



RESEARCH

Is the Availability of Informal Care Associated with a Lower Uptake in Formal Home Care? An Application to Personal Care in the Netherlands

Daisy Duell*, Marielle Non†, Anne Marieke Braam†, Lara Leloup† and France Portrait*

Context: Long-term care (LTC) costs within member countries of the Organisation for Economic Co-operation and Development (OECD) are rising steeply, thereby presenting a challenge to the financial sustainability of most LTC systems. A seemingly attractive policy measure is to decrease the use of (expensive) publicly financed LTC and to increase the provision of informal care.

Objectives: This paper assesses how 1) the use of publicly financed LTC and 2) the uptake of entitled LTC care are related to the availability of informal care. Our study only considers personal care as it might be more easily replaced by informal care than other more complex types of care. Personal care includes tasks like bathing, toileting, dressing, and helping with eating.

Methods: We have access to unique Dutch nationwide data from 2013, which contain information on care entitlement, care use, potential informal caregivers, and clients' characteristics. Craggit regression analyses were used to analyse the data.

Findings: Only 58% of the maximal amount of entitled hours for formal personal care was used. A lower uptake is observed when children moved out. Also, individuals with a healthy partner use about 19% less formal personal care than the average of 11.5 hours per month. Moreover, individuals with an unhealthy partner use about 7% more formal care.

Limitations: We had access to data on availability of informal care and not on the actual informal care provided.

Implications: Older individuals use less publicly financed personal care than expected based on their needs and the relatively low uptake of entitled care can partially be explained through informal care.

Keywords: informal care; home care; personal care; uptake of entitled care; long-term care

1. Introduction

The populations of most Western countries are ageing. This has a substantial impact on (health) care needs and consequently on the use of healthcare and long-term care (LTC) (Spillman and Lubitz, 2000; Wu *et al.*, 2014). LTC is defined by Norton (2000) as “care for chronic illness or disability instead of treatment of an acute illness”. During the last decade, LTC costs within OECD countries have risen quite steeply, thereby potentially challenging the financial sustainability of most LTC systems in the future (OECD.Stat, 2018). As a result, governments have been forced to take action and to reform their LTC systems in order to maintain the accessibility and affordability of LTC for all older individuals. A seemingly attractive policy measure is to decrease the use of (expensive) publicly financed LTC and to increase the provision of informal care, as such care is often cheaper (Koehly *et al.*, 2015; Van den Berg, Brouwer and Koopmanschap, 2004).

Informal care is mostly unpaid care provided from within the social network of the individual. Informal care can be provided by different types of caregivers, for instance the partner, adult children, other family members, neighbours, friends, or others from the patient's social network (SCP, 2010). Geerlings, Pot, Twisk, and Deeg (2005) and Pinguart and Sörensen (2011), for instance, showed that partners are one of the most important sources of informal caregiving. In addition, Brandt, Haberkern, and Szydlik (2009) demonstrated that having adult children was related to the provision of informal care and practical help with household tasks. Brandt, Haberkern, and Szydlik (2009) also found differences in the level of help provided by children between Southern and Northern European countries, depending on the availability of professional care. Furthermore, literature reveals that daughters are more often caregivers than sons, and female partners are more likely to provide informal care than male partners (Spillman and Pezzin, 2000). Moreover, Spillman and Pezzin (2000) showed that proximity of potential and active informal caregivers is of considerable importance. Finally, a patient's gender, socioeconomic status, and/or

* Vrije Universiteit Amsterdam (VU), Talma Institute, NL

† CPB Netherlands Bureau for Economic Policy Analysis, NL

Corresponding author: Daisy Duell (d.duell@vu.nl)

ethnic background are likely to result in differences in the decision-making process on informal care by both care recipients and caregivers (Min and Barrio, 2009; Bradley *et al.*, 2004; Byrne, Goeree, Hiedemann, and Stern, 2009).

On average, in OECD countries, 13% of individuals aged 50 years or older provide informal care at least once a week (OECD, 2017). It is however unclear how many and to what extent people receive informal care, as this is likely to be underreported and varies greatly according to cultural norms (OECD, 2017). As just seen, informal care is mostly provided by unpaid caregivers and is therefore generally perceived as less expensive than formal care (Koehly *et al.*, 2015; Van den Berg, Brouwer, and Koopmanschap, 2004). However, providing informal care can also have associated (physical and mental) health and employment consequences for carers, which may lead to additional (delayed) costs (Bauer and Sousa-Poza, 2015). Also, if informal care is of inferior quality, it could result in additional health care costs for the care receiver. Moreover, using more (unpaid) informal care would only be successful in decreasing the costs of care if it reduces the reliance on paid care. The question is whether and to which extent formal care and informal care are substitutes for each other. As shown below, existing studies come to different conclusions.

What has been shown is that the amount of informal care received is related to the amount of formal LTC also received (i.e., care provided by formal, typically paid, caregivers) (Bonsang, 2009; Yoo *et al.*, 2004; Litwin and Attias-Donfut, 2009; McMaughan Moudouni *et al.*, 2012). On the one hand, previous studies have reported that informal care could be a substitute for formal home care¹ (replacing paid care with mostly unpaid care), especially in the provision of personal care for mildly disabled people (Bolin, Lindgren, and Lundborg, 2008; Bonsang, 2009; Bradley *et al.*, 2004; Plaisier, Broese Van Groenou, and Deeg, 2011; Van Houtven and Norton, 2004; Yoo *et al.*, 2004). Additionally, Van Houtven and Norton (2004) and Charles and Sevak (2005) found that informal care can also reduce the probability of nursing home admission. This may be explained by financial incentives to save money by not paying for formal care or by older individuals having a preference for receiving care from their family or friends rather than receiving it from professional caregivers (Van Houtven and Norton, 2004). Finally, there could also be regulations in place that ensure that no or less formal care is granted in case of availability of informal caregivers (Kromhout and De Klerk, 2018). This also may be effective the other way around, as regulations in place to increase the provision of formal care could lead to a decrease in informal care (Pickard, 2012).

On the other hand, there is evidence that informal care is less likely to be a substitute for formal care as disability levels increase (Walker, Pratt, and Eddy, 1995). This may be the case for instance when someone needs help 24 hours per day. Moreover, other studies have shown that the amount of informal care utilised does not decrease as the number of received formal LTC hours increases (Li, 2005; McMaughan Moudouni *et al.*, 2012; Penning, 2002), which indicates that informal caregivers keep providing care,

independently of the formal LTC hours offered. This shows that formal and informal care may also complement each other (Davey *et al.*, 2005; Geerts *et al.*, 2012; Litwin and Attias-Donfut, 2009). Litwin and Attias-Donfut (2009), for instance, showed that complementarity is very common, especially in case of a great need for care. Moreover, Geerts *et al.* (2012) showed that in many countries both forms of care are complements rather than substitutes. In addition, in case of a complementary relationship, formal caregivers are generally more likely to take on the more medically demanding and physical care, whereas informal caregivers are more likely to take on the less demanding types of care (Brandt *et al.*, 2009).

