether the changes are the result of the long-term care reforms: that would require at least three measurements. We shall return to this in the discussion section.

Key words unpaid help, volunteering and informal help

In this report, informal care is interpreted as 'all help provided to a person with health impairments needing help by someone from their immediate social setting' (De Klerk et al. 2014). Less intensive help, help given to fellow household members and help provided to residents of institutions is also included in this interpretation. Help given to people with no health impairments, for example babysitting healthy grandchildren, falls outside the definition.

Informal help goes beyond what in the Netherlands is called 'usual help' (help which could reasonably be expected to be given by a partner, parents, children living at home or other household members).

The provision of help and support by a volunteer (also referred to here as 'care volunteering' or simply 'volunteering') is confined in this publication to those offering support to people with health impairments who need help and with whom the volunteer does not (initially) have a personal relationship. It includes both those volunteering for a care or welfare organisation and volunteers working in ‘unorganised’ structures (such as civic initiatives), and also encompasses both regular and occasional volunteers.

Unpaid help is understood here to include both informal care and care volunteering. It encompasses all help and support for people with a diversity of health problems that is not provided on a professional basis.

The central question was subdivided into a number of constituent questions, each of which is addressed separately in one of the chapters of this report. A brief summary of the results for each constituent question is first given below, following which we reflect on the outcomes.

Question 1

What is the extent of unpaid help (informal care and care volunteering) in the Netherlands and did any changes occur between 2014 and 2016?

Approximately 32% of Dutch citizens aged over 16 (more than four million people) provided informal help in 2016. Of this total, around 750,000 (17%) were providing long-term (more than three months) and intensive help (more than eight hours per week). Informal help is interpreted broadly in this study; as well as care per se, it also includes providing transport, administrative help or emotional support. Over 8% of informal helpers only provide emotional support or company for someone with health problems.

In 2016, 8.5% of those aged over 16 (more than a million people) engaged in care or support volunteering; just under 6% (nearly 800,000 people) did so on a regular basis.

If we exclude occasional volunteers, just over 34% of over-16s provided unpaid help; if occasional volunteers are included, the figure rises to 36%, making a total of around five million people (including occasional volunteering). There was no change in the share of unpaid helpers between 2014 and 2016, though slightly more people in the 55-64 age group began volunteering.

These percentages and numbers are (albeit well-reasoned) estimates of those providing informal care and volunteering. People sometimes find it difficult to judge whether they are providing informal care or volunteering, especially those engaged in ‘unorganised’ volunteering.

The majority (62%) of those who know someone who needs help provide help to that person. Whether someone provides help depends on the relationship: those who do not provide help but who do know someone who needs help often live some distance away from those needing help, for example grandparents, aunts or uncles (designated here as ‘other family’), friends, acquaintances or neighbours.

Whether people provide help depends a also on restrictions (such as lack of time due to work commitments, or health impairments), demographic characteristics (women and 45-74 year-olds relatively often provide help) and experiences or opinions (people who have worked in the care sector or who regularly attend church, the synagogue or the mosque more often provide help). People also often cite as a reason for not providing help that others are already helping or that they live too far from the person needing help (De Klerk et al. 2015). The differences between subgroups in providing informal help or care volunteering were also present in 2014.

Question 2

How willing are citizens to support each other and have there been any changes in that willingness?
The majority of Dutch citizens believe that people with family or friends who need help should provide help (69% and 60%, respectively). This does not necessarily mean that they think this help should be provided mainly by the recipient's own network: two-thirds believe that looking after their parents when they need help is more a task for the government than for the family. Some changes took place in these views between 2014 and 2016: more people think that family and friends should help, and fewer people believe that caring for parents who need help is a task of the government (69% in 2014 and 63% in 2016). However, a minority believe that people who need help should receive it as far as possible from family, friends or neighbours (23% in 2016). This is a marked reduction since 2010 (41%): people thus increasingly feel that there are limits to the help that the recipient's network should be expected to provide.

It is difficult to gauge whether people who are currently not providing unpaid help will do so in the future. We can only ask about people's intentions; whether they will actually offer help will depend on the circumstances, such as who requires help and where they live. More than two-thirds (68%) of those who are not providing informal help or engaged in care volunteering say they would be willing to help. There may be all kinds of restrictions, however: just under 40% of those not providing help so they have no time to do so; around 20% say they are unable to help because of health problems. In 2016, a quarter of these non-helpers said they would be able and willing to help: they are willing, have the time and have no health problems. The figure two years earlier was slightly higher (29%). People in 2016, especially younger people, say they have less time. People who are willing but unable to help often have full-time jobs or small children, and have relatively little time to provide help.

