

Informal caregiving, a healthy decision?

Determinants and health-related
consequences of providing informal
care

Judith Bom, Pieter Bakx, Erik Schut and Eddy van Doorslaer

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Summary and policy recommendations

The demand for long-term care (LTC) is growing in most OECD countries (OECD, 2017). LTC can be provided by formal and informal caregivers, and striking the right balance between both types of care is a challenge. In this Netspar Survey Paper we first analyze from an economic perspective the trade-offs involved in this balancing act, by a review of the relevant economic literature. Next, we focus on one particular aspect of this trade-off: the negative health effects of providing informal care. We systematically review the growing number of empirical studies that aim to identify the causal effects of providing informal care on caregivers' health.

Insights from this paper may be especially relevant for the Netherlands, since its public long-term care expenditures are among the highest in the OECD and are expected to grow substantially in the coming decades (OECD, 2017; Eggink, Ras & Woittiez, 2017). Worries about the financial sustainability of LTC provision led to a radical reform of the LTC system in 2015. One of the aims of this reform is to encourage substitution of formal by informal care. For instance, by amendment of the Social Support Act (*Wet maatschappelijke ondersteuning* or Wmo, 2015), citizens are no longer entitled to formal care from their municipality when their social network is capable of providing sufficient informal care.

Our review of the economic literature suggests that the individual decision to provide informal care is likely to depend on personal characteristics and the institutional context. Informal caregiving is likely to be concentrated among individuals with lower opportunity costs, or with fewer other activities competing for their time, such as people without a paid job. This implies that the burden of informal caregiving and the associated negative health effects are likely to be unequally distributed across the population. Based on insights from the Health Monitors of 2012 and 2016, we indeed note that in the Netherlands retirees and part-time workers more often provide informal care than full-time workers.

The potentially high and unpredictable costs for caregivers provide an argument for government intervention. Governments might relieve those who are likely to be most exposed to negative effects of the caregiving burden by subsidizing or organizing formal care. However, this could drive up public expenditures by crowding out too much of the informal care supply. To ensure that public money is spent effectively, governments could encourage appropriate self-selection of individuals, for instance by subsidizing the uptake of private LTC insurance and by setting the quality level of publicly available formal care. Deciding upon the optimal combination of instruments is difficult, however, as this depends on the prevailing social norms and altruistic

preferences in society. The stronger these norms and preferences are, the lower the risk that informal care is crowded out by public subsidies for LTC.

Based on our systematic review of the literature, we conclude that informal caregiving can have negative consequences for the health of the informal caregiver. Various studies show that informal caregiving can negatively affect the caregiver's health. The stress and physical strain involved in caregiving tasks can lead to both mental and physical health problems. Informal caregiving is, for example, linked to symptoms of depression, increased drug intake, and an increase in self-reported pain. The strength of these effects varies between subgroups of informal caregivers. Several recent studies indicate that female, and married caregivers, and those providing intensive care may experience larger negative effects of caregiving. These are also the groups that provide informal care most often. These groups may experience a larger caregiving burden as they face other responsibilities on top of caregiving duties. Another explanation could, especially for women, be the pressure that is felt to provide care, making it more difficult to quit caregiving tasks when they become too burdensome (Pinquart & Sörensen, 2003).

Future research should provide additional insights into these different subgroups of caregivers, specifically for the Dutch context. As this study shows, encouraging informal care may have important drawbacks. Our review thereby highlights the importance of accounting for the consequences of informal caregiving when making a trade-off between formal and informal care. Our findings furthermore emphasize the need for interventions aimed at reducing the negative impact of caregiving. Investing in support for informal caregivers by offering respite care or by organizing support groups could reduce the negative effects of informal caregiving. Policymakers should specifically target those subgroups of caregivers that carry the largest burden of informal caregiving.

Samenvatting

Voordat je het weet sta je als burger zelf voor de keuze: ga ik wel of geen mantelzorg verlenen? Hoewel het een makkelijke keuze lijkt, is deze eenvoudig bedrieglijk. Naast het verlenen van mantelzorg wordt van burgers namelijk ook verwacht dat zij langer doorwerken. Bovendien kampen vooral oudere mantelzorgers vaak zelf met gezondheidsproblemen, die mogelijk samenhangen met het verlenen van mantelzorg. Moeten we dan maar steeds meer zorg overlaten aan professionele zorgverleners? In dit survey paper staan twee vragen centraal. Ten eerste bespreken wij wat de economische theorie ons leert over de keuze tussen mantelzorg (informele zorg) en professionele (formele) zorg en de implicaties daarvan voor overheidsbeleid. Vervolgens zoomen wij in op één aspect van het verlenen van mantelzorg, namelijk in hoeverre dit gepaard gaat met negatieve gezondheidseffecten.

In de economische literatuur bestaat veel aandacht voor de invloed van persoonskenmerken en institutionele omstandigheden op de keuze om mantelzorg te verlenen. Op grond van deze inzichten is het aannemelijk dat het verlenen van mantelzorg niet evenredig wordt verdeeld over de (volwassen) bevolking, maar vooral neerkomt op mensen met een lager inkomen of zonder betaald werk. Dit betekent dat een bepaalde groep burgers negatieve gezondheidseffecten van mantelzorg zou kunnen ondervinden. Hoewel overheidsingrijpen gewenst is om burgers te beschermen tegen deze onevenredig verdeelde en mogelijk hoge kosten van mantelzorg, kunnen interventies ook nadelige effecten hebben. De economische literatuur laat zien dat overheidsinterventies, zoals collectieve financiering van formele langdurige zorg, kunnen leiden tot suboptimale uitkomsten wanneer ze mantelzorg teveel verdringen. De rol van deze verdringingseffecten verandert echter wanneer de sociale normen of de altruïstische voorkeuren om informele zorg te verstrekken belangrijker zijn.

Voor de inschatting van het effect van overheidsinterventies om formele dan wel informele zorgverlening te bevorderen is meer inzicht in de gezondheidseffecten van mantelzorg noodzakelijk. Naar de causale gezondheidseffecten van mantelzorg is de afgelopen jaren in diverse landen onderzoek gedaan, maar een overzicht van deze bevindingen ontbreekt. Met dit survey paper beogen wij om in deze lacune te voorzien door middel van een systematische review van de literatuur van het beschikbare empirische onderzoek naar de gezondheidseffecten van mantelzorg. De opgenomen studies laten zien dat mantelzorg inderdaad tot negatieve effecten kan leiden, zowel op mentale als fysieke gezondheid. De aanwezigheid en grootte van deze effecten zijn echter niet gelijk voor de verschillende groepen mantelzorgers. Vooral vrouwelijke en getrouwde mantelzorgers, en personen die intensief mantelzorg verlenen ervaren

negatieve gezondheidseffecten van het verlenen van mantelzorg. Zorgelijk is dat deze groepen ook de groepen zijn die het vaakst mantelzorg verlenen. Een mogelijke verklaring voor de grotere gezondheidseffecten is dat deze groepen mantelzorgers naast het verlenen van mantelzorg andere verantwoordelijkheden hebben. Ook zouden deze groepen, vooral vrouwen, zichzelf meer verplicht kunnen voelen om mantelzorg te verlenen, waardoor ze minder snel geneigd zijn te stoppen bij overbelasting.

Dit paper laat zien dat de keuze tussen formele en informele zorg complexe afwegingen vereist. In Nederland wordt steeds meer een beroep gedaan op de sociale omgeving, wat resulteert in een groeiend aantal mantelzorgers. Mantelzorg is echter niet gratis, want het onttrekt verzorgenden aan de arbeidsmarkt en kan gepaard gaan met een negatief effect op hun gezondheid. De negatieve effecten zullen afgewogen moeten worden tegen de kosten van formele zorg. Daarnaast kunnen de negatieve effecten van mantelzorg mogelijk worden gereduceerd door te investeren in mantelzorgondersteuning in de vorm van respijtzorg of steungroepen. Aangezien niet iedereen in dezelfde mate wordt geraakt door het verlenen van mantelzorg, zouden deze interventies mogelijk specifiek kunnen worden gericht op bepaalde groepen mantelzorgers.

1. Introduction

Many individuals face the decision whether to provide care for a spouse, family member, friend, or neighbor who needs help with running the household or personal care on a regular basis for a longer period. This help is defined as informal care and is typically unpaid. Alternatively, a formal, i.e. professional caregiver, may provide this long-term care (LTC).