Empirical evidence shows that individuals who have been granted formal care do not always use it (Arrighi, *et al.*, 2015; Bakx, Douven, and Schut, 2016; Guthmuller, Jusot, and Wittwer, 2014). For instance, in the Netherlands, which is the country with the highest expenditures on LTC per capita compared to other OECD countries, up to 12.5% of all individuals that were granted formal home care do not use any of it (**Table 1**; Bakx *et al.*, 2016). Moreover, of the individuals that were granted personal care, a relatively large group of the individuals receiving home care, only around 67% of the entitled care is used (calculated average, **Table 2**; Bakx *et al.*, 2016). An explanation may be that individuals who have been granted care might not be willing to use their entitlement right away but choose to wait for their most preferred formal care provider to become available (services may be available but not of a form the care recipient considers to be appropriate), or might only use it when other possibilities, such as self-management or the use of social networks or informal care, are exhausted (Litwin, 2004). Another likely explanation is that individuals who have unstable or difficult to predict needs for care are granted more care than required at the initial assessment in order to cover unforeseen increases in needs (Non *et al.*, 2015). Out-of-pocket payments could be another reason why individuals decide to postpone the use of formal care for as long as possible (Bakx, *et al.*, 2015). In this case informal care, which is (mostly) unpaid, could be used as a substitute for formal care to avoid out-of-pocket payments. Shortage of care facilities or care workers could also explain why individuals who have been granted formal care do not always use it.

Table 1: Category Entitled hours per week.

Category	Hours per week
1	0–1.9 hours
2	2–3.9 hours
3	4–6.9 hours
4	7–9.9 hours
5	10–12.9 hours
6	13–15.9 hours
7	16–19.9 hours
8	20–24.9 hours

Table 2: Descriptive statistics patient characteristics stratified by personal care use.

Characteristics*	Total study population (#) 180,457	Use PCB (within group %) 12,241	Use in kind (within group %) 130,841	No use (within group %) 37,375
INFORMAL CARE VARIABLES				
Partner				
No partner	122,472	48	72	59
Healthy partner	38,673	39	17	32
Unhealthy partner	19,312	13	11	9
Children				
No children	27,264	11	16	14
At least one son and no daughters	31,505	16	17	19
At least one daughter	121,688	73	67	67
Distance from children				
A child living at home	11,749	19	7	7
A child living in the same neighborhood	55,060	38	37	33
A child living within 0–2 km	46,384	25	31	31
A child living within 2–10 km	23,278	10	15	16
A child living within > 10 km	16,722	7	11	13
CASE-MIX VARIABLES				
Ethnicity				
Autochthonous	155,581	55	89	85
Moroccan and Turkish	5,017	23	1	3
Western	15,645	10	8	9
Antillean	2,745	7	1	2
Other non-Western immigrants	1,469	5	0	1
Gender				
Male	54,350	35	29	33
Female	126,107	65	71	67
Use of another form of LTC				
No	75,139	15	68	39
Yes	105,318	85	32	61
Age				
60–70 Years	20,645	34	8	15
70–80 Year	50,394	36	25	35
80–90 Years	86,442	24	52	43
90 Years or older	22,976	6	15	7
Dominant somatic health problem				
No	10,778	9	6	4
Yes	169,679	91	94	96
Income categories				
<€ 17,700 per year	33,937	22	22	16
€ 17,700–€ 20,500 per year	30,333	13	20	15
€ 20,500–€ 25,000 per year	31,401	15	20	18
€ 25,000–€ 34,000 per year	33,149	15	20	24
>€ 34,000 per year	34,580	35	18	26

* A one-way ANOVA test showed that all of the characteristics were significantly different across personal care use expressed in categories at a p-value < 0.001.

In our study we use the Netherlands as a case study, as it is a country with relatively high expenditures on LTC (OECD. Stat, 2018). In the Netherlands older individuals (65+) accounted for almost 13% of the population in 1990; the share of older individuals has been increasing ever since, and it is expected to have doubled by 2040 (CBS, 2012). To anticipate this increase it is becoming more and more important to strive towards a more cost-effective Dutch LTC system.

This paper contributes to the literature by assessing how the availability of various sources of informal care is related to the use of formal personal care by means of unique administrative data from the Netherlands. Our study only considers personal care; even though this type of care clearly requires knowledge about such as how to move and handle an older person with complex care needs, it can to some extent be more easily replaced by informal care than other more complex types of care (such as nursing care). Therefore, we believe personal care to be the most interesting type of home care to study in the context of burgeoning LTC expenditure. Moreover, in the Netherlands, personal care is the type of formal home care that is used most often and therefore is quite expensive (of all types of formal home care more than 50% is spent on personal care) (CBS, 2019). The nationwide data includes individual-level information on: 1) the granted amount of formal personal care, 2) the actual amount of formal personal care use, 3) the availability of potential informal caregivers, and 4) demographics including the household income. As the data includes the granted amount of formal personal care, we are able to correct for differences in the need for care between individuals. Moreover, in the Netherlands the out-of-pocket payments are income dependent; therefore, the household income allows us to roughly proxy for financial incentives.

This paper further contributes by assessing the difference between entitled formal care and formal care actually used (the uptake of entitled care) at the individual level. We relate this uptake to the presence of a spouse and to the presence of children, where we take into account the health situation of the spouse, the gender of the children, and the distance between the parent in need of care and the children. In this way, our analysis provides additional insights into the extent of possible substitution between formal and informal care. Unfortunately, we do not have information on the actual amount of care that the potential informal caregivers provided. Therefore, we are not able to measure substitution, in terms of hours of provided informal care substituting for formal care. However, the wealth of the data we have available uniquely allows us to study the difference between granted and used care and relate this difference to potential informal caregivers.

The following section provides a background to the Dutch LTC system, both formal and informal care. In Section 3, we discuss the data and methodology that we exploited to provide insight into informal care and its relation with 1) formal care use and 2) the uptake of entitled care. We first provide information on the data, followed by the study population, the dependent variables and the independent variables. Thereafter, we present our descriptive statistics, the main statistical analyses and sensitivity analyses.

Section 4 shows the results derived from these analyses. Finally, Section 5 discusses the results by comparing them to scientific literature, leading to our main conclusions.

2. Background: Long-Term Care in the Netherlands

Allocation system of formal LTC

Within the time frame of this research, the provision of LTC in the Netherlands was regulated by the Exceptional Medical Expenses Act (EMEA; in Dutch: *Algemene Wet Bijzondere Ziektekosten*). This act provided universal coverage² and included institutional LTC and most types of home care (e.g., personal care, nursing care, and social participation support) (Schenk *et al.*, 2014). The needs assessment for the care covered by the EMEA was carried out by highly qualified professional assessors from the Care Needs Assessment Centre (CNAC; in Dutch: *Centrum Indicatiestelling Zorg*). The CNAC granted the entitlements and defined the type and amount of LTC to which patients were entitled. We were granted access to this nationwide data, which allowed us to make use of the results of the CNAC assessments and some additional health characteristics. This assessment of needs and granting of entitlements was a centrally regulated process, where care was granted based on the most important dominant and secondary health problems, to enable fair access to LTC across the Netherlands.