When asked about specific situations, it transpires that people who are not providing help are more willing to do so if the recipient is closer to them. Around two-thirds (65%) of non-helpers with a parent living outside the home say they would be able and willing to spend half a day per week helping their parents with the household, doing shopping, doing odd jobs or providing transport. That is a comparable percentage to 2014. The main reason for not offering help is that their parent does not need it. Restrictions (travel distance, lack of time) may also play a role, or the fact that the relationship is not good enough.

The inclination to help neighbours is much lower: just over one in three (of the 93% who are not already providing help to neighbours) say they would be willing to provide occasional help, and one in six would do so on a weekly basis. Whether people are willing to provide help depends among other things on which neighbour it is, i.e. whether the potential helper knows and likes them. The kind of help also plays a role, as does when it needs to be provided and how intensively.

Roughly one in ten people who are not active as volunteers say that if asked they would be willing to volunteer for one or two hours per week to help people with health issues or problems of old age. Reasons for not being willing to do so are mainly lack of time, health impairments or advanced age, but also not knowing where to register or a lack of appealing volunteering opportunities.

Question 3

What are the characteristics of informal helpers, the help they offer and the consequences of that help, and can any changes be discerned?

Three types of informal helpers can be distinguished based on the social relationship between the informal helper and the recipient of their help: those who mainly help close family members; those who help other family members; and those who help friends or neighbours (De Boer et al. 2009; Timmermans 2003).

13% of informal helpers provide help to a partner and 6% to a child (usually living at home) with health problems. They are often the recipient's main helper. Help for children is often provided by (working) women and help for partners by men. Partners usually help because of physical problems; parents often help a child with mental health issues or an intellectual disability. Those helping close family members feel it is completely natural to do so, but also provide help because no one else is available, because the recipient prefers to be helped by them and/or because they wish to defer or avoid calling in professional carers. The care provided to a partner is often very intensive (averaging 20 hours per week), and care for children is often long-term (eleven years on average at the time of the survey).

A large share (42%) of those helping wider family members (the second informal help category) are providing support to parents and parents-in-law, though help is also given to other family members such as brothers, sisters, grandparents, aunts or uncles (20%). This help is provided for an average of five hours per week over a period of four years, and is often shared with professional carers from a care institution. Their motives are predominantly positive: they are supporting their relative out of affection and a belief that it is the natural thing to do. The care recipients are often beset with long-term physical disabilities or memory problems (dementia). One in five family helpers travel for more than half an hour, and half have a job for 32 hours a week or more.

The third type of informal helpers help friends and neighbours. On average, they provide help for four hours a week over a period of five years (see also Egging et al. 2011). This help is often provided because of long-term physical problems, but also because of mental or psychosocial problems. These 'non-kin' helpers (i.e. no family ties with the recipient) enjoy helping, often saying, "I am happy to do it for this person". They also derive predominantly positive experiences from providing help, for example enjoying the happy moments and enjoying the feeling that helping gives them. The majority provide help together with others; less than one in ten report that they are the central informal helper for the recipient.

In total, almost one in ten helpers experience severe burden due to providing help. This applies particularly for women, 35-44 year-olds, informal helpers performing lots of tasks and those providing intensive help. The type of disability/impairment is also important;

informal helpers helping someone who needs a lot of attention, displays aggressive behaviour, is terminally ill or has a mental health disorder relatively often suffer high burden. The negative consequences of providing help vary depending on the relationship; 16% of those providing informal help to partners and 20% of those helping children experience relatively high burden. Those providing help to fellow household members also relatively often report that they are not always able to keep their patience, which can lead to shouting at or rough treatment of the care recipient. 15% of partners say that they will be able to continue providing help for a maximum of six months. Those helping partners also relatively often report that their relationship with the care recipient has deteriorated since they began providing help.

Those providing help to family members experience average levels of burden. Those helping friends or neighbours receive a lot of appreciation from the care recipient, and they often see their mutual relationship improve and feel the least burdened of all helpers.

The average number of hours and number of years that people provide help did not change between 2014 and 2016. Moreover, compared with the figures from 2014, high burden is no more (or less) common among helpers then in 2016.

