Summary

Paid work and informal care

Quality of life and use of support at work

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Summary and conclusions

Background, design and definitions

Almost two million people in the Netherlands combine doing a job with providing informal care, i.e. helping a loved one with health problems. More and more people are expected to combine working with providing informal care in the future (Van Campen et al. 2016; Roeters et al. 2016), driven by factors such as a rise in the number of (very elderly) older persons (Statistics Netherlands (CBS) 2017) and the number of people with chronic illnesses (National Institute for Public Health and the Environment (RIVM) 2018), coupled with the greater emphasis being placed on help provided by people's social networks (e.g. in the Social Support Act 2015), and also the rising labour participation rate (CBS 2015).

Against this backdrop, gaining a scientific insight into this combination of work and informal care and its impact on quality of life is particularly desirable. The Netherlands Institute for Social Research (SCP) has a rich tradition of carrying out research on work and informal care (De Boer & Plaisier 2015; Josten & De Boer 2015a; Verbeek-Oudijk et al. 2018). To date, however, little is known about the impact of combining work and informal care on the quality of life of people in work, nor about the role played by the care situation (who is receiving the help) and the support received at work.
While some research has been carried out on the relationship between flexibility at work and caring for children, household work and work-life balance (Chung & Van der Lippe 2018; Peters et al. 2011), to date no attention has been given to combining work and informal care and who is (and is not) able to reconcile the demands imposed by these two activities.
In this report we look at the quality of life of working informal carers and at the options open to them for making it easier to combine work and care tasks. Quality of life is measured here as overall satisfaction with life and perceived time pressure (Bijl et al. 2017; Boelhouwer 2016; Deeken et al. 2003; Verlet & Callens 2010).

Research questions

This publication addresses the following questions:

- How many people are combining paid work with providing informal care, and what is their care situation? (Chapter 2)
- What is the relationship between providing (intensive) informal care and workers' quality of life, and how does this differ across subgroups? (Chapter 3)
- What role do the characteristics of the care situation play in the quality of life of working informal carers? (Chapter 3)
- How much use do working informal carers make of leave or support at work, and does this differ between subgroups? (Chapter 4)
- To what extent is there a relationship between use of leave and support and the quality of life of working informal carers? (Chapter 4)

We will first summarise the results before presenting a few conclusions.

Data source used

The data used in this report are drawn from the Informal Care (IZG) study carried out by the Netherlands Institute for Social Research (SCP) in the autumn of 2016 (De Klerk et al. 2017). For that study, more than 3,800 respondents (aged 16-69 years) were selected who have paid work for at least 12 hours per week; of this total, more than 1,100 were providing informal care. Where relevant, we look more closely at working people who provide intensive informal care (for at least 8 hours per week) (272 respondents). The respondents are people who at the time of the survey were combining paid work with providing informal care. However, people may also have adapted their work to enable them to provide informal care. It is for example known from earlier research that some informal carers reduce their working hours temporarily or permanently (De Boer & Plaisier 2014). It is also known that providing informal care can be an obstacle to (increased) participation in paid work. For example, the most recent edition of the Emancipation Monitor (*Emancipatiemonitor*) shows that some women report that they work part-time because they are providing informal care, while others would like to work more hours or go back to work when they no longer need to provide informal care (Portegijs & Van Den Brakel 2018).

How common is combining paid work and informal care?

In total, a quarter of Dutch people aged 16-69 years combine a job of 12 hours per week or more with providing informal care – almost two million people. That figure breaks down to 31% of working women and 22% of working men. These 'task-combiners' have full weeks. Men with a care task devote the most time overall to work and informal care, at around 45 hours per week (39 hours at work plus six hours providing informal care); the total for women is 34 hours per week (28 hours at work plus six hours' informal care). Roughly 20% of those who combine work and informal care – approximately 400,000 people – are providing intensive informal care. They work an average of 31 hours per week and provide informal care for an average of 21 hours (52 hours in total).

What help do task-combiners provide, and to whom?

Most working informal carers provide help to a parent or parent-in-law; 9% care for their partner and 7% for their child. Half of those who provide informal care to a partner or child provide intensive help. Working men who are providing intensive informal care mostly provide that care to their partner; women in comparable situations relatively often care for a parent or parent-in-law.

Over half of working people who are providing intensive informal care feel they have to do so because the person needing the help only wants to receive it from them, or because no one else is available. We refer to this as the 'informal care trap'.