Actual use of formal care

After the CNAC granted LTC, individuals could either choose to receive a personal care budget (PCB; in Dutch: *Persoonsgebonden Budget*), or to receive the care in kind. A PCB is an amount of money with which individuals entitled to LTC can buy care and hire care providers themselves. Therefore, patients with a PCB have more control over the way care is provided (Ministry of Health Welfare and Sports (Netherlands), 2007). The PCB can be spent either on formal LTC or on informal LTC. For those choosing care in kind, regional care offices are responsible for purchasing care by local providers, giving individuals actual access to the granted LTC (Non *et al.*, 2015).

Patients have to pay contributions out of their own income when using personal care in kind or by means of a PCB. In 2013, such personal contributions for care provided at home were relatively low and were calculated based on the income and age of the patient and his/her partner in 2011, as well as on 8% of a households' capital (CAK, 2013). In 2013, the out-of-pocket payments for formal home care equalled on average 350 euro per patient per year (CBS, 2019).³

Informal care

In the Netherlands, one in five adults provides informal care for a period longer than three months or for more than eight hours a week (SCP, 2013). Most of these caregivers are women and aged between 45 and 65 years old. (SCP, 2019). For 13% of all informal caregivers, the partner is the caregiver; 6% of all informal caregivers are parents; 42% of all informal caregivers are the children, in about 17% of all informal caregivers they are friends or neighbours and in 22% the informal caregiver is someone else (SCP, 2019).

In the needs assessment for the care covered by the EMEA, “customary care” was taken into account and referred to care that partners, parents, adult children and other household members were expected to provide. Regarding personal care, only care provided by partners and in short-term situations (up to three months) was considered to be customary care (CIZ, 2013; Grootegoed, Van Barneveld, and Duyvendak, 2015). In addition, informal care provided by people outside the household was generally not taken into account; however, if informal care was voluntarily available and the patient mentioned that he or she wanted to receive this care, it could be taken into account (CIZ, 2013). This paper considers three important sources for informal care, namely partners, children living at home and children who had moved out.

While reading this paper, it is important to keep in mind that both the decision regarding whether formal home care is granted and the amount of formal home care that is granted do not take into account all potential informal caregivers. For instance, the needs assessment process regarding personal care only considers partners as potential informal caregivers and children only in very specific cases. Therefore, we expected the difference between the care granted and used, that is, the non-usage of care, to be relatively large. In other words, if informal care partly substitutes formal home care, we would expect more care to be granted than needed, leading to less uptake of entitled care.

3. Method

Data

We have had access to non-public microdata from Statistics Netherlands (CBS) on the personal care of the entire Dutch population for the year 2013. This data is derived from five administrative databases. First, the CNAC provided data on personal care entitlements granted. Second, the Central Administrative Office (CAK) provided information on the use of care. This information was based on the personal contributions individuals need to pay when they actually use care. Third, information on PCB was derived from the Dutch Health Care Information Centre (*Vektis*). Fourth, information on income was derived from the Dutch Tax Department (in Dutch: *Belastingdienst*). Fifth, background characteristics, such as gender, marital status, household composition, and number of children were derived from the Dutch Municipal Personal Records Database (BRP, formerly the GBA). All data in this study is at the individual level and could be merged using a unique identification code given to every person in the data registers.

Study population

For this study, all somatic⁴ and psychogeriatric⁵ patients of 60 years and above who were entitled to receive personal care for the second four-week period of the year 2013 were identified. Each healthcare year consists of 13 periods and does not necessarily start on the first of January. The healthcare year 2013 started on 31st of December 2012, the second period started on January 28th and ended on February 24th. This period was selected because the supply and use of personal care in the last period and first period of a year may be affected by the holidays in December. Also, data on personal care use in a period in

the middle of the year could be distorted because of summer holidays. Individuals were excluded from the study population when, during the selected time frame, the number of entitled hours or type of home care changed because the difference between the care granted and used is likely to be influenced by this. Furthermore, other reasons for exclusion were events that could have affected the use of formal care, and in turn our results, such as moving to another municipality or change in household size. Finally, all individuals who died during the observation period were excluded, because otherwise also in this case it might have affected our data on use and the difference between the care granted and used. This resulted in 180,457 individuals. Moreover, where a PCB was granted (in 7% of all cases), we did not have information on the amount of personal care actually used. These observations were therefore excluded from our main analyses. The total number of individuals in the study population without individuals who received a PCB was 168,216. Due to missing observations in two of our variables (“health care costs made within the year 2011” and “distance to the nearest hospital including an outpatient clinic”), 161,236 individuals were finally included in our main analyses.

Dependent variables

Variable characterising use of formal care: our first dependent variable measures the number of minutes of personal care actually used during the observation period.

Variable characterising the difference between entitled and used care: our second dependent variable measures the uptake of entitled care indicates whether individuals use less or more care than they are allowed to. The needs for personal care were expressed in different categories with different range widths of 2 to 4.9 hours per week (shown in **Table 1**). Data on the actual use of personal care was expressed in minutes per four-week period; to be able to calculate the uptake of entitled care, both sets of data were expressed in minutes of personal care per four weeks.

This dependent variable is a categorical ordered variable and is constructed as follows. If the number of minutes used is within the lower and upper boundaries of the personal care category a patient is entitled to, the dependent variable is equal to 8 (a score equal to 8 is therefore independent of the category/number of hours granted). If the number of minutes used is below the lower boundary of the personal care category a patient is entitled to, but above the lower boundary of the previous category, the dependent variable is 7. If this is 2 classes lower, then the dependent variable is 6, and so on. In case of non-usage the dependent variable is 0 and if the number of minutes used is more than the upper boundary of the personal care category a patient is entitled to, the dependent variable is 9.

Independent variables

Several variables to proxy the availability of informal care were included in the model. These variables included two partner dummies indicating having 1) a partner not entitled to LTC (we considered him/her as a healthy partner), 2) a partner entitled to LTC, and 3) no partner as the reference. Two dummies based on having children were

also included indicating having 1) at least one son and no daughters, 2) at least one daughter, and 3) no children as a reference. Finally, four dummies characterizing the distance from the nearest child were used 1) a child living in the same neighborhood, 2) a child living within 0–2 kilometres, 3) a child living within 2–10 kilometres, 4) a child living within > 10 kilometres, and a child living at home as a reference.