Question 4

To what extent do informal carers share the help with other informal helpers or formal caregivers? Do they work with them, and have there been any changes in this regard?

One in eight informal carers (12%) is the sole helper. This is much more common among people helping someone in their own household (33%) than among informal carers of a person outside their own home (7%). These percentages are comparable with those from 2014.

Informal helpers who share the care for someone outside their own home may do so with other informal helpers (e.g. brothers or sisters) in an informal help network, with professional carers (e.g. domiciliary care employees, district nurses, case managers, volunteers) in a professional help network, or with both other informal helpers and with professionals in a mixed help network. Care professionals are often involved in the care of people with a terminal illness or dementia. By contrast, helpers of people with mental disorders are relatively often on their own.

Compared with 2014, there are more informal carers sharing the care for someone outside their own household in an informal help network (32% in 2014 and 41% in 2016), and fewer who share this help with care professionals, with or without other informal helpers (42% and 34%, respectively). The fact that fewer people share the help provision with professionals, while there are no more informal helpers, could suggest that there are fewer professionals or that professionals mainly step in when there is no informal helper. Whether the latter is the case falls outside the scope of this study and therefore cannot be verified here.

In general, the cooperation with other informal helpers works well; less than one in ten informal helpers experience problems in coordinating with other informal helpers. Informal helpers of people with an intellectual disability least often have problems with this, while informal helpers of people with a mental disorder and those providing intensive informal help more often have difficulties. One in three informal helpers has occasionally had a difference of opinion with other informal helpers. This is reported more often by people helping someone with a mental problem, dementia, and intellectual disability or a terminal illness.

Most informal helpers also take a positive view of the cooperation with professionals. Three-quarters of those who share the provision of help with professionals report that they are able to discuss the care, and nine out of ten informal helpers are able to coordinate the care readily with professionals. Only one in 20 informal helpers say they often have a difference of opinion with one or more professionals. Informal helpers are less positive regarding the ability to share in decisions about the care and about the amount of attention that care professionals pay to them. Roughly half are dissatisfied on both these points, the same proportion as in 2014. The general practitioner is the most frequently cited professional (then homecare or a district nurse) who does have an eye to their well-being; two-thirds say that no professional shows an interest in their well-being.

Roughly nine out of ten informal helpers helping someone in an institution share that help not only with professionals but also with another informal helper, often a family member. A quarter of informal helpers who are helping someone in an institution were asked by the institution if they would be willing to help with the care. Two-thirds can always or often discuss things with the care staff. This figure was the same in 2014. However, one in five feel there is rarely or never any interest in their own well-being. We are unable to compare this with 2014, because no questions on this were included then.

Question 5

What support needs do informal helpers *have and what support do they use? Have any changes occurred in this and what consequences does an unmet need for support have for informal* helpers *and those they are helping?*

Most informal helpers feel they have sufficient knowledge, competence and skills to provide help. However, 16% lack certain skills and 18% feel that they lack some knowledge; this applies equally for those providing intensive or non-intensive help. Informal helpers who lack certain knowledge or skills relatively often cite knowledge about or skills for dealing with the care recipient on a day-to-day basis, followed by a lack of practical knowledge about the illness. People helping someone with dementia, an intellectual disability or a mental problem, particularly, report a shortage of knowledge and skills.

Informal helpers can receive support from the local authority or the care administration office aimed at reducing the care burden, such as respite care (e.g. daycare, overnight accommodation or a volunteer who temporarily takes over providing help), as well as material or financial support. One in five receive respite care. These forms of support are used slightly more often by intensive helpers, and respite care is used particularly by those helping someone with an intellectual disability or dementia. One in ten informal helpers say they need respite care but do not receive it. In one in three of these cases, the care recipient did not want the respite care; one in eight found it too expensive, among other things. Between 3% and 4% of informal carers receive material and financial support.

The burden felt by an informal helper is of course also determined by the totality of help received by the recipient. Around 70% of informal helpers feel that all in all the recipient receives sufficient help and support (19% say this is not the case and 13% do not know). Informal helpers providing help to someone with an intellectual disability, dementia or mental problem, in particular, relatively often regard this help as inadequate.

More than half of those who feel the help is inadequate believe that more help should be provided in the home by professionals. The recipients themselves were not interviewed in this study, but their need for care and support has been covered in several other studies (Feijten et al. 2017; Putman et al. 2017).