In all developed countries, governments subsidize or organize some level of formal care. Aside from formal care, also informal care is often promoted by policy. Dutch policy, for example, stimulates citizens to seek help in their own social network before turning to government-funded formal care (WMO, 2015; CIZ, 2017). When informal care and formal care operate as substitutes (see e.g. Bolin, Lindgren & Lundborg, 2008; Bonsang, 2009), governments need to balance the costs and benefits of both alternatives to achieve the appropriate mix of the two.

This paper aims to shed light on this LTC puzzle in two ways. First, we analyze the trade-offs that governments face when subsidizing or organizing formal care. We do this by providing an overview of the economic literature regarding these decisions and focusing on what these models mean for the role of government in LTC.

Second, we zoom in on one specific downside of informal care: the individual health effects of providing informal care. We focus on these effects because they are potentially major and irreversible – most caregivers are older and vulnerable

Textbox 1: Financing of long-term care in the Netherlands

The Netherlands has a comprehensive public LTC financing system. This has a legal basis in the Long-Term Care Act (*Wet langdurige zorg – Wlz*), the Social Support Act (*Wet maatschappelijke ondersteuning – Wmo*) and the Healthcare Insurance Act (*Zorgverzekeringswet – Zvw*). The types of LTC covered under these separate acts are respectively (1) institutional care and home health care; (2) social support, assistance, and housekeeping services; and (3) nursing and personal care (Non et al., 2015).

Costs are kept in check through rationing measures that target both the supply and demand side (Bakx et al., 2015). On the supply side, the provision of LTC is rationed by imposing budgets, i.e. regional provider budgets (and regulated maximum prices) for LTC benefits covered by the Long-Term Care Act and block grants to municipalities for providing Social Support Act services. On the demand side, co-payments are required for care provided through these two Acts. Furthermore, access to care provided under the Long-Term Care Act can only be obtained via the independent care assessment agency (*Centrum Indicatiestelling Zorg, CIZ*). This agency assesses whether someone is eligible for formal care based on centrally set eligibility criteria (CIZ, 2017). Local authorities assess eligibility for care via the Social Support Act. In this eligibility assessment, the social context is taken into account. Hence, individuals are encouraged to rely on their social network before making use of formal care.

Textbox 2: Informal care in the Netherlands and Europe

The share of caregivers has risen over the years. In some cases, informal caregivers may be paid from LTC insurance (through cash benefits). Informal care thus does not necessarily refer to unpaid caregivers but to caregivers outside formal employment contracts. According to data from the Dutch Health Monitors of 2012 and 2016 (N > 350,000 in both surveys), weighted to represent the Dutch population, the share of informal caregivers has grown from 19.3% to 23.1% of the adult population. This represents an increase of almost 20% in four years in the total number of informal caregivers. Based on these numbers, we estimate that in 2016 more than 3 million individuals provided some form of informal care. Currently, more females than males provide informal care, although male participation is growing. In 2012, about 30% of the caregivers were male; by 2016, male participation had risen to 35%.

Both male and female caregivers provide around 9.5 hours of care a week on average. This average is higher for older caregivers (aged ≥ 65) as these provide about 14.5 hours of care a week. A similar trend is present when comparing the caregiving intensity between low-income and high-income quintiles. Individuals in the lowest income quintile provide twice as many hours of informal care compared to individuals in the highest quintile (12 hours compared to 6 hours of care per week). A majority of Dutch caregivers have a paid job, and caregiving is furthermore concentrated among the older inhabitants. Most caregivers are aged 45–60, since of this group over 30% provided informal care in 2016. As to occupation, we note that homemakers, pensioners, and part-time employees more often provide informal care compared to full-time working employees (see table 1).

The share of the Dutch population that provides informal care is similar to that in neighboring countries. The Netherlands, and other Northern and Central European countries strongly differ, however, from the countries in Southern and Eastern Europe when it comes to the intensity of care provided. In the Netherlands, about 20% of caregivers provide intensive informal care (20+ hours per week), whereas this share is over 30% in the Czech Republic and about 50% in Spain (Colombo, Llena-Nozal, Mercier & Tjadens, 2011).

Table 1: Share of informal caregivers per subgroup

	2012 (% of total)	2016 (% of total)
Full 19+ population	19.3	23.1
<i>By gender</i>		
Men	13.3	16.6
Women	22.6	25.7
<i>By occupation</i>		
Homemaker	24.8	27.8
Part-time employee	23.1	26.4
Full-time employee	15.0	18.7
Pensioner	19.3	24.8
<i>By age</i>		
19–40 years	11.6	13.0
40–65 years	26.0	30.3
65+ years	18.1	22.5
<i>By income</i>		
Lowest income quintile	15.3	16.9
Highest income quintile	21.1	24.1

* Note that various confounding variables may underlie these descriptive statistics. Data weighted to represent Dutch population, results based on own calculations using Gezondheidsmonitor 2012 and 2016

Textbox 3: The need for government intervention

Expected LTC expenditures over the lifecycle are high – on average about 35,000 euros for men and 91,000 euros for women (Hussem et al., 2016) – and highly uncertain. Therefore, insurance against these costs is welfare-improving. However, private long-term care insurance covers no more than a few percent of all long-term care spending (OECD, 2017). Reasons for this low uptake include correlated risks, asymmetric information, consumer myopia, and a rational choice of parents who expect that the level of informal care provision will negatively depend on the level of long-term care insurance (see Boyer, De Donder, Fluet, Leroux & Michaud, 2017; Brown & Finkelstein, 2009; and Cremer, Pestieau, & Ponthiere, 2012 for more comprehensive overviews).

This market failure to provide adequate coverage against the financial risks associated with LTC use is one of the reasons for government intervention in LTC financing. An important other reason is solidarity, as irrespective of market failures not everyone has the means to purchase insurance. Public LTC insurance, as opposed to subsidization and regulation, can overcome some of the problems that inhibit adequate private coverage. However, public insurance may be inefficient due to moral hazard, e.g. consumers using more – or more expensive – formal care or because potential informal caregivers underreport their ability to provide care (Barr, 2010; Bakx et al., 2015).

themselves – and more difficult to compensate financially than, say, foregone labor market opportunities. In several countries the health effects of informal caregiving have been investigated empirically. However, a systematic overview of the results of these studies is lacking. To fill this gap, we provide a systematic review of the empirical literature aimed at estimating the causal effects of informal care on health. We conclude this paper by summarizing the insights from both theoretical and empirical literature. Based on these insights, we formulate policy recommendations for the Dutch situation.

2. The trade-off between formal and informal care: an economic perspective

Not everyone has a potential informal caregiver, and the costs of hiring a formal caregiver can be very high, placing a large financial burden on dependent individuals (Colombo et al., 2011). Furthermore, private LTC insurance that could protect individuals against the high costs of care has limitations, leading to a low uptake (Brown & Finkelstein, 2009). For these reasons, governments often subsidize or even organize the provision of formal long-term care for at least the poorest part of the population. Indeed, in most OECD countries the majority of LTC costs is financed from public budgets (OECD, 2010; European Commission, 2015).

Informal and formal LTC are partly substitutes (e.g. Bolin et al., 2008; Bonsang, 2009), and individuals may decide to use either of the two types of care.¹ Economic literature provides some insight into what determines these decisions. We summarize this literature and discuss potential implications for the role of government in LTC.

2.1 The role of labor market productivity

A useful economic model to provide insight into a person's decision to provide informal care is the Roy model about the self-selection of workers into different occupations (Borjas, 1987; Heckman & Honoré, 1990; Heckman & Sedlacek, 1985). Nocera and Zweifel (1996) were the first to apply the Roy model to the decision to provide informal care. In this model, the caregiving decision lies with the caregiver, not with the person in need for care, and the potential caregiver maximizes expected utility. Utility can be derived from consumption, leisure, and potentially from caregiving. In maximizing utility, caregivers face a budget and time constraint.

Because of the trade-off between leisure, paid work, and caregiving, the opportunity costs of caregiving are foregone wages and leisure time. A person's decision to provide care is based on his or her reservation wage for providing care. This is especially dependent on the wage that one could earn in the labor market. Other elements affecting this reservation wage are productivity, real wage, and preferences towards leisure and consumption. Productivity in this model refers to a person's productivity in caregiving and to the productivity in using consumption goods (relative to the price of these goods).

