Summary

Foresight study of informal care for elderly people in 2040

A regional foresight study for the next 20 years

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Original title:
Toekomstverkenning mantelzorg aan ouderen in 2040
978 90 377 0930 8

The Netherlands Institute for Social Research
The Hague, November 2019

Summary and discussion

Study outcomes

In the period 2014-2016, approximately 215,000 independent community-dwelling older people in the Netherlands aged 75 and older (19%) were receiving informal care.[1] Over that same period, 2.1 million adults were providing help to someone aged over 75 with health problems; 1.1 million of them were providing this help for four hours or more per week. Our estimates of the number of providers of informal care in the future are based on this latter form of more intensive informal care.

According to our forecasts, the number of people receiving informal care will increase by around 70% between 2018 and 2040, from just under 230,000 to almost 390,000 (assuming a steady improvement in the health status of 75-84 year-olds). The number of people providing informal care (for four hours or more per week) to these older people living independently will rise much less strongly over the same period, by less than 7% (from 1.11 million to 1.18 million). If we set the giving and receiving of informal care against each other, therefore, we see that a sharp reduction is on the cards in the ratio of the number of people providing informal care to the number of potential recipients. Where in 2018 there were five informal carers for each recipient, according to our forecasts that will have fallen to around three to one by 2040.

The biggest change for the future is in the forecast growth in the number of very elderly persons providing care to each other, from 10% of those providing informal care to peers being aged over 75 in 2018 to almost 18% in 2040, an increase of almost 80%. Older informal carers often provide many hours of care.

In the regions of the Netherlands where the population is contracting, a bigger shift will take place between the age groups than elsewhere, with relatively more over-75s providing care to peers and those aged 50-74 providing less, which in practice often means fewer children providing care for their parents. The greater pressure on informal care in contracting regions also came out clearly in the study by De Jong and Kooiker (2018), which looked at the potential number of informal carers per recipient based on the Oldest Old Support Ratio (the ratio between the number of 50-74 year-olds and the number of over-85s in the population).

Considerations underlying the choices and assumptions made

A number of caveats need to be applied to these results. First, in our forecast giving and receiving informal care were uncoupled from each other and multiplied separately from each other by the population numbers from the (regional) population forecasts. Informal care is a form of mutual caregiving which is based on a personal bond, and this connection is much stronger than is modelled here; it is thus for example possible that a growing demand for informal care will also elicit a growing supply. This could be investigated in a micro-simulation in a model, for example using agent-based modelling (Noble et al. 2012;

Rand & Wilensky 2015). At present, the data needed to do this are not available; this would require follow-up research.

Second, changes in demand for informal care in the future are dependent on a large number of factors which could not be incorporated in this report. For example, it was not possible to include anticipated developments in the mental health of older persons (e.g. dementia), which means only the relatively favourable development of physical health problems and their influence on mobility impairments is included. Future changes in the physical health of older persons were only taken into account in the forecast of the number of informal care recipients. Not making allowance for better health status of those providing the care (because a one-to-one relationship with providing informal care cannot be established) could mean that informal caregiving has been underestimated, since (poor) health can be an impediment to providing informal care (see De Klerk et al. 2017). Better health could therefore lead on the one hand to more informal carers; on the other hand, an improvement in health could mean that people remain active on the labour market for longer, potentially making it more complicated to provide informal care (Henkens & Van Solinge 2017). Among those providing informal care, the labour market participation rate of women and older people (of both sexes) could also play a role, but this was also not included in the forecasts. This could have resulted in an overestimate of informal caregiving, especially if we take into account the fact that both men and women will continue working for longer. It is impossible to determine the outcome of these opposing trends, but it seems plausible to assume that the trends towards better health and greater labour market participation will more or less cancel each other out.

The calculations also made no allowance for technological developments which could on the one hand have a positive impact on the independence of older persons, but on the other could increase pressure on informal carers because of increased remote responsibility (i.e. when they are not with the care recipient) (Van Campen et al. 2016).