Support could also be aimed at strengthening the resilience of informal helpers by increasing their knowledge and skills. One in six informal helpers seeks out information and advice, and over a quarter of intensive helpers do this. The proportion who follows a course or training or join contact groups of other helpers is small, at just a few percent. Some informal helpers find it difficult to ask for support; this is most often the case for people helping someone with a mental disorder: one in five of them find it difficult to ask for support.

One in three informal helpers are unaware of the existence of informal helper support. That is unchanged compared with 2014. Intensive informal helpers are no more aware of the available support than non-intensive informal helpers. A quarter of informal helpers who need support and are not receiving it say they would not know how to ask for it. It is mainly relatively young informal helpers (aged up to 34 years) who are unaware of this support. Helpers of children or someone with an intellectual disability are more often aware of the available support than helpers of parents/parents-in-law or those helping someone with a terminal illness or temporary physical problem. It is often someone from their own circle who informs them about the available support; the role of professionals such as the GP, district nurse or local authority in this regard is limited.

Local authorities have an obligation to include an indication in their regulatory structure of how informal helpers are given an annual token of appreciation. A small proportion of informal helpers (one in 14) say they have received such a token of appreciation from the local authority, for example in the form of a gift voucher, bouquet of flowers or an invitation to an informal carers' day. One in eight intensive helpers receive a personal token of appreciation.

An unmet need for support and finding it difficult to ask for help increase the burden felt by those providing informal help. These informal helpers are also at greater risk of losing their patience when providing help. Informal helpers who do not feel entirely up to the task (sufficient skill, knowledge, competence), also feel severely burdened.

Question 6

Who are the volunteers providing help and support, what do they do and how do they feel about volunteering and the support and cooperation with others?

Just over half (53%) of care volunteers volunteer regularly in an organised context; one in five occasionally volunteer in an organised context; one in six volunteer regularly but outside an organised context; and 10% provide occasional help not through an organisation. Volunteers mainly offer companionship and emotional support, supervising activities and helping with transport. The proportion who help with supervising activities was lower in 2016 than in 2014 (34% versus 41%). It is unclear precisely why this is so. Volunteers mainly help people with long-term physical disabilities (38%), dementia or memory problems (27%) or with an intellectual disability (18%). Compared with 2014, more volunteers were helping people with dementia in 2016 (27% versus 20%).

Volunteers often volunteer because they want to help someone else and because they enjoy doing so. One in ten are more or less obliged to volunteer, for example in return for a benefit or as part of a non-profit internship. Almost one in five say they find volunteering stressful.[1] This is relatively common among volunteers helping terminally ill clients or people with mental disorders.

Roughly two out of five volunteers providing care and support find it difficult to stop volunteering, and almost half think there would be no one to take over if they did stop: the ‘volunteer trap’. Three-quarters think they will still be volunteering a year from now.

Around half of care volunteers have at some time had contact with professionals. Nine out of ten feel they are taken seriously, enjoy the cooperation and feel the division of tasks is clear. This has not changed over time. However, some volunteers feel that professionals show too little interest in their well-being (one in five say that professionals sometimes show an interest in this and 8% say that they rarely or never do so). One in six volunteers say they are performing tasks which in reality should be performed by professionals, for example because the professionals have too little time. The majority of them feel they are equipped to do this (this is partly because many volunteers have a background in the care sector), but 15% do not (and 10% do not know).

Two out of five have contact with informal helpers. Volunteers are slightly more critical about the ability to coordinate with informal helpers than with professionals: more than a third feel that this is sometimes, rarely or never possible (and almost two-thirds think it is often or almost always possible).

Just over four out of ten volunteers receive support from a volunteer organisation; 53% do not. Not every volunteer needs support.

Many volunteers have liability insurance and sufficient training opportunities, but 46% and 40%, respectively, do not (or are unaware of it). Almost three-quarters receive no reimbursement of travel or out-of-pocket expenses. Volunteers are generally satisfied with the degree of support, appreciation and contact with other volunteers, but 11% would like more support. Around half of this group would like someone to listen; a third would like some form of training or reimbursement of expenses; and a quarter would like something else. These are often people who have been volunteering for a long time.

One in ten volunteers do not know where to go for advice, information or support; this was also the case in 2014. This applies for one in five volunteers working in an unorganised context (compared with one in 20 ‘organised’ care volunteers).