Additionally, the following variables were included to characterize potential differences in needs for LTC. Analyses were controlled for health status by including 1) a variable that showed whether the individual had a dominant somatic health problem (equal to 1), or not (in other words having a psychogeriatric problem, equal to 0), 2) a variable that showed whether the individual was granted other entitlements to LTC in the second period of 2013 (equal to 1), or not (equal to 0), and 3) a continuous variable that showed the public health care costs⁶ during the year 2011 (per 1000 euro). In addition, analyses were controlled for gender and age. Previous literature showed that demographic characteristics such as age (Bakx, Schut, and Van Doorslaer, 2013; De Meijer *et al.*, 2011; Koopmanschap *et al.*, 2010) and gender (Mudrazija, Thomeer, and Angel, 2015) are related to formal care utilisation (Babitsch, Gohl, and Von Lengerke, 2012). They were therefore included in the analyses. Age was divided into four categories: 1) 60–70 years of age (reference), 2) 70–80 years of age, 3) 80–90 years of age, and 4) 90 years of age or older. The variable gender was equal to 1 in the case of females and 0 in the case of males. Interaction terms between the age categories and gender were also included in the statistical models. In addition, income has also been reported as a factor related to formal care use (Goda, Golberstein, and Grabowski, 2011; Schomerus *et al.*, 2013). Therefore, income categories were included in the analyses as well: 1) less than € 17,700 per year (reference), 2) € 17,700–€ 20,499 per year, 3) € 20,500–€ 24,999 per year, 4) € 25,000–€ 34,000 per year, 5) > € 34,000 per year. Analyses were controlled for ethnicity using dummies: 1) Autochthonous (reference), 2) Western immigrant, 3) Moroccan and Turkish, 4) Antillean, and 5) other non-Western immigrants. This was done in order to account for cultural differences that might explain a difference in use of LTC. Finally, living near facilities such as a general practitioner, physiotherapist and pharmacy facilitates the participation of older individuals in daily life (Shinkle, 2010). It is therefore expected that persons living near facilities are less likely to rely on formal services. Therefore, we included a variable indicating the distance to the nearest hospital including an outpatient clinic (in m).

Descriptive statistics

In support of our main analyses, descriptive statistics were calculated for each dependent variable, informal care variable and case-mix variable. One-way ANOVA tests were used to test whether these variables were distributed differently across personal care use expressed in categories (no use, use in kind, and use by means of a PCB) and across the uptake of entitled care expressed in categories.

Main statistical analyses

A Craggit model was first used to obtain more insight into whether the availability of informal care was related to the amount of LTC use, conditional on using care in kind (Model 1). Second, we used a Craggit regression model to assess whether the availability of informal care was related to the uptake of entitled care expressed in categories conditional on using care in kind (Model 2). A Craggit analysis is a two-stage model, and thus can be used to accurately estimate the association between informal care variables and our outcome variable while taking into account the effect of the decision whether using care in kind. We have chosen to use this two-stage model instead of other models such as the Tobit model, as it is a more flexible model: it combines a Probit model in the first tier and a truncated normal model in the second tier and allows the outcomes to be determined by separate processes (Burke, 2009). In other words, the probability of using a certain amount of the entitled formal personal care, given that an individual used care in kind, does not have to be determined by the same underlying processes (i.e., the same parameters). By doing so, and by performing the post-estimation methodology of Burke (2009) while bootstrapping 100 times, we were able to calculate the average partial effects on the unconditional expected value of the informal care variables and corresponding standard errors. Statistical analyses were performed using Stata 12.1. When confidence intervals are reported, these regard 95% confidence intervals; in other words, the parameter was considered statistically significant when its associated p-value < 0.05.

Sensitivity analyses

Individuals with a PCB could use a combination of formal and (paid) informal care. As mentioned, we do not have information on the amount of care used and we had to exclude all individuals with a PCB from our main analyses. In order to assess to what extent the individuals with a PCB differ from the ones without, we estimated a probit model with as dependent variable a dummy variable taking the value 1 if an individual has a PCB and 0 otherwise.

In addition, in order to find out whether our main conclusions regarding the uptake of entitled care would change if our dependent variable was constructed slightly different, we estimated model 2 with a dependent variable that refers to the relative difference in percentages between the upper boundary of the category of entitled personal care hours and the actual used minutes in a four-week period for personal care. The dependent uptake variable included in the sensitivity analyses is a continuous variable and is equal to 0 in the case of non-usage, to 1 in the case of 1% usage, and to 2 in case of 2% usage, etc. This variable is therefore more sensitive to a very slight difference between the need and use, but in turn also picks up more random noise, compared to our main categorical variable.

Finally, we performed a robustness check to find out whether a time lag of one month between the needs assessment and actual use changes our overall conclusions. We did so in order to correct for the fact that actual use could have been delayed because of organisational issues and is therefore (in the previous analyses) wrongly

interpreted as non-use or less use of personal care than initially granted. We did so by excluding all personal care entitlements that were not granted before 1-1-2013.

4. Results

Descriptive statistics

Table 2 displays the total study population and the study populations stratified by the way the care was purchased. Most individuals opted for care in kind (72.5%) and the average amount used was 11.5 hours during the observation period (about one month). In addition, 7% of the individuals had a PCB and 21% did not use their entitlement to personal care during the observation period. Most had no partner (67.9%) and had children (85%). In addition, relatively more individuals who used care in kind had no partner, as compared to individuals who used no care and used a PCB. Overall, the biggest differences in characteristics between the groups can be seen between individuals with a PCB and individuals using care in kind. The proportion of women was highest in individuals using care in kind and lowest in PCB users (71.3 and 64.8% respectively). Also, 89.3% of the individuals using care in kind were of Dutch nationality, but in the group with a PCB substantially lower, namely 55.0%.

The descriptive statistics from **Table 2** also suggest that the majority of individuals who receive an entitlement for personal care do not have a partner and/or have at least one daughter. Most individuals receiving an entitlement for personal care do not have children that live at home and the further away the children live the more likely one is to use care in kind or to not use care at all. Also, the number of children do not seem to influence the choice of using care. In addition, having a healthy partner makes one less likely to use care and not

having a partner or having an unhealthy partner makes one more likely to use care in kind. In addition, the case-mix variables suggest that the older one gets the more likely you are to use care in kind. Also, while the number of individuals receiving an entitlement for care is about the same for each of the income categories, individuals with higher incomes seem less likely to use care.

The one-way ANOVA test show that all informal care variables and the case-mix variables are significantly different across the uptake of entitled care with regard to personal care use expressed in categories.

The difference between the amount of personal care granted and used was on average 42%, which indicates that only 58% of the maximal amount of entitled hours is used. This was calculated by dividing the total number of hours used by the total number of hours granted, including no use as 0 hours. **Figure 1** shows the distribution of the uptake of entitled care across personal care categories. **Figure 1** illustrates that most individuals have either no difference in the care needed and used, a difference of only 1 category, or did not have any use.