Nocera and Zweifel (1996) conclude that for all individuals the reservation wage for caregiving is positive. The height of this reservation wage, reflecting the willingness

¹ Throughout this paper, we make use of economic terminology and refer to the 'decision' to provide informal care instead of 'determinants' of providing informal care, which is more common in e.g. public health.

to provide informal care, could, however, differ. As the reservation wage for care depends on the wage that someone can earn in the labor market, high earners will be less likely to provide informal care, for they would forego more income by providing care. Furthermore, highly productive caregivers, for example because they live closer to the care recipient, would be more inclined to provide care compared to less productive caregivers. Lastly, individuals strongly valuing consumption will be less willing to cut back on working hours and are therefore less likely to provide informal care.

Next to dedicating time to provide care themselves, individuals may help their dependent family member by hiring a formal caregiver. This might especially be the case for individuals who are employed full-time and for relatively high earners. This trade-off is considered explicitly by the Roy model used by De Zwart, Bakx & van Doorslaer (2017), where the decision is framed as a choice between informal caregiving and working but having to pay for formal care. The decision depends on the trade-off between wage and the cost of paying for formal care. This model shows that the individual decision to provide informal care might be driven not only by individual productivity, but also by contextual factors, namely the costs associated with formal care consumption.

This rather simplified model provides two important insights. First, it shows that informal caregiving – and hence the burden of caregiving – is not likely to be equally distributed across the population of potential caregivers: some people are more likely to take on caregiving tasks than others. Second, it shows that in case a government would have perfect information about which people will provide informal care, it may target formal care to people who do not have a potential caregiver in their network.

However, when the government has *imperfect* information, subsidizing formal care may result in moral hazard because people may *pretend* to be unwilling to provide informal care in order to receive governmental aid (Jousten, Lipszyc, Marchand & Pestieau, 2004). To reduce moral hazard, a government could take measures to encourage self-selection towards the type of LTC that is optimal from a societal perspective. This will be discussed in the following sections.

2.2 The role of intra-family strategic behavior

A second set of economic models focuses on a specific type of potential caregivers and care recipients: adult children who may take care of their parents when these become dependent on help. In these models, caregivers are not viewed as the decision makers but as agents in a principal-agent setting in which they may be convinced to provide care to their principal – their parent – through the prospect of a bequest

(Zweifel & Struwe, 1996; Cremer & Roeder, 2017).² These models consider a society consisting of two generations, parents and children, and two periods. Moreover, instead of a distinction between formal and informal LTC, they identify three potential sources of LTC: the family providing informal care, the market providing formal care via private insurance, and the state providing formal care via public insurance. These three options are assumed to be close or perfect substitutes.

In these models, utility-maximizing parents derive utility from wealth. Parents face uncertainty about whether they will become dependent but know under which conditions to expect informal care from their children. Based on the potential help that parents expect from their children in case of illness, the parents decide in the first period whether to spend part of their wealth on private LTC insurance or to save it as a bequest to their children. These expenditures would yield a drop in utility at the cost of the insurance or the bequest. In the second period, parents may become dependent and need LTC, with insurance or informal care protecting them against LTC expenditures. The children decide their level of labor and informal care supply in period two, based on their wage and the expected bequest from their parent.

Cremer and Roeder (2017) show that the outcomes of this strategic game are sub-optimal and hence imply that government intervention may be welfare-improving. The authors mention that without government interference, several inefficiencies may arise. First, parents might purchase insufficient insurance when the insurance premium involves significant loading costs or due to limited financial possibilities. Second, the labor supply may be inefficiently low because the level of the bequest depends on the amount of informal care a child is able to supply. Children who work more would have less time to provide informal care. Their parents in turn need to hire formal care, resulting in a lower bequest for the children. A caregiving-dependent bequest hence implies a tax on labor as additional labor earnings are partly 'taxed away' by a drop in the bequest. Third, the supply of informal care might be inefficiently low because children do not account for the possibility that parents value the help of their children more than care provided by a formal caregiver. Parents with limited ability to pay in this model are the ones in highest need of public aid. These parents experience a double burden as they cannot purchase insurance and are unable to induce their children to provide informal care via a bequest.

The authors discuss several interventions to overcome inefficiencies, all differing based on the informational context. A key element in these interventions is the need

2 Knoef and Kooreman (2011) (among others) further extend these models by including siblings' caregiving interactions, but this is beyond the scope of this review.

for subsidization of informal care, as otherwise not enough care is provided. Most importantly, the models show that public aid does not necessarily crowd out informal care when children are non-altruistic. When children solely provide care because their bequest is dependent on doing so, they do not consider publicly provided LTC as an alternative when making their caregiving decision. In case parents do not have the resources to purchase insurance or to transfer part of their wealth to their children, publicly funded care might even enhance informal caregiving. When the state offers some level of public care, parents save money, which they can use as a bequest to induce their children to provide additional informal care.

2.3 The role of altruism and social norms

While the previous sets of economic theories assume 'selfish' motives to providing informal care, the third set of theoretic models acknowledges that informal caregiving might be provided as a deed of altruism or due to social norms. Social norms, which make a person feel obliged to provide care, could be culturally determined (e.g. "it is one's duty to care for a sick relative") but can also differ based on caregiver characteristics (e.g. "daughters and daughters-in-law have more caregiving tasks than sons and sons-in-law"). These social norms have been incorporated in some theoretical models. Barigozzi, Cremer and Roeder (2017), for example, assume that daughters feel a stronger obligation to provide care than sons and hence suffer disutility when they provide less informal care than the average child. Social norms may partly explain the observed gender differences in the supply of informal care.

Altruism, on the other hand, refers to the utility that children derive from helping their parents; this concept has thus far received more attention in literature than social norms. Pestieau and Sato (2008) assume that children are altruistic and willing to help their parents if needed.³ In their model, children derive utility from consumption and providing help. The effect of help on utility depends on the amount of help provided and someone's level of altruism.

The type of help – LTC provision or financial aid – given by children is based on their labor market productivity, as reflected in their labor income. Children with low market productivity lose less when they give up work to provide LTC by dedicating time to their parents. As a result, these children tend to provide a higher level of informal care. The amount of informal care that people are willing to provide drops when their labor productivity increases, down to a certain point where the amount

3 We will focus on the 2008 paper as this one includes the market as a potential source of LTC, whereas the 2006 paper solely accounts for family and state provided care

of care provided is minimal. From this point, children earn enough to provide LTC in the form of financial aid. From this point onwards, the level of monetary aid provided increases when productivity increases. If children are altruistic, the model predicts that the total amount of support will be U-shaped.

The model furthermore assumes that parents know how much help to expect from their children. Based on this knowledge, parents decide to purchase private insurance or to leave part of their wealth to their children. The model demonstrates that differences in the productivity of children may result in inequalities in the care received by their parents. Parents with low- and high-earning children can rely on help from their children. The remaining group has to purchase private insurance or to rely on governmental support. Government support is needed for the parents who do not receive enough help from their children and are unable to purchase private insurance. The state could furthermore improve social welfare by subsidizing informal care when children are not fully altruistic. In such a situation, children do not completely account for the utility gain of their parents and provide less than the optimal value of help.

The authors examine various types of government interventions assuming imperfect information. They show that the optimal type of government intervention is a combination of measures that induce rich parents to purchase private insurance and that guarantee the public provision of care to poor parents. To achieve this, the state should encourage appropriate self-selection by setting the level of subsidy for the uptake of private insurance and the quality level of public nursing homes in such a way that rich parents will value private insurance over public nursing homes.