S.2 Discussion

Many Dutch people (around 36% of those aged over 16) provide informal help in the form of informal help for family members, friends or neighbours or in the form of care and support volunteering. Many of these informal helpers and volunteers are doing well. They provide help because they enjoy doing so, derive pleasure from it and have no need for support. In this discussion we focus mainly on those aspects which warrant extra attention and reflect on a number of findings. We begin with the number of people who are giving or able to give unpaid help and then look at a number of vulnerable groups of helpers and their support and who could help out here.

No differences between 2014 and 2016 in proportion of unpaid helpers

This study shows that the proportion of informal helpers or volunteers in Dutch society did not change between 2014 and 2016. The expectation sometimes expressed that people, and especially women, will provide a more informal help because local authorities are looking more emphatically at what people's social networks can do for them (Atria 2015) is not confirmed in the period covered in the study. In addition, those already providing help have not increased the amount of help they are giving. This need not be a negative finding, because no change does not necessarily mean a deterioration. Moreover, it may be that local authorities are offering the same degree of (customised) support as before the introduction of the Wmo 2015, or that many existing clients have retained their professional help. This would mean that local authorities and district nurses were providing the same level of care and support in 2016 as in 2014. However, it could also mean that there are more people who are not receiving help or support. It is impossible to say which of these is the more likely. Although we know that the number of persons who made use of customised provisions and services in the period 2014-2016 (which from 2015 onwards were funded through the Wmo 2015) declined according to the records of the Central Administrative Office (CAK) from 876,000 in 2014 to 729,000 in 2016 (Boelhouwer & Pommer 2017), but we have no information on the use of general or customised provisions and services for which no co-payment is required from the user. There are some local authorities which regard help with the household or daytime activities as a general provision (Boelhouwer and Pommer 2017).

This study shows that compared with 2014 there are more informal helpers helping as part of an informal network, and fewer helping in a professional or mixed network. However, the number of informal helpers has not increased This could mean that people are less often able to obtain professional help, but it could also mean that professional carers are increasingly helping in situations where there is no informal helper. Research among people with (mainly physical) impairments shows in any event that the use of publicly funded care remained reasonably constant in the period 2014-2016 (Putman et al. 2017).

The fact that few differences are found between 2014 and 2016 may be linked to the fact that the period studied here covers only two years and that all manner of transitional schemes were in place for existing clients around the introduction of the Wmo 2015 and the Wlz. Despite having surveyed a broad section of the population, we may have obtained too little information about specific subgroups. In order to track developments in the longer term, a new survey would be needed a few years from now. A further addition to this caveat is that this report primarily presents a national picture, and it is quite possible that changes have occurred in some municipalities. However, the material collected for this study is not suitable for answering such local questions.

Citizens set more limits in their views on unpaid help

One of the motives behind the reforms in long-term care in the Netherlands is to increase people's engagement in society (looking after each other more). This study suggests that this engagement has not yet changed: a comparable high proportion of citizens do provide unpaid help. What did change in the period between 2014 and 2016 were the views on providing informal care. For example, more people than previously think that family or friends should look after each other when someone needs help because of health problems. A smaller proportion (though still a large majority) also feel that caring for older persons in need is a task for the government. This does not yet imply that people more often think that the recipient's network should play a greater role than previously: the share who believe that people should receive as much help as possible from their own network has fallen sharply in recent years (2010-2016). This appears to suggest that, while citizens believe that people should help each other, there are limits to this: it should not be too much and this help should mainly be seen as additional. In other words, adequate professional support continues to be important.

Time is an important determinant of the ability to provide unpaid help

While many people give unpaid help, there is also a large group (around two-thirds of the population) who do not. One reason that many of them are not providing help is that they do not know anyone who needs it. Where people do know someone who needs help, it is often someone who is further removed from them, such as family members in the second or third degree. A key reason for not offering help is that others are already providing help. These people who are somewhat removed from a person in need of help could however perhaps play a role in relieving a central carer. The fact that this has not yet happened may be due in part to reticence in asking for and/or offering help (Kooiker and de Klerk 2015; Linders 2010). They may also not realise what they could do to help. The recipient themselves can also play a role by accepting more help from others. This may also apply for informal helpers, especially those helping partners and children, who often say they provide help because the recipient wants them to be the person who helps them.

Whether or not people will begin giving help in the future is very difficult to assess. Much will depend on the circumstances: who needs help, whether others are helping, but also perceived restrictions and the opinions of the potential helper all play a role.