Personal care use

Table 3 shows the bootstrapped results from the Craggit analysis regarding the association between informal care and the amount of personal care use conditional on having used any personal care at all (Model 1). The results displayed in **Table 3** show that having at least one daughter significantly increases the amount of formal care used. When interpreting the variables having children and the distance from children together, one observes that having at least one daughter increases the amount of care used in kind when she lives at home. Hav-

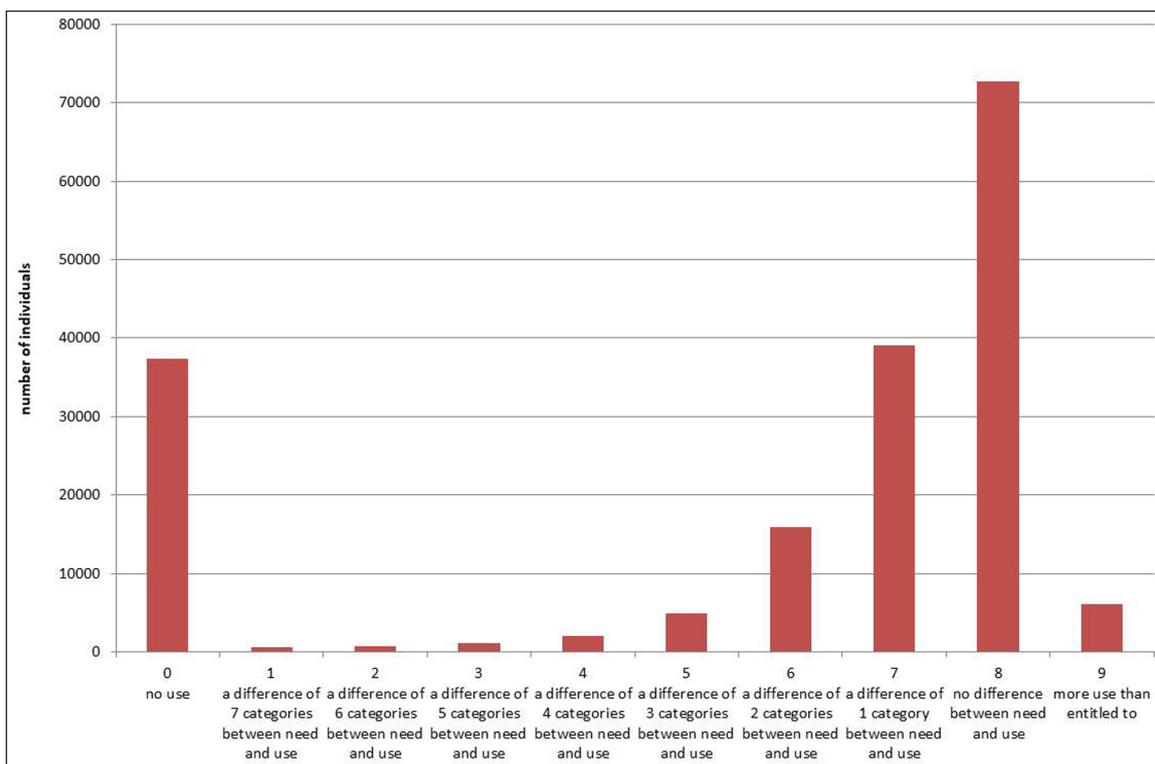


Figure 1: Distribution of the uptake of entitled care.⁷

Table 3: Bootstrapped post-estimation Craggit analysis on the association between informal care and the amount of use conditional on having used personal care.

Model 1	Personal care use 161,236 observations	
Variables	Coefficient	P-value
Partner		
<i>No partner (ref.)</i>		
Healthy partner	-133.128	0.000
Unhealthy partner	49.270	0.000
Children		
<i>No children (ref.)</i>		
At least one son and no daughters	10.620	0.359
At least one daughter	23.990	0.024
Distance from children		
<i>A child living at home (ref.)</i>		
A child living in the same neighborhood	-58.202	0.000
A child living within 0–2 km	-73.815	0.000
A child living within 2–10 km	-63.086	0.000
A child living within > 10 km	-59.293	0.000

ing at least one daughter decreases the amount of formal care used in kind when she lives on her own. In addition, the coefficients of the variable “distance from children” indicate that the most important factor in relation to the amount of care used is whether or not the children live at home: when children live in their own house (independently of how far they live), our subjects use on average about 60 hours of care less a month, than when children live at home. Finally, we see that having an unhealthy partner is significantly and positively associated with using formal care in kind. When interpreting these variables, we find that having a healthy partner, as compared to having no partner, is associated with a decrease in use of formal personal care of 133.13 minutes (1.9 hours). This decrease is 19% of the average number of minutes/hours used (697 minutes/11.5 hours). Also, when having an unhealthy partner, as compared to having no partner, we observe an increase in use of formal personal care of 49.27 minutes. This increase is 7% of the average number of minutes used.

Difference between amount of granted care and care actually used (uptake of entitled care)

In order to find out to what extent different informal care sources may be seen as a substitute for formal personal care, we assessed the association between the availability of informal care and the uptake of entitled. **Table 4** shows the bootstrapped results of the Craggit model (in which we control for those who did not use any entitled personal care in kind, Model 2). For clarification, a negative coefficient indicates that the greater availability of informal care is associated with a smaller uptake of entitled care (i.e., a larger difference between personal care

Table 4: Bootstrapped post-estimation Craggit analyses on the association between informal care and personal care use and the uptake of entitled care.

Model 2	Uptake of entitled care in categories 161,236 observations	
Variables	Coefficient	P-value
Partner		
<i>No partner (ref.)</i>		
Healthy partner	-0.552	0.000
Unhealthy partner	0.446	0.000
Children		
<i>No children (ref.)</i>		
At least one son and no daughters	0.178	0.000
At least one daughter	0.190	0.000
Distance from children		
<i>A child living at home (ref.)</i>		
A child living in the same neighborhood	-0.134	0.000
A child living within 0–2 km	-0.418	0.000
A child living within 2–10 km	-0.447	0.000
A child living within > 10 km	-0.540	0.000

need and use). All informal care variables are significantly associated with the uptake of entitled care. We observe a negative association with having a healthy partner and the uptake of entitled care and a positive association with having an unhealthy partner and the uptake of entitled care, as compared to having no partner at all. Thus, having a healthy partner is associated with an increase in the difference between personal care need and use, and having an unhealthy partner is associated with a decrease in the difference between personal care need and use, as compared to having no partner. The magnitude of the association can be computed for all types of individuals and also for each of the categories of the dependent variable (results not shown).

In addition, having children at home is positively associated with the uptake of entitled care and having children who have moved out is negatively associated with the uptake of entitled care, as compared to children living at home. Thus having children at home, as compared to having no children, is associated with a decrease in the difference between personal care need and use. Similarly, having children who have moved out, as compared to children living at home, is associated with an increase in the difference between personal care need and use.

Sensitivity analysis using personal care by means of a PCB

Table 5 shows the results from the Probit analyses on the probability of using a PCB. Most importantly, this table illustrates that individuals without a partner are less likely to have a PCB than those with a healthy partner (p-value = 0.000) and those with an unhealthy partner (though the coefficient is only significant at a 0.1 level). In addition,

Table 5: Results informal care in relation to a PCB.