Cremer, Gahvari and Pestieau (2017) extend this analysis by assuming that different levels of altruism exist. This extension provides insight into the optimal amount and type of LTC insurance that should be supplied considering that the state cannot condition its support on the default of altruism (as this is unobservable and prone to moral hazard). The role of insurance (public and private) is studied assuming two forms of insurance supplied by the public sector: topping up and opting out. Either the state provides a lump-sum subsidy for formal care that persons can top up; or it provides LTC in kind, which elderly people decide to use or to opt out from. Which option leads to the optimal outcome depends on the altruism levels of the children in the population. If most children are highly altruistic, the opting-out scheme is preferable because highly altruistic children will let their parents opt out of this scheme and provide care themselves. After all, these children would provide more help than the state would and hence receive a higher utility from providing care themselves. In this situation, governmental aid is spent solely on those who need it, i.e. parents whose

children are not sufficiently altruistic to help. By contrast, a topping-up scheme is optimal when the altruism of most children is very low. As children with low levels of altruism would not provide enough care to be the sole caregivers, a topping-up scheme makes use of their limited supply of informal care instead of letting them opt out from informal care completely. In case children are moderately altruistic, the optimal level and type of public LTC is more difficult to define. Under an opting-out system, the level of public insurance coverage should then be small enough to convince children to provide informal care, leading to a downward distorted supply of publicly provided care.

Both models show that altruistic children, in contrast to selfish children, take governmental interference into account when deciding upon the level of informal care to supply. In such situations, the level of publicly supplied care could crowd out as well as enforce informal care. Although the government is unable to observe altruism directly, it has the possibility to steer informal care decisions, for example via the quality of publicly provided nursing homes, the form of public LTC provision (lump sum or in-kind), and subsidies for the uptake of private LTC insurance.

2.4 Societal trade-off between formal and informal care

The above-mentioned models demonstrate (i) how individual characteristics and the institutional context shape a person's caregiving decision and (ii) that government needs to account for the response of caregivers when it intervenes in the financing and provision of LTC. As a variety of elements shape one's decision to provide care, not everyone is equally likely to be a caregiver and therefore not equally likely to experience negative consequences. Combined with the fact that children often cannot fully insure themselves against the negative consequences of caregiving on the market, this provides an efficiency argument for government intervention, either by reducing the need to provide informal care or by compensating caregivers for the negative consequences of caregiving.

However, government may not be able to achieve the optimal allocation of formal and informal care because of imperfect information about a potential caregiver's ability and willingness to provide informal care, and because of strategic behavior on the part of both caregivers and care recipients. Therefore, government policies that reduce the need to provide informal care (e.g. through public provision or private insurance subsidies) should encourage appropriate self-selection to ensure that public money is spent effectively. Potential instruments to achieve this (desirable) self-selection are (i) the quality of publicly provided care, (ii) in-kind provision of care (rather than a lump sum cash benefit), (iii) subsidization of insurance, and (iv)

taxation of labor earnings and bequests. However, the three sets of models we have discussed show that the optimal combination of instruments to achieve this self-selection depends on assumptions regarding social norms and the level of altruism of children – two aspects that are notoriously hard to measure.

3. Health-related consequences of providing informal care

Our review of the economic literature highlights the complexity of the trade-off between formal and informal care. One important element in this trade-off are the costs of informal caregiving, including the potentially negative health effects on the informal caregiver. A number of recent empirical studies have attempted to identify the causal effect of informal caregiving on health, but a synthesis of these findings is lacking. To fill this gap, we have conducted a systematic review of the studies that estimate the health effects of informal caregiving.

We focus on the health effects of informal caregiving for three reasons. First, the effects are potentially major and irreversible, especially considering that most caregivers are older and vulnerable themselves. Second, health effects are a risk for all caregivers whereas labor market effects can only occur for working-age caregivers. Lastly, it is more difficult to financially compensate health effects than other effects such as foregone labor market opportunities.

Several studies have attempted to estimate the negative health impact of informal caregiving. Early systematic literature reviews and meta-analyses regarding the topic often find evidence of a negative effect of informal care (e.g. Vitaliano, Scanlan & Zhang, 2003; Pinquart & Sörensen, 2003; Pinquart & Sörensen, 2007). None of these studies specifically account for the possibility that certain groups of individuals select into caregiving. Yet, as described in the previous section, children with lower health expectations or a lower propensity to work are potentially more inclined to take up the caregiver role for their parents (Schulz, Visintainer & Williamson, 1990). The health states of caregivers and non-caregivers therefore already differ before commencing caregiving tasks. One should account for this endogeneity in the caregiving decision when estimating the causal effect of informal care on health.

There are various methods to identify causal effects, with the conceptually simplest method being a randomized control trial (RCT). In RCTs, individuals are randomly assigned to either a control group or a treatment group, which makes comparisons between both groups possible. However, such random assignment is infeasible for informal caregiving, as we cannot randomly assign individuals to a caregiving task. In the absence of RCTs, quasi-experimental methods can be used to uncover a causal relation. Here, the selection into the treatment and control groups is carefully modelled.

Several studies have over the years used such quasi-experimental methods to overcome the selection problem related to informal caregiving. We are the first to systematically review this relatively new strand of literature. In order to provide an

objective, transparent, and replicable overview of the literature we have carried out this review systematically following PRISMA guidelines (Moher et al., 2009). We sought to address the following question: *What impact does providing informal care to elderly or older family members have on the health of the caregiver?*

3.1 Review methodology

Eligibility criteria

We included studies based on the following eligibility criteria:

1. The article focuses on informal caregiving to elderly or older family members.
2. The article estimates the health impact of informal caregiving on the caregiver.
3. The article is aimed at finding a causal relation between informal caregiving and caregiver health using any one of the following quasi-experimental methods: propensity score matching, simultaneous-equation models (instrumental variables), regression discontinuity designs, difference-in-difference models, or Heckman selection models.
4. The article is written in English.
5. The article is not a conference abstract, letter, note, or editorial.

Our specific focus on informal care to adults/elderly is in light of the fact that various definitions of informal caregiving exist. For example, many authors refer to looking after (healthy) children as providing informal care. Our definition of informal care solely includes providing care to a person in need, and is in this case limited to care to elderly or older family members.

To limit our search to studies making causal estimations, we searched for papers using econometric techniques that enable causal estimations in the absence of RCTs. We limited our search to five quasi-experimental methods, following the overview of Antonakis, Bendahan, Jacquart and Lalive (2014).

Search strategy and data sources

For all criteria, we defined keywords as well as Medical Subject Headings (MeSH) and Embase Subject Headings (Emtree terms). We searched the following databases covering social sciences as well as bio-medical literature: MEDLINE, Embase, Web of Science, and Scopus.⁴ An overview of the search strategy, which was set up with the

⁴ We did not search the CENTRAL database, which covers studies using RCTs, as our research question cannot be answered by studies using this research design.

help of an information specialist, can be found in Appendix 1. All search results were stored in RefWorks, our main platform for keeping track of the literature review. We did not register a systematic review protocol.

We furthermore used Google Scholar to identify any additional papers. This search engine could help in retrieving papers that (i) have not been published yet, or (ii) missed relevant search terms in their title and abstract. For this manual search, we used a search strategy similar to the search string used for the other databases. We hand-searched the first 150 Google Scholar hits. When articles were deemed eligible for review, they were added to the list of full-text review articles. All searches were carried out in August 2017.

Review procedure

Three reviewers screened the titles and abstracts of all articles based on predefined eligibility criteria. Before commencing the review, the criteria were discussed to guarantee shared understanding. The researchers screened the articles (two researchers per article) based on title and abstract. To avoid bias, authors and journal names were not visible during this screening stage. If the article adhered to all inclusion criteria, it was then selected for full-text review. In this second stage, all included articles were reviewed full-text by two researchers, based on the inclusion and exclusion restrictions. As the specificity of eligibility decisions differed per stage, eligibility criteria were again discussed before commencing the full-text review. For both stages, differences in screening results were discussed and resolved by dialogue, and if needed the third researcher would act as judge. An overview of the inclusion and exclusion restrictions per stage can be found in Appendix 2.

Data abstraction

Data were extracted from the included articles using a predefined extraction table. The following items were recorded from each article: the author(s) and year of publication; country/region of interest; care recipient; definition of informal care; sample characteristics of the caregivers; health outcome measure; estimation technique; and main findings of the study. As we do not aim to provide a meta-analysis of the results, the main study findings were recorded qualitatively based on presence and direction, not on effect size. The results were synthesized in a narrative review.

Quality assessment

To assess the methodological quality of the included studies, methodological information from the papers was extracted using a predefined extraction form designed to

fit the methodologies used in the included articles. This form summarized the most important methodological elements of the papers. We did not calculate quality scores for the studies, but instead explained the methodological differences between the studies in narrative terms. For the studies using matching approaches, we indicated the extensiveness of the matching approach based on the suggestions by Lechner (2009).