A proportion of non-helpers say they would be willing to provide help but are unable to do so due to lack of time. They include workers in full-time or large part-time jobs. To enable them to offer help, leave arrangements at work and understanding colleagues would be important, for example (De Boer and Plaisier 2015; Plaisier et al. 2015a). The share of people who would be willing to help but do not have time increased between 2014 and 2016, especially among younger people. The reduction in (youth) unemployment in the Netherlands may play a role here.

Finally, there is also a substantial group who do not wish to provide help. It is unclear how they would react if someone in their personal setting needed help or care; often, people who encounter a situation where a close family member needs help will change their minds and offer help (De Klerk et al. 2014). The quality of the relationship obviously plays a key role here.

Vulnerable informal helpers in the spotlight

People who are helping partners or children are relatively often severely burdened. Earlier research has shown that roughly one in five informal helpers experiences difficulties in asking for help (De Klerk et al. 2015). (Encouragement of) sharing the care with others or use of respite care is therefore of particular importance in preventing this group of helpers from becoming severely burdened.

One in five of all informal helpers in 2016 were providing help to someone (often a parent or parent-in-law) with dementia or memory problems. The fact that providing informal care to someone with dementia can be stressful is reflected in this study, for example in the fact that a relatively high proportion of informal helpers of people with dementia feel that their relationship with the help recipient has deteriorated, that they receive little in return from the help recipient and that, if the situation remains as it is, they will not be able to continue providing the help for another year; this is also supported by findings of other research (Vernooij-Dassen et al. 2017). Informal helpers of people with dementia, in particular, often do not consider themselves sufficiently competent and say that they lack knowledge on how to deal with the condition of the person they are supporting. Reinforcing their competences and visible appreciation by local authorities and professionals is important for this group of helpers.

One group of helpers who are perhaps less visible but who are also often suffering excessive burden are informal helpers of people with mental health problems, such as anxiety, depression, psychosis or addiction. 14% of all informal helpers face such issues. They too feel often that they are not sufficiently competent because of the often complex behavioural and other problems of the person they are helping. They moreover relatively often feel that there is no one who would be able to take over providing the help if they were unable to do so – not just because people with mental problems regularly have more difficulty maintaining a social network, but also because privacy concerns prevent them from asking others for help or because they judge that other members of the social network may not possess the necessary competencies. There are indications that this group experience more frequent differences of opinion with other informal helpers and more often find it difficult to discuss their concerns with others.

6% of informal helpers provide help to someone with a terminal illness. They often provide intensive and complex help to a loved one who is going to die, making the task emotionally stressful as well. Consequently, they are often under great strain and less able to keep up the help for a long period, despite the fact that they often share the help with professionals. That cooperation often works well. There is however occasional disagreement between informal helpers. Roughly half those in this group lack sufficient knowledge about the recipient's disease, a gap that could be filled by providing courses or specific information.

Support for informal helpers: early identification and detection of issues

A first requirement for supporting informal helpers is early identification and detection of issues. This is an area where there appears to be room for improvement. This study, for example, shows that professionals such as social care workers and district nurses by no means always take the informal helpers into account. Research by Movisie also shows that community social care teams often do not get around to cooperating with, let alone supporting informal helpers (Nanninga et al. 2017). GPs and nurse practitioners can also play a role in identifying risky informal help situations, as can those who conduct home interviews on behalf of the local authority with those requesting Wmo-funded support. Research among informal helpers of people who applied for Wmo support in 2015 showed that those informal helpers who were present at the home interviews felt that in most of the interviews no attention was given to the support they themselves were providing (Feijten et al. 2017).

Accessibility could be improved

A second precondition is optimum accessibility of support. There are indications that access to respite care could be improved. This study has shown that one in five informal helpers who need respite care but do not receive it say that there is no suitable respite care available or that there is a waiting list. One in ten are not eligible and one in eight find it too expensive. A complicating factor when using support is that concepts such as 'informal help' and 'informal helper support' are technical policy terms, which those concerned by no means always recognise, for example, simply seeing themselves as the son or daughter of the help recipient, not as his or her 'informal helper'. Approximately half of informal helpers who are helping for more than eight hours per week do not regard themselves as informal helpers. This could indicate that the informal helper support that is offered under that name is not reaching this group, because they do not recognise themselves in it and do not realise that they could make use of it (Linders et al. 2013).