Variables	Sensitivity analysis: Using a PCB 180,457 observations	
	Coefficient	P-value
Partner		
<i>No partner (ref.)</i>		
Healthy partner	0.190	0.000
Unhealthy partner	0.032	0.099
Children		
<i>No children (ref.)</i>		
At least one son and no daughters	0.259	0.000
At least one daughter	0.336	0.000
Distance from children		
<i>A child living at home (ref.)</i>		
A child living in the same neighborhood	-0.113	0.000
A child living in within 0–2 km	-0.201	0.000
A child living within 2–10 km	-0.231	0.000
A child living within > 10 km	-0.294	0.000
Gender		
<i>Male (ref.)</i>		
Female	0.009	0.695
Age		
<i>60–070 (ref.)</i>		
70–80	-0.469	0.000
80–90	-0.806	0.000
90 or older	-0.709	0.000
Gender* age		
Female * 70–80	0.047	0.128
Female * 80–90	0.174	0.000
Female * 90	0.168	0.001
Dominant somatic health problem		
<i>no (ref.)</i>		
Yes	-0.482	0.000
Ethnicity		
<i>Autochthonous (ref.)</i>		
Moroccan and Turkish	1.427	0.000
Antillean	1.068	0.000
Other non-Western immigrants	1.305	0.000
Western	0.303	0.000
Income categories		
<i>< € 17,700 per year (ref.)</i>		
€ 17,700–€ 20,500 per year	-0.066	0.001
€ 20,500–€ 25,000 per year	-0.147	0.000
€ 25,000–€ 34,000 per year	-0.192	0.000
> € 34,000 per year	0.105	0.000
Use of another form of LTC		
<i>No (ref.)</i>		
Yes	-0.953	0.000
Health care costs are made within the year 2011	0.002	0.000
Distance to the nearest hospital including an outpatient clinic	0.000	0.000
Constant	-0.515	0.000

Table 5 shows that individuals with children (irrespective of where they live) are more likely to have a PCB than others. Also, those in the highest income category are more likely to receive a PCB and those in the second-highest income category are less likely to receive a PCB compared to the individuals in the lowest income category. Finally, younger individuals and ethnic minorities are more likely to have a PCB than others.

Sensitivity analysis uptake of entitled care expressed in percentages

Table 6 shows the bootstrapped results regarding the association between the variables for informal care with the uptake of entitled care expressed in percentages. These analyses confirm our main results.

Robustness check time lag

We re-ran our main analyses after exclusion of the individuals who obtained their entitlements after 1-1-2013. Again, this did not change our main conclusions.

5. Discussion

With ever-increasing LTC costs, and governments overlooking possibilities to contain these costs, it has become increasingly important to assess whether informal care use partly substitutes for formal LTC. Therefore, the main aim of this paper was to analyse the extent that LTC use (namely personal care) and the difference between actual use and needs were related to availability of informal care.

First, a considerably large mean difference equal to 42% between granted personal care and actual use is observed,

Table 6: Bootstrapped post-estimation Craggit analyses on the association between informal care and personal care use and the uptake of entitled care.

Variables	Uptake of entitled care in percentages 161,236 observations	
	Coefficient	P-value
Partner		
<i>No partner (ref.)</i>		
Healthy partner	-7.400	0.000
Unhealthy partner	3.157	0.000
Children		
<i>No children (ref.)</i>		
At least one son and no daughters	1.322	0.001
At least one daughter	1.502	0.000
Distance from children		
<i>A child living at home (ref.)</i>		
A child living in the same neighborhood	-2.736	0.000
A child living within 0–2 km	-3.590	0.000
A child living within 2–10 km	-3.812	0.000
A child living within > 10 km	-4.628	0.000

which indicates that only 58% of the maximal amount of entitled hours is used. Also, when comparing the categories of personal care granted and actual use, non-usage of entitled care is observed in 60% of all observations. This large figure is in line with what we would expect based on earlier findings about non-usage in the Netherlands (Bakx *et al.*, 2016; Tenand, Bakx and Van Doorslaer, 2018). The difference between 58% (described in our paper) and 67% (Bakx *et al.*, 2016) may be explained by the different time frames under study and a difference in the duration of follow-up to see whether there is no use at all or the use of care is postponed.

Second, the results show that all informal care variables included in our analyses are associated with a) formal personal care use, and b) the uptake of entitled care. More specifically, our findings show that having a healthy partner is associated with a 19% decrease in use of formal personal care compared to having no partner. Such a decrease in formal home care use is also found in other literature, for instance in the paper of Yoo *et al.* (2004), which shows that the availability of a female spouse caregiver is associated with a maximum reduction of 30.6% annual formal home care expenditure per older male. Moreover, we find that having a healthy partner is the most important source of informal care. This is also in line with the studies of Balia and Brau (2014), Portrait, Lindeboom, and Deeg (2000), and Yoo *et al.* (2004). Having an unhealthy partner is associated with a decrease in the difference between personal care needs and use, as compared to having no partner at all. This is again in line with the previous studies of Bakx and De Meijer (2013) and Hiedemann, Sovinsky, and Stern (2018), who found that a disabled partner is often less able to provide informal care and is therefore positively associated with receiving more LTC. Another possible explanation might be that an unhealthy partner, who is already receiving LTC, might have more knowledge of the LTC system, the corresponding processes, and what it might offer them. Furthermore, even though our findings show that having children is associated with the use of formal personal care, our results also illustrate that having children is not only associated with a larger probability of the use of formal personal care, but also with a smaller difference between granted care and actual use. Even though it is possible that children are providing unpaid care at the same time as their parent receives formal care (a complementary relationship), this contradicts what we would expect based on the studies of SCP (2010), Tarricone and Tsouros (2008), and Triantafillou *et al.* (2010). However, when interpreting this effect combined with the effect we found for the distance from children, we observe that having children only leads to more use of formal personal care and a smaller difference between granted care and actual use in the case of children living at home. Therefore, a plausible explanation for this might be that this effect is observed for children who may be in need of help from their parents instead of the other way around. In other words, when children are living at home when they are grown, they might not be the ones that are taking care of their parents, but may be unhealthy and dependent on care or help themselves. Another explanation might be

that children may help their disabled or reluctant parents to gain access to formal care. It could also be that patients at first choose to delay applying for formal care as they may prefer informal care, but when this situation is no longer tenable, they then use a relatively large amount of formal care.

Third, less formal personal care is used as children move out, and this leads to an increase in the difference between personal care needs and use (the actual use of formal care is less than what is needed). The results imply that children living at home give less informal care to their parents, as compared to children who have moved out. Also, in this case a possible explanation could be that when children live at home, they still may need help from their parents and may therefore not be able to take as good of care of their parents as when children are independent and have moved out. In addition, these results imply that children who have moved out should also be taken into account in the process of assessing needs by the CNAC experts.