Days on which informal care is provided

More than one in three working informal carers often or almost always provide care on (or after) a working day. The remainder provide help on days off during the week or at the weekend. A third of informal carers who also provide help on working days are occasionally telephoned at work by or on behalf of the person for whom they are caring. Having to leave work is less common, but still affects one in seven informal carers who provide care on working days. These are mainly people providing intensive informal care.
More than seven out of ten (73%) of working informal carers say they have no difficulty combining work and informal care. A quarter report that they do have (some) difficulty with this; 4% find it very difficult to combine working and providing care. It is mainly those providing intensive help who have difficulty or great difficulty with this combination (one out of three). Two third of the respondents experience no difficulty in combining work and care.

Quality of life of task-combiners

Working people who provide intensive informal care are substantially less satisfied with their lives than workers who are not providing informal care. Working men who provide intensive help are more often dissatisfied than women in a comparable situation.
Providing help to a partner or child is more often related to dissatisfaction with life than providing care to other relatives or acquaintances. This is probably due to the greater emotional involvement and the impact on daily life of providing help to a partner or child compared with helping people who are less close to the informal carer. Informal carers of people with mental health problems (such as anxiety, depression or addiction) also have lower than average life satisfaction.
Another aspect of quality of life is perceived time pressure. Those combining providing intensive informal care with a job experience relatively high time pressure, as do people who feel they are in an 'informal care trap'. Working informal carers who are helping someone with a terminal illness, someone with an intellectual disability or someone with mental health problems also more often feel under time pressure, regardless of their working hours or other characteristics of the care situation. The conclusion that working and providing informal care can be combined still stands, but needs to be qualified, because specific groups of working informal carers are found to have a poorer quality of life.

Flexibility at work

Problems with time can sometimes be overcome by adjusting working hours. For example, half of working informal carers are often able to take a day off work unexpectedly when necessary, and one in five have total freedom to determine their own working hours. This naturally depends on the occupation concerned – a checkout assistant or nurse will for example have less scope to arrange their own working hours than someone with an office job. There is thus a substantial group of working people who have little or no possibility of working flexibly.

Leave or days off

On average, one in four employees who provide informal care give up holiday days in order to provide informal care. Taking paid leave is less common (one in ten) and taking unpaid leave (often long-term) even less so (6%). The least attractive option is reporting sick, with only 4% doing this. Those providing intensive help make more use of one or more forms of leave to enable them to do so than those providing less intensive help. Men, people in full-time work, people helping in a terminal care situation and people caring for their partner or child relatively often take holiday days.

Contact with line manager on providing informal care

Over half of employees who provide informal care have informed their immediate superior of this. Most of those who have not told their superior would do so if there were a reason for doing so, for example if they needed to provide more help or if the health of the person they were caring for were to deteriorate. Three-quarters of those who have spoken to their superior about their care task received a sympathetic hearing. Those caring for family members in the first degree (partner, parent or child) and those providing terminal care relatively often feel they receive understanding. One in six give a neutral response and 4% are plainly dissatisfied with the degree of understanding shown by their line manager.
One in five of those who informed their superior agreed arrangements with them, often concerning the ability to take time off immediately when necessary or to work flexible hours.
People who have informed their line manager about their care task or who have flexibility in organising their working hours experience less time pressure. The line manager thus plays a crucial role in supporting workers who are providing informal care, intensive or otherwise: if they are able to offer a sympathetic ear or flexibility, they can reduce the time pressure on working informal carers.

Reflections

This report shows that many people combine working with providing informal care and that a high proportion (70%) of these task-combiners feel they are well able to manage this combination. This may also be because many of them do not provide help on working days, but in their free time. The impact of providing informal care on leisure time falls outside the scope of this study.

Understanding from line managers

This study shows that more than half of employees who are providing informal care have informed their line manager of this. A proportion thus do not do so, the vast majority because they did not feel it was necessary. Engaging in dialogue (where there is reason to do so) can generate understanding and (if the nature of their work permits this) lead to more flexibility or (temporary) time off. This is of particular importance for those providing intensive help; they are the group who report interruptions at work due to informal care and experience lower satisfaction with life than others. If they have discussed their situa-