More knowledge and skills desirable for informal helpers

A third way of supporting informal helpers is by increasing their knowledge and skills, in addition to providing practical support such as respite and care-sharing. Informal helpers who feel competent are less likely to feel under escalating stress and that they are no longer able to keep their patience. This could be a way of preventing informal help from going 'off the rails' and contributing to the quality of care. If the district nurse does not have time for this, this could be something for a case manager or support worker. It should be noted that there are also informal helpers who deliberately choose not to upskill because they do not wish to be seen in the role of a professional, but as ‘just’ the partner, parent, child or friend of the person they are helping. Ensuring the availability of sufficient professional help where needed is therefore an important form of support for informal carers.

Volunteers also need support

People often do not realise that volunteers can also become overburdened. Although volunteers provide less complex and intensive help than many informal helpers, they do frequently provide support to vulnerable people, such as those with dementia, long-term physical disabilities or a terminal illness. In 2016, volunteers were helping someone with dementia more often than in 2014 (27% of volunteers versus 20%). This may be because more people with dementia continue living at home. One in five of these volunteers find it burdensome providing this help. Volunteers may also feel trapped because they find it difficult to stop volunteering or think there is no suitable successor. This latter point shows how important it is to recruit and retain sufficient volunteers.

A sixth of volunteers say they occasionally perform tasks that should really be the job of professionals, for example performing tasks that fall outside their ambit (e.g. administration, cleaning or accompanying a patient to and from hospital) or providing personal or nursing care. A small proportion feel uncertain about this. These volunteers could benefit from more support, for example someone with whom they can coordinate their duties. There is also room for improvement in the coordination with informal helpers: a third of volunteers who have contact with informal carers say that this is rarely or never possible. Roughly one in ten care volunteers need (more) support, for example in the form of a course, training or reimbursement of expenses, but also very often just someone to listen. Around one in ten volunteers do not know where to turn for advice.

Professionals still take too little account of informal helpers

Approximately one in three informal helpers are helping someone who is also receiving professional care and support at home (e.g. from a district nurse, help with the household or a (home) support worker). Although informal helpers are generally satisfied with the cooperation with these professionals, around half are dissatisfied with their ability to share in decisions about the care. More than half also say that these professionals take little account of their well-being as informal helpers. Similar figures were also found in 2014.

Other professionals could also play a role in monitoring the well-being of informal helpers. GPs are for example often cited as professionals who have informal helpers on their radar. Local authorities and informal help support centres, obvious places where the interests of informal helpers should figure prominently, were the least often mentioned as places which look out for the welfare of informal helpers. The role of GPs or nurse practitioners could perhaps be developed further, for example through (increased) cooperation with local authority informal help support centres and support workers in GP practices.

Care and support volunteers also generally take a positive view of the cooperation with professionals, but find that professionals by no means always take account of volunteers.

The division of tasks between volunteers and professionals is also not always clear. Some volunteers report that they perform tasks which fall outside their ambit. A majority feel that they have to perform these tasks, for example because they would otherwise not be done.

What can the different actors do?

Informal help appears to be something that happens between the giver and receiver of that help, and that is indeed the case, as long as everything is going well. If that is not the case, there are several organisations that can play a role in supporting informal helpers. Based on the results of this study, we formulate a number of solution pathways that could be taken up by specific actors: informal help support centres, local authorities, voluntary organisations and support centres, care organisations and GPs, and finally informal helpers and volunteers themselves.[2] National government could play a facilitating role here, for example by offering a knowledge infrastructure (Faasse en Koens 2017; Putters 2017) or by running a broad awareness-raising campaign to inform informal helpers about the available support (TK 2016/2017a).

Informal help support centres

This study suggests that informal helpers are largely unaware of informal help support centres. By the same token, there does appear to be a need among informal helpers for a place where they can go with questions and where they can speak to someone who understands the problems that informal helpers can face and knows about the available support. This is especially relevant since so many informal helpers evidently feel ignored by professionals, if they are even involved in the care for their loved one. A support centre should as a minimum be easy to access, and located somewhere that informal helpers visit frequently – perhaps in a GP surgery, hospital or online.

Many informal helpers are getting along very well, and do not need a support centre. Those who do need support are often specific groups, such as informal helpers of people with dementia and mental problems. An important aspect for which a relatively high proportion of informal helpers would welcome support, especially in these groups, is in dealing with the care recipient; dealing on a day-to-day basis with someone who has memory problems or is severely depressed is often very stressful. This is not something that can be expressed and measured in terms of hours or tasks, but is something that is perhaps not sufficiently well embedded in local authority policy and recognised by informal help support centres, leading these informal helpers to feel that an informal help support centre cannot help with their problems. Dementia care case managers and socio-psychiatric nurses do have this specific knowledge and could play an important role in conveying this knowledge and supporting informal helpers.