Fourth, the results from our analyses on care granted by means of a PCB indicate that when having a healthy partner, one is more likely to use a PCB. This may be explained by the fact that these healthy partners may be able better to arrange home care or deliver informal care themselves, both financed through a PCB. However, as we do not know the amount of a PCB that is spent on formal care as opposed to the amount spent on informal care, we cannot investigate how a PCB truly influences the substitution of formal care by informal care. In addition, due to the differences in availability of informal caregivers and in other characteristics between the group of individuals having a PCB and the other groups, the results from using care by means of a PCB may somewhat deviate from our main results. This indicates that exclusion of the individuals with PCBs from the main analyses would probably slightly bias the main results. However, as only 7% of individuals choose to use personal care by means of a PCB, we believe the impact of this would be limited. Overall, based on the results from our analyses on using a PCB, we are able to conclude that our main findings on using personal care in kind would not lead to very different conclusions even if we had more information on the personal care costs for people who received a PCB, as most of the results from the robustness check are in line with our main findings and the differences found can be explained.

As discussed before, we believe this paper to be an important contribution to the current literature by assessing 1) how the availability of various sources of informal care is related to the formal use of personal care, and 2) whether the availability of informal care can partly explain the difference between granted and actually used personal care. We were able to do so by using a unique nationwide dataset. This is the most important strength of this paper as this data includes information on: 1) the granted amount of formal personal care, 2) the actual amount of formal personal care used, and 3) potential caregivers. Moreover, the data enables us to comprehensively correct for differences in need at a patient level.

This study included somatic and psychogeriatric patients of 60 years and older who were entitled to personal care in the second four-week period of 2013. This was a large

sample size that was representative of the Dutch population as a whole. However, due to some limitations, the findings of the current study must be interpreted with some caution, because no data was available on the actual informal care provided. Therefore, it could be that the variables used to characterize informal care within this research do not cover all dimensions of the informal care actually used. Nevertheless, we do have information on the most important informal caregivers. It is assumed that these variables, such as having a partner and children, may be considered as valid proxies for the availability of informal care as they are important sources of informal care in many countries (Bolin, Lindgren, and Lundborg, 2008). Moreover, as only people who requested LTC and were entitled to LTC were included in the study, it is possible that people who receive sufficient informal care do not request formal LTC, although they would have been entitled to it if they did. However, data on LTC from the Longitudinal Aging Study Amsterdam (LASA, Huisman *et al.*, 2011) shows that latent demand for formal care is relatively small. Also, as explained in the introduction, informal care is taken to some extent into account in the needs assessment. Both aspects could have led to an underestimation of the true relationship between availability of informal care and use of formal care. Finally, in this study cross-sectional data was used. In future studies longitudinal data could be of interest, as there may be a time lag between the needs assessment and the actual use of care. In order to control for this effect, we performed a robustness check that showed that when excluding all entitlements that were not granted before 1 January 2013, the overall conclusions do not change.

To conclude, we can infer that older people use less formal personal care than expected based on their needs and that these needs are likely to be partially met through informal care provided by a partner or adult children. These insights may be especially valuable to countries exploring options to reform their LTC system in order to contain costs. One of the issues that emerges when wanting to implement the findings of this study, and in line with previous studies of, for instance, Twigg (1989) and Twigg and Atkin (1994), is that policy makers then have to consider how informal care provided by partners and adult children could be taken into account in a LTC system. The above-mentioned papers discuss different dynamic models and various conditions to consider in order to do that. Broese van Groenou and De Boer (2016) also underline the complexity of the informal caregiving phenomenon as many actors are involved and the caregiving environment is dependent on many different behavioural aspects but also on policy and societal developments. The authors suggest considering policy measures related to reimbursements, pension benefits, legal obligations, and career benefits in support of informal caregivers. Similarly, the study of Hoffmann and Rodrigues (2010) describes pros and cons of having cash-for-care-benefit measures to help informal caregivers by giving them a "care allowance". Also, they describe measures that are often overlooked aimed at offering (care) services to informal caregivers to support them. In sum, while we recommend policy makers to

consider whether informal care provided by partners and adult children should be taken into account in a LTC system, more research is needed on how this should be implemented. In this respect, changes in family structures, for example having fewer children and more divorces, should also be considered. In addition, the mismatch between actual use and entitled LTC may be of interest to policy makers as this may in fact be due to some inefficiency in the assessment of needs; otherwise the supply of LTC might fall short. Furthermore, the different preferences of patients could play a role. In this regard, gains may especially be made in assessing needs in older individuals with a healthy partner or having children who have moved out, since these individuals are more likely to use a smaller share of their entitlement.

Notes

- ¹ Care provided outside of a nursing home or care institution by formal caregivers who receive compensation for their services to treat individuals in need such as elderly, chronically ill, or people with a disability.
- ² Universal coverage is defined by the WHO (2020) as: “ensuring that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation, and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the users’ financial hardship.
- ³ To put this into perspective: in 2013 each hour of personal care used amounted to an average of €50. So if an individual for instance uses up to two hours of personal care a week this will add up to an amount of € 5200 a year, of which only a small part is payed out of pocket (CBS, 2020).
- ⁴ A somatic disorder or limitation is often caused by a current somatic (physical) illness or condition. If there are permanent limitations, not caused by disorders of the nervous system or the musculoskeletal system (bone/musculature, joints, and connective tissue), the health problem somatic illness is applicable (Duell *et al.*, 2019).
- ⁵ Psychogeriatric health problems are a result of a disease or disorder in or of the brain. Often there is an impairment of the emotional capacity, intellectual capacity, and/or memory capacity. An example is of a psychogeriatric health problem is dementia (Duell *et al.*, 2019).
- ⁶ Health care costs made within the medical care sector. This is care covered under the Dutch Insurance Act, which includes most importantly care provided by GPs and medical specialists.
- ⁷ In our dataset, more use than entitled to is observed in only 3.4% of the observations. The observed used hours solely refer to publicly funded hours. Individuals might be utilising more formal care than they are entitled to in case, for example, the volume of publicly funded care initially granted was too low. An explanation for this is that clients often face increased needs over time and that an entitlement from even a few weeks ago may be outdated. Pending a re-assessment, the care provider may be forced to provide more hours than entitled. Note that we have excluded individuals

who receive a re-assessment during the care period studied to rule this out as much as possible, but it still may occur in a few cases (i.e., the re-assessment has not yet taken place). Another explanation may be that clients temporarily need extra care. This can be the case when an informal caregiver is ill or when the client has had an accident.

Ethics and Consent

Under Dutch law, this study did not require approval from an Ethics Review Board because it did not fall within the scope of the Medical Research Involving Human Subjects Act (WMO).