tion with their line manager, are able to adjust their working hours or find it easy to take a day off, they experience less time pressure. This report also describes a number of other vulnerable groups, such as 'trapped' informal carers (those who feel they have no option but to provide care) who experience above-average time pressure. A comparable conclusion can be drawn for informal carers of people with a less visible disability or illness, such as depression or an anxiety disorder. Not only do they experience more time pressure, they are also less satisfied with their lives.
Ideally, the initiative for the dialogue about an informal care situation should not always have to lie with the employee; a proactive approach by a line manager who knows what is going on in the informal carer's life can help the employee sustain the combination.
It is however legitimate to ask how far the responsibility of employers extends in this regard. That is a question with which employers themselves also wrestle, as recent research has shown. Many employers feel responsible for their employees' balance between work and care tasks, but do not always take steps to facilitate this, or see no possibility of doing so (Van Echtelt & De Voogd-Hamelink 2017a). By no means all organisations enable their employees to determine their own start and finish times or to telework. Moreover, in many informal care situations, a high level of stress is often unavoidable (Plaisier et al. 2017). This can be the case where the care recipient has behavioural problems, for example, or can be caused by grief regarding a sick loved one who is going to die in the foreseeable future. An employer can show understanding and offer flexible solutions, but other support is often also needed, for example from the carer's network, respite care (the ability to hand over the care task to someone else temporarily) or other support that can be offered by local authorities under the Social Support Act 2015 (*Wet maatschappelijke ondersteuning 2015*).

Work and care leave

The Dutch Work and Care Act (*Wet arbeid en zorg*) is also an important part of the support for working informal carers. The group entitled to short and long term leave was expanded in 2015. Employees can now not only take leave to care for a sick partner, child or parent, but also for another household member, a sibling, grandparent, grandchild or other person with whom they have a social relationship. This has increased the scope for combining work with providing informal care.
Our study found no relationship between use of leave and the quality of life of working informal carers. This may be because they do not need to take leave, but also because they have become accustomed to their situation and taking leave would have little impact on their quality of life. This strategy is described in the literature as the adaptation model (Swinkels et al. 2018). The informal carers who participated in our study often provide help over several years (De Boer & De Klerk 2017). It may also be that use of leave bears no relation to quality of life because leave is used precisely by those who have the greatest difficulty in combining working with providing informal care: the negative effect on quality of life is then effectively cancelled out by the leave arrangements.

The absence of a relationship may also be linked to the degree to which taking leave is enough when people are faced with an intensive and long-term care situation (Kremer et al. 2017), for example if a parent is diagnosed with dementia but continues to live at home. How much leisure time, holiday and other leave does this consume, and how many employees can afford to lose salary in order to ensure that their parent receives proper care (Portegijs et al. 2015)? Long-term leave (within each 12-month period, people in the Netherlands are entitled to take up to six times the number of hours they work per week) can offer only a partial answer to this, an interpretation supported by the fact that relatively few workers regard taking paid leave as the best way of enabling them to (better) combine work and informal care.
Employers have their own judgements to make: they benefit from employees who are performing well (who may need leave), but may also benefit from the lowest possible use of leave by their employees. If all the available leave was actually taken by everyone who is entitled to it, their employment volume would reduce (Timmermans 2004); this could have considerable consequences for the labour market, especially in the care sector. In the public debate, care leave is often suggested as a solution to enable people to combine work and informal care, yet its use remains low (De Meester & Keuzenkamp 2011; Portegijs 2018). Further research will be needed if we wish to gain a better understanding of this form of support. A key question would then be what judgements employees and their partners on the one hand and employers on the other make regarding the use of (paid and unpaid) care leave. As a corollary to this, an estimate could be given of the degree to which this support helps them maintain the balance.

Flexibility

Working informal carers report that flexible working hours are one way of enabling them to combine work with providing informal care (chapter 4). If their work is less tied to a particular place and time, this is likely to make it easier to combine work and care tasks. Employees can then take leave and can also accompany a sick parent to the doctors during and outside office hours, for example. They can also respond quickly to unpredictable care situations. The results show that having the flexibility to take a day off or adjust their working hours when needed lowers the time pressure on working informal carers.

Provision of informal care is set to come under greater pressure in the years ahead (De Jong & Kooiker 2018), and at the same time the pressure on people to work will also increase. The ability to take leave is important in enabling people to combine these tasks, but our study shows that flexibility and understanding by the line manager is also a factor in ensuring good quality of life for working informal carers. In fact this does not apply exclusively for informal care, but also holds true for combining working with caring for children (Allen et al. 2012).
The role of the local authority has also increased since the introduction of the Social Support Act; it is the local authority which, based on an interview with care applicants and their informal carers, assesses the capabilities of citizens and the amount of professional sup-

port needed. It is not known whether and how they take the employment situation of potential informal carers into account in making this judgement.

Conclusion

All in all, the conclusion of this study is that if Dutch society wishes to focus on (more) provision of informal care, including by people in paid work, it will be necessary to find a viable way to enable people to combine work and informal care tasks. This in any event means more attention at the workplace for employees' care obligations. In addition to flexible working hours, understanding by line managers and colleagues is at the top of the wish list of employees with an informal care task. A substantial proportion of employees do not know what would help them best to improve the balance. If the employer engages in dialogue with the employee, a start can be made in answering this question, even though the answer will sometimes lie outside their sphere of influence.