The forecasts also take no account of the anticipated effects of recently implemented policy. It is plausible that the demand for informal care will be different in 2040 from what is assumed here, for example if the availability of professional care has changed greatly by then. For the growth in the number of jobs in elderly care to keep pace with the number of people in the population aged over 75, almost 350,000 extra full-time and part-time jobs would be needed in 2040 compared with 2016, according to calculations by Daalhuizen and colleagues (Daalhuizen et al 2018). Whether this will be achievable is a very moot point, partly in view of the already considerable shortages on the labour market. Any changes in the access criteria for nursing home and other care could also have consequences for the demands placed on informal care. If older persons remain living at home for longer, even as their health problems become more complex, this will require more intensive care.

Another potentially important factor for informal care in the future concerns the combination of housing and care. All manner of trial and pilot projects have been rolled out in the recent past, which show that small-scale community residential facilities in the neighbourhood could make providing help and care easier.[2] A crucial question is whether it proves possible to scale up these residential models. At this point in time this appears unlikely, but

if it should prove possible, it is plausible that by 2040 many care-dependent older persons will be living in housing of this type, leading to lower pressure on caregivers than suggested in our calculations. Private residential care facilities are also likely to play a bigger role in the future than at present (Plaisier & Den Draak 2019).

It goes without saying that forecasts are always hedged in with uncertainty. As regards population developments, those uncertainties stem from birth rates, mortality rates and foreign migration. The uncertainty as regards mortality rates is of particular relevance in this study. A greater increase in life expectancy than that assumed in our forecast would mean there will be more older people within a few decades; conversely, if life expectancy rises more slowly, there will be fewer older persons. The trend in the care needs of older persons can also not be determined with any certainty.

Reflections

People aged 50-74 years will continue to provide a substantial amount of informal care in the future. The biggest change for the future is in the forecast growth in the number of very elderly persons providing care to each other, What are the likely consequences if a growing group of very elderly persons become increasingly dependent on people in their own age group over the course of the next two decades? We discuss a few of these consequences from the perspective of the older caregivers and receivers themselves, of the implementing agencies in municipalities and of the local authority as a director of activities (Putters 2017).

Older caregivers and receivers

Older people vary in the care they receive. One in five receive help exclusively from their social network; a third receive only publicly funded help from the home care services (Social Support Act (Wmo) and Health Insurance Act (Zvw)) and one in seven receive only help they pay for themselves (De Klerk et al. 2019). One in eight older persons receive both publicly funded and informal help. The composition of the support networks of older people is likely to change due to the rapid changes taking place in Dutch society due to increasing population ageing and the curtailing of publicly funded provisions (Broese van Groenou et al. 2017). Recent research has for example already shown that professionals provide help jointly with informal carers less often than in the past (Plaisier 2017). This could be an indication that professionals are more often providing care to older people who have no informal carers. If this trend continues, the support networks of older people will increasingly be made up of their partner, relatives, friends, neighbours and volunteers, with less support from home care professionals. We also need to be aware that not everyone will be automatically willing to receive help from loved ones. That may be linked to the dependency this entails, but also to things such as the lack of a good relationship with people who would be able to provide help.
There are indications that their higher education level means that older people in the future will be more assertive and will take more control of the care they wish to receive (De Klerk et al. 2019). It may be that these older people will more often make use of

domestic help they pay for themselves or of welfare and other services. Yet not all older people will be able to organise and control their care in this way, for example older persons with a low educational level, with weak digital skills, with a small network or with a low income (De Klerk et al. 2019). Earlier research has shown that one in five older persons do not have a social network which is able to offer the level of help and support they need (Putman at al. 2016). These older persons will continue to rely on publicly funded care.