3.2 Results

Search results

Our searches yielded 1,257 articles in total. After eliminating duplicates, our search findings totaled 621 articles. The hand-search resulted in five additional articles. From the 626 articles, 575 were excluded for a variety of reasons. Often the studies did not focus on informal caregiving but on another type of care. Furthermore, various studies were excluded as they did not estimate the impact of caregiving, but reviewed the efficacy of a specific intervention to improve the health of caregivers. Eventually 51

Figure 1: Flowchart of screening phases

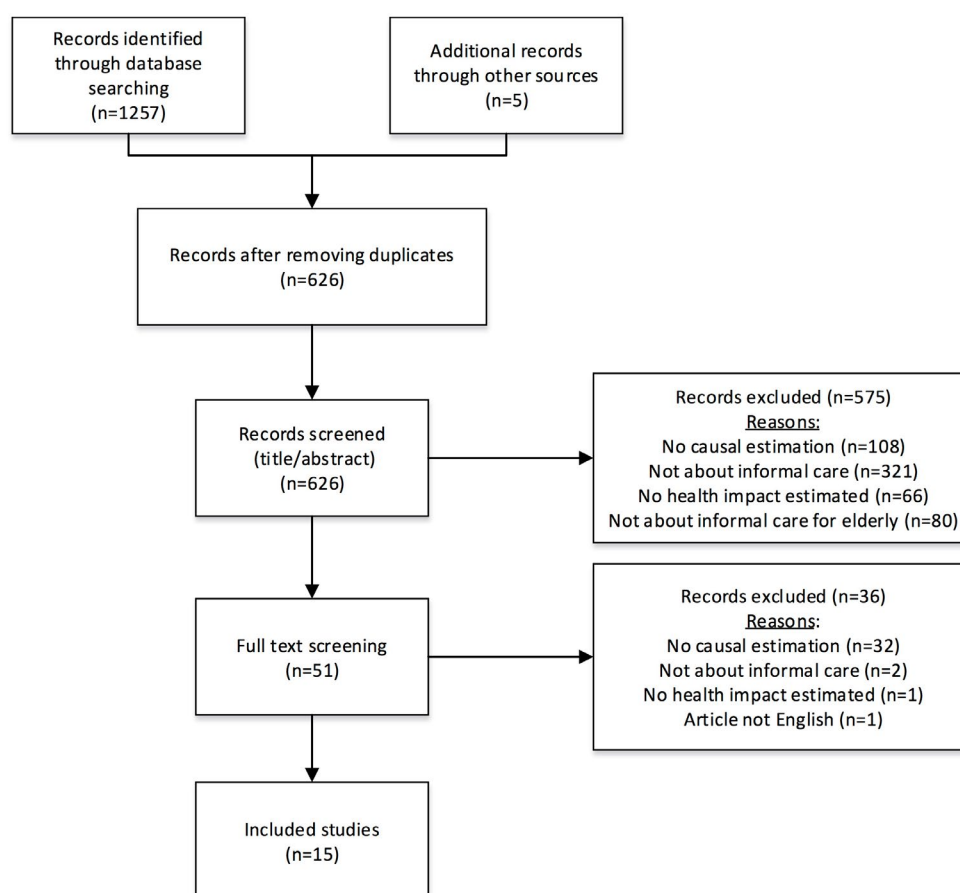


Table 2: Characteristics and results of the included studies. Abbreviations: PSM: propensity score matching; 2SLS: two-stage least square; D-in-D: difference-in-difference; IV: instrumental variable; MCS & PCS: Mental Component Scale and Physical Component Scale

Authors	Country /Region of interest	Care recipient	Definition of informal care	Sample characteristics of caregivers	Health measure	Methods	Lechner (2009) matching procedure used	Results (if applicable, subgroup for which effect is found)
Brenna and Di Novi (2016)	Europe	Parent	Providing assistance to a parent, step-parent, or parent-in-law at least on a weekly basis Distinction: Intensive informal care (excludes caregivers helping with domestic chores)	Women aged 50-75	Depression (Euro-D)	PSM	Yes	↑ Euro-D (Southern Europeans) <i>larger effect when providing intensive informal care</i>
Coe and Van Houtven (2009)	US	Parent	Spent at least 100 hours since previous wave/in the last 2 years on helping parents/mother/father with basic personal activities like dressing, eating, and bathing	Men and women aged 50 - 64, with only a mother alive	Mental health (CES-D 8); physical health (self-assessed health (SAH), diagnosed heart condition and blood pressure).	Simultaneous-equation models (2SLS, Arellano-Bond)	N/A	Continued caregiving: ↑ CES-D 8 (married males and females) ↑ Heart condition (single males) ↓ SAH (married females) ↑ SAH (married males) Effects after 2 years: ↑ CES-D 8 (married females) ↑ Heart condition (single males) Initial caregiving: ↑ CESD-8 (married females)
Di Novi, Jacobs and Migheli (2015)	Europe	Parent	Women providing care to elderly parents living in or outside the household in the past twelve months almost weekly or almost daily	Women aged 50-65 having a parent with bad or very bad health	Self-assessed health; quality of life (CASP-12)	PSM	Yes	↑ SAH (North and Continental European caregivers) ↓ CASP (Continental European caregivers) ↑ self-realized and pleasure in life (caregivers in Continental and Mediterranean Europe) ↓ able to control life and autonomous (caregivers from Continental Europe)
Do, Norton, Stearns and Van Houtven (2015)	South-Korea	Parent (in-law)	Any informal care provided to parents-in-law	Women with living parent (in-law) aged 45+	Pain affecting daily activities; fair or poor self-rated health; any outpatient care use; OOP spending for outpatient care; any prescription drug use; OOP spending prescription drug	Simultaneous-equation models (2SLS, IV-probit)	N/A	↑ Pain affecting daily activities, health self-rated as poor, OOP outpatient care (daughters & daughters-in-law) ↑ Any outpatient care use, any prescription drug use (daughters)
Fukahori, Sakai and Sato (2015)	Japan	Family member living in the same household	A family member in the same household who is in need of care	Males and their spouses aged 50-64	Employment rate, working hours, self-reported health, satisfaction with leisure time and life	PSM	No	↓ Likelihood of participating in work No impact on SAH or life satisfaction (results not presented in paper, mentioned in text)
Goren, Montgomery, Kahle-Wroblewski, Nakamura and Ueda (2016)	Japan	Adult relatives with Alzheimer's disease or dementia	Persons currently caring for an adult relative, with Alzheimer's disease or dementia	Men and women aged 18+	Comorbidities; depression (PHQ-9); work productivity (WPPI); SF-36 PCS and MCS; healthcare resource utilization	PSM	No	↑ PHQ-9, MDD ↓ SF-36 PCS, MCS and health utilities ↑ Depression, insomnia, anxiety and pain ↑ Absenteeism, overall work impairment and activity impairment ↑ Emergency room and traditional provider visits in the past six months
Heger (2016)	Europe	Parent	Any caregiving activities to parent (help with personal care and practical household help provided outside or inside the household). Distinction: daily, weekly and any frequency of caregiving.	Men and women aged 50-70	Depression (EURO-D); indicator whether someone suffers from ≥4 depressive symptoms.	Simultaneous-equation models	N/A	↑ Euro-D, 4+ depressive symptoms (females) <i>larger effect when more intensive informal care</i>
Hernandez and Bigatti (2010)	US	Individual with Alzheimer's disease or a physical disability	Caring for an individual with Alzheimer's disease or a physical disability within the past year	Hispanic Americans aged 65+	Depression (CES-D 20)	Direct matching	No	↑ CES-D 20