Local authorities

Earlier research has shown that many informal helpers feel that the most important support would be more understanding and appreciation (Schyns and de Boer 2015). Local authorities have an important tool for realising this: they are required to set out in their regulatory structure how they provide informal helpers with an annual token of appreciation. This could for example take the form of a financial reward, an informal helpers' day or a small gift. Only a small proportion of informal helpers say they have received such a token of appreciation. It may be that local authorities do not have a clear picture of who the informal helpers in their municipality are, or do not know how to give form to the appreciation in a way that is recognised as such by informal helpers.

Voluntary organisations and support centres

A key issue in volunteering is also the need to find new people who are willing to volunteer whilst also retaining those who are already active as volunteers. Around a tenth of those currently not acting as care volunteers say they would be willing to do so if asked. There are few differences between the various groups here. Actively approaching people to ask if they would be prepared to volunteer thus appears to be an important way of recruiting new volunteers; around three out of ten volunteers began in this way. Existing or former informal helpers with positive experiences might also be willing to volunteer. Locations where courses are organised for informal helpers could for example also offer information about volunteering. Where people go in search of support themselves, it is important to provide clear information, for example on the demand for volunteers. Some people encounter obstacles when seeking to register as volunteers, such as waiting lists for the type of work they want to do or the need for induction.

It is important that those active as care and support volunteers receive appreciation, but also practical support, for example in the form of training or reimbursement of expenses. This also applies for people who do not volunteer through an organisation; they too need appreciation and sometimes support. Finally, it is important to prevent volunteers from going beyond their limits, for example by offering support with tasks about which they are uncertain or by deploying professionals to perform certain tasks.

Care organisations

Care organisations need to create more scope than at present for supporting informal helpers. An evaluation of district nursing (Francke et al. 2017), for example, shows that three-quarters of district nurses and care workers say they frequently encounter overburdened informal helpers. It may be that the focus of professionals is already shifting away from care that is centred on the client to care that is focused on 'the client and their system'. In the home setting, in particular, a care recipient cannot be seen in isolation from their day-to-day setting and their loved ones. Informal helpers can be seen as co-professionals: people who are able to take over part of the care and who make an important contribution to the care. In reality, however, this study shows that many informal helpers are also 'co-clients' with their own needs (Twigg 1989). Those needs may be for knowledge and practical skills, or more help and respite care, but also a need for acknowledgement of their emotions, for example the need to be seen and heard when an informal helper sees the health of the person they are helping deteriorating. Care professionals can play an important role here, if only by highlighting the issue, listening and giving informal helpers good information about the available support.

General practitioners

GPs also appear to have an important role in identifying signs that informal helpers are suffering excessive strain or that care situations are going off the rails. Many informal helpers cite the care recipient's or their own GP as an important person (alongside domiciliary care workers) who monitors their well-being. Particularly where there are no other professionals visiting the care recipient’s home, the role of the GP or nurse practitioner can be crucial. GPs and informal help support centres could perhaps collaborate more, and there is a good argument for locating informal help support centres physically in GP surgeries or a health centre, for example offering informal helper consultation hours at set times.

Informal *helpers* and volunteers themselves

Very many informal helpers and volunteers are doing well. They enjoy providing help and derive a positive experience from doing so. However, there are also informal helpers and volunteers for whom it all becomes too much. It is not just professionals who can highlight this; they themselves can also raise the alarm in good time and ask for support. That support could take the form of (more) professional help, respite care, help via an informal help support centre or support from a volunteer coordinator, but also help from others in the network. This support could enable the informal helper to continue for longer, and that is beneficial not just for the helper themselves, but also for the person they are helping. In short, informal helpers and volunteers have the right to look after themselves properly. Ultimately, everyone benefits from that.

Notes

1 This figure cannot be compared with the percentage of heavily stressed informal helpers, because the two proportions are determined differently (for volunteers a score out of ten is used as a measure, while for the burden felt by informal carers a validated scale is used, see chapter 4).

2 Representatives of informal helpers also themselves indicate what they consider important from local authorities, sometimes citing very specific examples; see for example the Advieskaart Mantelzorg en Overbelasting by Mezzo, which may be consulted [in Dutch) at www.mezzo.nl.