Wmo help desk staff or care professionals

A recent survey of local authority assessment officers suggested that they 'regularly' or 'often' explore the resilience of informal carers during assessment interviews with Wmo applicants (Kromhout et al. 2018) Informal carers themselves experience this differently. Feijten and colleagues (2017) found in their study that half the informal carers who had been involved in a home interview to assess the support needs of the applicant had concluded that the help they were providing was disregarded and that their support needs were not discussed. One in three informal carers also feel that home care professionals pay too little heed to them (De Klerk et al. 2017).

It is therefore desirable that employees of local authorities and home care organisations develop more sensitive antennae in this regard. One way of doing this would be to be more alert and proactive: professionals need to pay more heed to the informal carers they meet, their resilience and their (latent) need for support. Second, there are gains to be made in making services as accessible as possible: professionals could inform informal carers at various points in the care trajectory about the support available from the local authority. Informal carers often do not know what kinds of support exist and how they can access them (De Klerk et al. 2017). This underlines the importance of reducing the amount of red tape for citizens. Informal carers want to spend as little time as possible filling in forms, carrying out administration and looking up rules and regulations.

The envisaged growing group of older people caring for partners could be an important target group for local authorities and home care organisations. These carers are sometimes less well able to find their way through the care system due to low literacy or a lack of digital skills, but are nonetheless at great risk of becoming overburdened because they spend a lot of time on providing care and are the sole carer. More focus could also be placed on sharing the help with others for this group, so that they are able to continue providing it for longer. If informal carers are overburdened, they may gradually and unintentionally go beyond their limits, potentially leading to inadequate or even 'derailed' informal care.

It should be more routine for care and welfare professionals to look at client's wider network and to involve other network members in providing the help, so that older informal carers are better able to share the help.

Local authorities as directors of the care

How much informal care can local authorities reasonably expect residents in their municipalities to provide, and when should help from 'genuine' professionals be made available? This question rears its head when we bear in mind that a growing proportion of care for

older persons will be provided by people who are elderly themselves and who may also need support. In those regions where the population is contracting and demand for care is set to be highest, relatively little publicly funded and informal care will be available as the younger generations leave for more urbanised regions. In these contracting regions more than elsewhere, therefore, informal care will fall on the shoulders of the older generations. The regional differences we found in the availability and take-up of informal care also beg the question of whether there is sufficient support available in those regions. This study shows that it is particularly important in these regions to anticipate the decline in the number of informal carers in good time.

Many people have the impression that wide inequalities have arisen in the way different local authorities perform their tasks (Dekker et al. 2018). This is regarded as unfair and unjust and may cause people to lose the confidence that their local authority will provide the necessary care and support. It would be useful to investigate in further research what people expect of the government as regards care and for which care tasks they regard informal or formal solutions as appropriate.

Thus far, the discussion in policy and public circles has been focused mainly on the question of how much informal carers can take on and what support they need – in other words, on maintaining the balance between supply and demand. Based on the results of this study, the gap between supply and demand will be wider in the future than at present, bringing the risk that too much will be asked of those providing help and that care recipients will have to go in search of new solutions for their care needs more often than in the past. This can be explained by the fact that the number of (very elderly) older people who need care or informal help is set to increase much more than the number of informal carers, while the pressure on care professionals will also increase. This report is a warning signal that the time to begin the discussion is now. What does this mean at local level? Which tasks do the Dutch public believe should be organised by the government and for which members of society, and what can people organise themselves, in their own network or their own neighbourhood? What support can informal carers expect from the local authority if they are unable to continue providing care? And what are the consequences of this? How does central or local government ensure that a basic level of care is guaranteed where needed, knowing that the demand for care will increase and the availability of informal care will decrease? This could necessitate upscaling to collaboration at regional level, but could also lead to changing insights into what constitutes a basic level of care. These are questions which are already current but which – as this report shows – will become even more pressing in the future.

Notes

1 For this study, we confine our interpretation of 'informal care' to help with cleaning in the household, help with personal care, nursing or support.

2 See the website of Aedes-Actiz Kenniscentrum Wonen-Zorg https://www.kcwz.nl/thema/woonvariaties/woonvormen