Authors	Country /Region of interest	Care recipient	Definition of informal care	Sample characteristics of caregivers	Health measure	Methods	Lechner (2009) matching procedure used	Results (if applicable, subgroup for which effect is found)
Hong, Han, Reistetter, and Simpson (2016)	South-Korea	Spouse with dementia	Persons living with a spouse with dementia	Men and women aged 19+	Physician-diagnosed stroke	PSM	No	↑ Odds of stroke
Kenny, King and Hall (2014)	Australia	Spouse, adult relative, elderly parent (in law)	Any time spent caring for a disabled spouse, adult relative or elderly parent/parent-in-law in a typical week. Distinction Care burden: Low (less than 5 h/w), moderate (5–19 h/w) and high (20 or more h/w)	16+ males and females	SF-36 PCS and MCS	PSM	Yes	After 2 years ↑ PCS (high care) <i>Effects for subgroups:</i> ↓ PCS (high caregiving females with a job) ↓ MCS (high caregiving females with a job) ↑ MCS (high caregiving males without job) After 4 years ↓ PCS (low and moderate care) ↓ MCS (moderate and high care)
Rosso et al. (2015)	US	Family member or friend	Currently helping ≥1 sick, limited, or frail family member, or friend on a regular basis? Distinction Low frequency ≤ 2 times per week; high frequency ≥3 times per week.	Women, 65–80 years old	Walking speed, grip strength, chair stands	PSM	No	After 6 years: ↑ grip strength (low-frequency caregivers)
Schmitz and Westphal (2015)	Germany	Unknown	Providing ≥2 hours per day on care and support for persons in need of care on a typical weekday	Women aged 18+	SF-12v2 MCS & PCS	PSM	Yes	Short term: ↓ MCS Longer term: No effects
Stroka (2014)	Germany	Anyone in need	Self-reported informal caregiving to sickness fund to receive allowance Distinction: Level of care needed	Males and females aged 35+	Drug intake	PSM + D-in-D	Yes	↑ Intake of antidepressants, tranquilizers, analgesics and gastrointestinal agents <i>Larger effect when more intensive care</i>
Trivedi et al. (2014)	US	Family member or friend	Any care provision in the past month to a friend or family member who has a health problem, long-term illness, or disability.	Non-institutionalized U.S. civilian population aged ≥18 years	Self-assessed mental health; general health; perceived social and emotional support; sleep hygiene	PSM	No	↑ Report >15 days of poor mental health & inadequate emotional support; ↓ Report fair or poor health (females) ↑ Report fair or poor health (males) ↓ Receive recommended amount of sleep ↑ Fall asleep unintentionally during the day
De Zwart et al. (2017)	Europe	Partner	Daily or almost daily caregiving activities (help with personal care) to partner for ≥3 months in the past 12 months.	Males and females aged 50+	Prescription drugs usage; the number of doctor visits in the past 12 months; EURO-D depression scale; self-perceived health	PSM	Yes	Short term: ↑ Euro-D, ↓ self-reported health; ↑ prescription drug use(females), ↑ doctor visits (females) Longer-term: No effect

articles were selected for full-text review. From these 51 articles, 36 were excluded in the full-text review round. The most prominent reason for exclusion at this stage was the methodology used, i.e. the aim of the study to identify a causal effect. Eventually, 15 articles were included in this systematic literature review. Figure 1 depicts the flowchart of screening phases.

All articles were published recently, the oldest dating from 2009, the latest accepted but waiting for publication at the time of the search. The articles were published in a variety of journals, mostly relating to health economics or gerontology. The articles cover various countries of interest, using European data (n=6); Asian data (n=4); US data (n=4), or Australian data (n=1). An extensive overview of all articles is given in Table 1.

Methodological quality of included studies

The fifteen included studies differ in their methodology and in the quality of the methods chosen. The table in Appendix 3 presents an extensive overview of the methods per study. We will discuss the most important elements regarding methodological quality in this section.

Three of the fifteen studies use simultaneous-equation models to overcome the endogeneity of caregiving. The instrumental variables used in these studies are roughly similar, including indicators of either the health of the parent (Do et al., 2015) or widowhood of the parent (Heger, 2016; Coe & Van Houtven 2009). The F-statistics showing the strength of the instruments used are included in the table in Appendix 3. They show to be of sufficient strength for all but one subgroup analysis according to Staiger and Stock's (1997) rule of thumb.

Most articles (n=12) use a matching design in order to compare caregivers and non-caregivers. As mentioned in our inclusion/exclusion criteria, we only included studies that matched respondents on health of the caregiver in order to avoid self-selection bias. However, the quality of the matching strategy differs per study and is dependent on the likelihood that the assumptions underlying the matching approach hold (see Rosenbaum & Rubin (1983) for an overview of these assumptions). We assess the strength of the matching strategies of the studies by applying the approach of Lechner (2009). This approach is aimed at improving the likelihood that the assumptions hold: his approach suggests matching individuals on pre-treatment covariates instead of current covariates and stratifying the sample according to the care provision in the previous year. The latter suggestion means that individuals who recently started caregiving (and did not do so last year) are only compared to individuals who did not provide care last year either. Doing so, potential influence of the treatment status on the covariates is avoided and pre-treatment differences in health are controlled for. Six of the twelve matching studies follow this approach and match on pre-treatment covariates and treatment status. We view the results of these studies as most reliable; these studies are marked as such in Table 1.

Lastly, we evaluated whether the included studies accounted for the so-called family effect. This effect refers to the impact of *caring about* an ill family member instead of the impact of *caring for* a family member (Amirkhanyan & Wolf, 2006; Bobinac, van Exel, Rutten & Brouwer, 2010). Do et al. (2015) and Heger (2016) specifically accounted for this family effect. Do et al. (2015) aimed to avoid picking up the family effect by focusing on (i) physical health effects and (ii) females who provide care to their parents-in-law. Heger (2016) aimed to disentangle the family effect from the caregiving effect by including separate variables to estimate the family effect and

the caregiving effect in the model. None of the other studies accounted for this effect, thereby potentially overestimating the effect of caregiving on health since the impact of caring for and the impact of caring about were not disentangled.

Comparability of studies

The different methodologies employed in the studies make it difficult to compare the effect sizes found. With a matching design, caregivers were matched to similar individuals who do not provide care. These studies hence estimated the health impact of informal care for the current informal caregivers. This effect is referred to as the Average Treatment Effect on Treated (ATET). When using instrumental variables in simultaneous-equation models, the Local Average Treatment Effect (LATE) is estimated. This represents the health impact of caregiving for those who started caregiving in response to the instrument, i.e. illness or loss of a parent. There are three potential methodological reasons for any observed differences in effect size between these two methods. First, effect sizes could differ as the ATET measures the impact of any form of caregiving while the LATE measures the impact of caregiving in response to severe illness or decrease. Second, the instrumental variables used might be weak, thereby leading to bias in the effect size. Third, there might not be accounted for the family effect, leading to different estimates.

The various definitions of informal caregiving and the variety of outcome measures further complicate a solid comparison of the findings of these studies. The definition of informal caregiving differs per study from providing care to a parent (n=5) or spouse (n=1), caring for anyone / a family member or friend (n=5), and informal care for someone with a specific illness (e.g. dementia) (n=2). Lastly, two studies proxy for informal caregiving by defining caregivers as persons living together with a family member or spouse in need. The studies also differ in their specification of caregiving, for example by restricting the sample to respondents who provide more than two hours of informal care per day.

In addition, various health measures were used to estimate the impact on health. Studies focus on the mental health impact (n=3), the physical health impact (n=4), or both (n=8). These health states are measured via either validated health measures, drug prescription data, or information on health care usage.

Synthesis of results

In spite of the differences in methodology and data, we can derive some important insights from the studies because they provide a fairly coherent picture. All but one of the fifteen studies found a short-term negative effect of informal care on health

for subgroups of caregivers. Only the study by Fukahori et al. (2015) did not find any impact of informal care on health. A reason for this could be the very rough proxy of informal care used in this study: household members were assumed to provide informal care when someone in the household needs care.

While all but one of the studies found a negative effect, the magnitude of the estimated effects differed substantially. For instance, the negative impact of informal care on *mental* health differed strongly per subgroup of caregivers. Nevertheless, most studies found negative health effects for female, married, or working caregivers. Estimates of the *physical* health impact of informal care were less stable and even differed in sign. While most studies found negative physical health effects, some studies found positive effects of informal caregiving on physical health. How physical health is measured appears to be crucial: when measured by self-assessed health, the short-run impact of caregiving is positive, whereas negative health effects are found when outcomes are measured by intake of drugs and reported pain. Di Novi et al. (2015) claimed that the positive impact of informal care on self-assessed health could be the result of a bias related to reference points. They argued that spending time with a person who is in poor health could lead to an increase in self-assessed health because people may take the poor health of the care recipient as reference point, even though the objective health level of the caregiver could have decreased.

A clear conclusion regarding the longer-term effects of informal caregiving cannot yet be drawn. As all studies used survey data, many were unable to estimate longer-term caregiving effects. Only five studies estimated effects over a longer time period. Both Schmitz and Westphal (2015) and De Zwart et al. (2017) did not find any longer-term effects of informal caregiving on health. Schmitz and Westphal concluded that there might not be large scarring effects of care provision; De Zwart and colleagues mentioned that selective attrition may have biased their results. The other three studies estimating longer-term effects found mixed results, showing both positive and negative effects of informal care. Kenny et al. (2014) found negative health effects two years after the start of caregiving for working female caregivers and positive effects for non-working caregiving males. Rosso et al. (2015) grouped all persons who provide informal care at baseline and found that after six years low-frequency caregivers have greater grip strength (representing physical health) than non-caregivers. The study by Coe and Van Houtven (2009) is the only one that compared persons who stopped providing care to persons who continued caregiving for two more years. They found negative mental health effects for females and negative physical health effects for males who continue caregiving.

4. Conclusion

Due to population ageing, most OECD countries have to deal with a growing demand for LTC. As often both formal and informal care can meet this demand, the key is to find the right balance between the two types of care. This paper aimed to provide insight into this trade-off by summarizing both theoretical and empirical literature regarding the costs and benefits of formal and informal LTC.

Our review provides two important insights. First, economic theory makes clear that not everyone is equally inclined to provide informal care. Both individual characteristics and the institutional context can shape a person's caregiving decision. Particularly persons with a lower income or who are unemployed are more likely to provide informal care and may thus experience the negative consequences of caregiving.

Second, our literature review shows that there is ample evidence of a negative impact of caregiving on the health of the provider. This caregiving burden can manifest itself both in mental and physical health effects. Important to note is that these effects differ strongly per subgroup of caregivers. Especially female, and married caregivers, and those providing intensive care appear to incur negative health effects from caregiving. This could be the result of having other responsibilities on top of caregiving duties, or, especially for women, because of a pressure that is felt to provide care. Such pressure may make it difficult to quit caregiving tasks when they become too burdensome (Pinguart & Sörensen, 2003).

As individuals may not be able to fully insure themselves against the consequences of caregiving, there is a need for government intervention to take away the necessity to provide care or to compensate the caregiver. Public provision of LTC or private insurance subsidies could solve this problem, but they may drive up costs by crowding out too much of the informal care supply. The extent to which crowding out is a problem depends on the strength of the prevailing social norms and altruistic preferences in society.

While this study does not (and did not intend to) offer a conclusive answer regarding the optimal mix of formal and informal care, the paper does highlight the complex trade-off that policymakers face. Formal and informal care each have their own costs and benefits. Subsidizing formal care can be costly but might relieve individuals from the caregiver burden, while stimulating informal care might have the opposite effect. Policies affecting either of the two types of care should therefore always consider their impact on the other form of LTC.

To further improve our understanding of the trade-off between the two types of LTC, we propose the following additional research. First, further research is needed about the different impacts of informal care on various subgroups of caregivers, as current studies do not provide conclusive insight into these differences. Knowing which groups are most strongly affected by informal care and understanding the drivers behind these effects may help policymakers decide how to reduce the negative effects of informal care and to facilitate a better targeting of support for informal caregivers. Second, research is needed into the long-term effects of providing informal care, given that most empirical studies have only measured short-term effects. Third, more research is needed to disentangle the family and the caregiving effect, since the caregiving effect might be overstated in most empirical studies as the family effect was not accounted for. Fourth, it would be worthwhile to gain enhanced insight into the impact of the various types of caregiving and their intensity. Next, given the potentially important role of the institutional context on the caregiving decision, more research on the health effects of informal care in the Dutch LTC system is imperative, since the number of empirical studies of this specific context is very limited.

Finally, this overview of current literature also raises important questions about the trade-off between formal and informal care in a larger context. Societal trends such as increasing female labor force participation and delayed retirement ages could affect the caregiving decision as well. Due to longer and increasing labor force participation, individuals may become less inclined to provide informal care, thus necessitating more formal care. However, when the provision of informal care mainly stems from a feeling of obligation (because of social norms or altruistic preferences), individuals would continue their caregiving duties, thereby facing a double burden of work and informal care. It would be interesting to explore these trends in future research.

Relevance for the Netherlands

Insights from this paper are relevant for the Dutch context. Dutch public long-term care expenditures are among the highest in the OECD and are expected to grow substantially in the coming decades (OECD, 2017; Eggink, Ras & Woittiez, 2017). Aside from the increase in long-term care expenditures, we also observe a growing number of Dutch informal caregivers. Between 2012 and 2016 the number of caregivers in the Netherlands grew by 20%, and currently more than 3 million adults are estimated to provide informal care (Gezondheidsmonitor, 2012, 2016). This surge in the supply of informal care could be driven by population ageing but may also be the result of the

policy changes related to the Social Support Act, which aim to stimulate reliance on social networks instead of governmental support (WMO, 2015).

An important empirical question is whether the burden of caregiving is equally shared among the Dutch population or whether it is primarily carried by specific subgroups with lower income and labor productivity, as predicted by economic theory. Data from the Health Monitors of 2012 and 2016, weighted to represent the entire Dutch population, show that some groups indeed provide care more often than others (see Table 1 in textbox 2). In 2016, almost 19% of people with a full-time job (more than 32 working hours a week) provide care compared to just over 26% of employees who work no more than 12 hours a week. Elderly persons also more often provide care than full-time employees, as about one fourth of retirees provide informal care. Although we see an increase in the propensity to provide care among nearly all identified subgroups, especially the participation of elderly rose sharply between 2012 and 2016. In contrast to theory, individuals in higher income groups provide care more often than individuals in lower income quintiles. Various variables may have confounded this result; richer individuals, for example, are often older and hence more likely to care for a spouse or parent. In terms of care intensity, lower income households do provide more hours of informal care.

The differences in the propensity to provide care between the various subgroups highlight the importance of considering the downsides of informal caregiving. After all, policies to stimulate informal care might only reach that part of the population that is already inclined to provide care. As a result, the costs of care affect only a specific part of the population.

In light of the growing number of caregivers, an important question is how to minimize the caregiving burden. Under the Social Support Act (2015), Dutch municipalities are obliged to provide support to informal caregivers. Examples of such interventions for caregivers are respite care and support groups. Respite care offers caregivers a short break by temporarily providing formal care to the person in need. Support groups offer advice and enable the sharing of experiences with other caregivers. However, many municipalities find it difficult to target informal caregivers who need this support (VNG, 2016). As shown from our literature review, not all caregivers are similarly affected by their tasks, and hence not all require this type of support. Female and married caregivers, and those providing intensive care turn out to experience larger negative consequences of informal caregiving. Policymakers might therefore especially target interventions to those individuals who need these most.

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Appendices

Appendix 1 – Embase search strategy

Facets	Search terms
Informal caregiving	((('caregiver'/de OR 'caregiver burden'/de OR 'caregiver support'/de) AND ('family'/de OR 'nuclear family'/exp)) OR (caregiv* OR care-giv* OR ((carer OR carer* OR caring) NEAR/6 (spous* OR husband* OR wife OR wives OR daughter* OR son OR sons OR informal* OR family OR relative OR relatives))):ab,ti)
AND Health impact	('health impact assessment'/exp OR 'psychological aspect'/de OR 'depression'/de OR 'mental stress'/de OR 'psychological distress assessment'/exp OR (((mental OR psychological* OR physical OR health) NEAR/6 (impact* OR effect OR affect* OR implication* OR status* OR aspect* OR profile* OR outcome*)) OR depressi* OR ((stress OR distress OR strain) NEAR/3 (carer OR caregiver*))):ab,ti)
AND Elderly or older family member	('aged'/exp OR 'geriatrics'/exp OR (aging OR ageing OR elderl* OR ((aged OR older) NEAR/3 (population OR relatives OR person*)) OR geriatric* OR geronto* OR spous* OR parent*):ab,ti)
AND Study design	(instrumental variable analysis/de OR 'regression discontinuity design'/exp OR ('propensity score' OR match* OR 'simultaneous equation' OR 'simultaneous equations' OR ((instrument*) NEAR/3 (variable)) OR Difference-in-differences OR 'Difference in differences' OR D-in-D OR ((Regression) NEAR/3 (discontinuity OR kink OR fuzzy OR sharp OR DD)) OR 'selection model' OR 'Heckman model'):ab,ti)
NOT Document type	([Conference Abstract]/lim OR [Letter]/lim OR [Note]/lim OR [Editorial]/lim)
AND Language	[english]/lim

Appendix 2 – Inclusion and exclusion criteria – Phase 1 (title/abstract screening) and Phase 2 (full-text screening)

PIOS			
Population	Focus informal care	Does the article focus on informal caregiving?	Yes – Include No – Exclude
Independent variable	Focus informal care for adult/elderly	Is this article about informal caregiving to an adult/elderly person (as compared to providing informal care by or to a child)?	Yes – Include No – Exclude
Outcome	Health impact	Does the article estimate the health impact of informal caregiving?	Yes – Include No – Exclude
Study design	Study design	Does the article use any of the defined methodologies in order to estimate a causal effect?	Yes – Include No – Exclude
<p><i>Phase 1: In case of matching – exclude when the article does not match on health of the caregiver (include in case matching procedure is unclear based on title/abstract)</i></p> <p><i>Phase 2: In case of matching – exclude when the article does not match on health of the caregiver</i></p>			

Appendix 3 – Methodological details of included studies

Authors	Data source	Sample representativeness	Data type	Sample size	Study design	Matching or IV strategy	Methodological quality	Family effect
Brenna and Di Novi (2016)	SHARE, 2004–2007 (2 waves)	Representative for the non-institutionalized population aged 50 and older	Longitudinal	Matched treated/Control 1,138/3,292	PSM	Matching on: demographics; family composition; socio-economic variables; information on parents receiving care; self-reported probability of receiving an inheritance; mental health status and caregiver status at the first wave.	Matching quality: matched on caregiver status and mental health in first wave	Not specifically considered
Coe and Van Houtven (2009)	HRS, 1992–2004 (7 waves)	Nationally representative for community-based population	Longitudinal	Sample continued caregiving=2,557 Sample initial caregiving=8,007	Simultaneous-equation models (2SLS, Arellano-Bond)	<u>IV continued caregiving:</u> Death of mother <u>IV initial caregiving:</u> Number of boys/girls in the household	Strength of instrument: F-statistics: 16–837 (continued caregiving) 6–18 (initial caregiving)	Not specifically considered
Di Novi et al. (2015)	SHARE, 2004 & 2006/2007	Representative for the non-institutionalized population aged 50 and older	Longitudinal	Matched treatment/control 535/1,825	PSM	Matching on: socio-economic variables; employment; family composition; occupation and income; previous SAH, CASP and caregiving status	Matching quality: Matched on caregiving status, SAH and CASP in first wave	Not specifically considered
Do et al. (2015)	Korean LSA, 2006–2010 (3 waves)	Nationally representative study of non-institutionalized adults aged 45 years or older	Longitudinal	n=2,528 (daughters-in-law) n=4,108 (daughters)	Simultaneous-equation models (2SLS, IV-probit)	IV: ADL limitations of the mother (–in-law) and of the father(–in-law)	Strength of instrument: F-statistics: 86 (daughter-in-law) and 37 (daughter)	Aim to avoid family effect by focusing on physical health and care for parents-in-law
Fukahori et al. (2015)	Japanese panel survey on middle-aged persons, 1997–2005	Randomly selected from the national population	Longitudinal	Matched treated/control 155/155 (males) 188/188 (spouses)	PSM	Matching on: employment, SAH, retirement, age, education and wage	Matching quality: Not matched on pretreatment status.	Not specifically considered
Goren et al. (2016)	Japan National Health and Wellness Surveys, 2012–2013	Stratified by sex and age to ensure representativeness of adult population	Cross-sectional	Matched treatment/control 1297/1297	PSM	Matching on: sex, age, BMI, exercise, alcohol, smoking, marital status, CCI (Charlson comorbidity index), insured status, education, employment, income, and children in household	Matching quality: Not matched on pretreatment status.	Not specifically considered
Heger (2016)	SHARE, 2004–2013 (4 waves)	Representative for the non-institutionalized population aged 50 and older	Longitudinal	n=3,669 (female) n= 2,752 (male)	Simultaneous-equation models	IV: Indicator of whether one parent is alive	Strength of instrument: F-statistics: 18–47	Estimate family effect by adding health of parent as variable to model
Hernandez and Bigatti (2010)	HEPESE, 2000/2001	Representativeness not discussed in article	Longitudinal (one wave used)	Matched treatment/control 57/57	Direct matching	Matched on: age, gender, socio-economic status, self-reported health, and level of acculturation	Matching quality: Not matched on pretreatment status.	Not specifically considered
Hong et al., (2016)	Korea Community Health Survey 2012–2013	Representative of the entire community-dwelling adult population in South-Korea	Cross-sectional	Matched treatment/control 3,868/3,868	PSM	Matched on: age, sex, education, household income, insurance type, current smoker, current drinker, and stress level.	Matching quality: Not matched on pretreatment status.	Not specifically considered
Kenny et al. (2014)	HILDA, 2001–2008	Representative sample of private Australian households	Longitudinal	Matched treatment/control 424 / 424	PSM	Matched on pre-treatment: age, sex, marriage/partner, children, work hours, income, education, country of birth, chronic health condition limiting work, partner with a chronic health condition, another household member with a chronic health condition, having at least one living parent and baseline year	Matching quality: Matched on baseline characteristics (pre-treatment)	Not specifically considered

Authors	Data source	Sample representativeness	Data type	Sample size	Study design	Matching or IV strategy	Methodological quality	Family effect
Rosso et al. (2015)	Woman's Health Initiative Clinical Trial (1993-1998)	Representativeness of sample not mentioned. Participants were recruited at clinical centers across the US from 1993 to 1998 to participate in clinical trials	Longitudinal	Matched treatment/control 2,138/3,511	PSM	Matching on: socio-demographic variables & health (smoking, chronic illnesses, obesity status)	Matching quality: Matching on baseline characteristics (not pre-treatment)	Not specifically considered
Schmitz and Westphal (2015)	GSOEP, 2002-2010	Representative longitudinal survey of households and persons living in Germany	Longitudinal	Matched treatment/control 1,235/29,942	PSM	Matched on: age of mother/father; mother/father alive; (age) partner; number of sisters; personality traits; socio-economic variables; health status	Matching quality: Matching on health before treatment Sample stratified by care provision at t=-1	Not specifically considered
Stroka (2014)	Techniker Krankenkasse (2007-2009)	Administrative data from largest statutory sickness fund in Germany	Longitudinal	Matched treatment/control 5,696/3,125,140 (males) 7,495/2,085,946 (females)	PSM + D-in-D	Matched on: socio-economic variables; employment; education; work position; health status	Matching quality: Matched pre-treatment, at baseline only non-carers	Not specifically considered
Trivedi et al. (2014)	BRFSS (2009/2010)	Nationally representative survey in the United States	Cross-sectional	Matched treatment/control 110,514/110,514	PSM	Matched on: socio-economic variables; household situation; employment, income, veteran status, immunizations within the previous year, exercise, tobacco use, self-identified physical disability, obesity status; healthcare access; and survey characteristics	Matching quality: Not matched on pretreatment status.	Not specifically considered
De Zwart et al. (2017)	SHARE, 2004, 2006, 2010, 2013	Representative for the non-institutionalized population aged 50 and older	Longitudinal	Matched treatment/control 404/10,293	PSM	Matched on: socio-economic variables; household situation; wealth; health status; health and age of spouse	Matching quality: Matched on pre-treatment covariates + sample stratified by care provision at t=-1	Not specifically considered.

Abbreviations: SHARE: Survey of Health, Ageing and Retirement Europe; HRS: Health & Retirement Study; HEPESE: Hispanic Established Populations for the Epidemiologic Study of the Elderly; HILDA: Household, Income & Labour Dynamics in Australia Survey; GSOEP: German Socio-Economic Panel; BRFSS: Behavioral Risk Factor Surveillance System; PSM: propensity score matching, 2SLS: two-stage least square; D-in-D: difference-in-difference, IV: instrumental variable

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