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Competing Interests

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References

- Arrighi, Y**, et al. 2015. ‘The non-take up of long-term care benefit in France: A pecuniary motive?’ *Health Policy*, 119(10): 1338–1348. DOI: <https://doi.org/10.1016/j.healthpol.2015.07.003>
- Babitsch, B, Gohl, D** and **Von Lengerke, T**. 2012. ‘Revisiting Andersen’s Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011.’ *GMS Psycho-Social Medicine*, 9: 1–15. DOI: <https://doi.org/10.3205/psm000089>
- Bakx, P** and **De Meijer, C**. 2013. ‘The Influence of Spouse Ability to Provide Informal Care on Long-Term Care Use.’ Available at SSRN 2407926. DOI: <https://doi.org/10.2139/ssrn.2407926>
- Bakx, P**, et al. 2015. ‘Going Formal or Informal, Who Cares? The Influence of Public Long-Term Care Insurance.’ *Health Economics*, 24: 631–643. DOI: <https://doi.org/10.1002/hec.3050>
- Bakx, P, Douven, R** and **Schut, FT**. 2016. ‘Does independent needs assessment limit supply-side moral hazard in long-term care?’ CPB discussion paper 327. Retrieved from: <https://www.cpb.nl/en/publication/does-independent-needs-assessment-limit-supply-side-moral-hazard-in-long-term-care>.
- Bakx, P, Schut, E** and **Van Doorslaer, E**. 2013. ‘Can Risk Adjustment prevent Risk Selection in a Competitive Long-Term Care Insurance Market?’ Tinbergen Institute discussion paper 13-017/V. Retrieved from: <https://www.tinbergen.nl/>

- discussion-paper/927/13-017-v-can-risk-adjustment-prevent-risk-selection-in-a-competitive-long-term-care-insurance-market. DOI: <https://doi.org/10.2139/ssrn.2202170>
- Balia, S** and **Brau, R.** 2014. 'A country for old men? Long-term home care utilization in Europe.' *Health Economics*, 23: 1185–1212. DOI: <https://doi.org/10.1002/hec.2977>
- Bauer, JM** and **Sousa-Poza, A.** 2015. 'Impacts of Informal Caregiving on Caregiver Employment, Health, and Family.' IZA DP No. 8851. Retrieved from: <http://ftp.iza.org/dp8851.pdf>.
- Bolin, K, Lindgren, B** and **Lundborg, P.** 2008. 'Informal and formal care among single-living elderly in Europe.' *Health Economics*, 17: 393–409. DOI: <https://doi.org/10.1002/hec.1275>
- Bonsang, E.** 2009. 'Does informal care from children to their elderly parents substitute for formal care in Europe?' *Journal of Health Economics*, 28: 143–154. DOI: <https://doi.org/10.1016/j.jhealeco.2008.09.002>
- Bradley, EH,** et al. 2004. 'Intended use of informal long-term care: The role of race and ethnicity.' *Ethnicity and Health*, 9: 37–54. DOI: <https://doi.org/10.1080/13557850410001673987>
- Brandt, M, Haberkern, K** and **Szydlik, M.** 2009. 'Intergenerational help and care in Europe.' *European Sociological Review*, 25: 585–601. DOI: <https://doi.org/10.1093/esr/jcn076>
- Broese van Groenou, MI** and **De Boer, A.** 2016. 'Providing informal care in a changing society.' *Eur J Ageing*, 13: 271–279. DOI: <https://doi.org/10.1007/s10433-016-0370-7>
- Burke, WJ.** 2009. 'Fitting and Interpreting Cragg's Tobit Alternative using Stata.' *The Stata Journal*, 9(4): 584–592. DOI: <https://doi.org/10.1177/1536867X0900900405>
- Byrne, D,** et al. 2009. 'Formal home health care, informal care, and family decision making.' *International Economic Review*, 50(4): 1205–1242. DOI: <https://doi.org/10.1111/j.1468-2354.2009.00566.x>
- CAK.** 2013. "Eigen bijdrage Zorg zonder Verblijf en Wmo 2013" [Brochure]. Retrieved from: <https://www.sherpa.org/wp-content/uploads/2014/01/brochure-CAK-folder-ZzV-2013.pdf>.
- CBS.** 2012. "Sociale monitor"; 1990–2011 [Dataset]. Retrieved from: <http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=SLNL&PA=70115ned&D1=0,3-4&D2=a&D3=a&HD=081106-1151&HDR=T,G1&STB=G2>.
- CBS.** 2019. "Opbrengst eigen bijdrage voor AWBZ-zorg in natura"; 2009–2014 [Dataset]. Retrieved from: <https://mlzopendata.cbs.nl/#/MLZ/nl/data-set/40029NED/table?dl=1F2F4>.
- CBS.** 2020. "AWBZ/Wlz-zorg in natura; productie (uitgaven en volume)" [Dataset] Retrieved from: <https://opendata.cbs.nl/#/CBS/nl/dataset/82789NED/table?searchKeywords=Wet%20langdurige%20zorg>.
- Charles, KK** and **Sevak, P.** 2005. 'Can family caregiving substitute for nursing home care?' *Journal of Health Economics*, 24: 1174–1190. DOI: <https://doi.org/10.1016/j.jhealeco.2005.05.001>
- CIZ.** 2013. "CIZ Indicatielijst, versie 6.0. Toelichting op de beleidsregels indicatiestelling AWBZ 2013, zoals vastgesteld door het ministerie van VWS." Driebergen: Centrum Indicatiestelling Zorg.
- Davey, A,** et al. 2005. 'Life on the edge: Patterns of formal and informal help to older adults in the United States and Sweden.' *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 60(5): S281–S288. DOI: <https://doi.org/10.1093/geronb/60.5.S281>
- De Meijer, C,** et al. 2011. 'Determinants of long-term care spending: Age, time to death or disability?' *Journal of Health Economics*, 30(2): 425–438. DOI: <https://doi.org/10.1016/j.jhealeco.2010.12.010>
- Duell, D,** et al. 2019. 'Practice variation in long-term care access and use: The role of the ability to pay.' *Health Economics*, 28: 1277–1292. DOI: <https://doi.org/10.1002/hec.3940>
- Geerlings, SW,** et al. 2005. 'Predicting transitions in the use of informal and professional care by older adults.' *Ageing and Society*, 25: 111–130. DOI: <https://doi.org/10.1017/S0144686X04002740>
- Geerts, J** and **Van den Bosch, K.** 2012. 'Transitions in formal and informal care utilisation amongst older Europeans: The impact of national contexts.' *European Journal of Ageing*, 9: 27–37. DOI: <https://doi.org/10.1007/s10433-011-0199-z>
- Goda, GS, Golberstein, E** and **Grabowski, DC.** 2011. 'Income and the utilization of long-term care services: Evidence from the Social Security benefit notch.' *Journal of Health Economics*, 30(4): 719–729. DOI: <https://doi.org/10.1016/j.jhealeco.2011.04.001>
- Grootegoed, E, Van Barneveld, E** and **Duyvendak, JW.** 2015. 'What is customary about customary care? How Dutch welfare policy defines what citizens have to consider "normal" at home.' *Critical Social Policy*, 35(1): 110–131. DOI: <https://doi.org/10.1177/0261018314544266>
- Guthmuller, S, Jusot, F** and **Wittwer, J.** 2014. 'Improving take-up of health insurance program: A social experiment in France.' *Journal of Human Resources*, 49(1): 167–194. DOI: <https://doi.org/10.3368/jhr.49.1.167>
- Hiedemann, B, Sovinsky, M** and **Stern, S.** 2018. 'Will you still want me tomorrow? The dynamics of families' long-term care arrangements.' *Journal of Human Resources*, 53(3): 663–716. DOI: <https://doi.org/10.3368/jhr.53.3.0213-5454R1>
- Hoffmann, F** and **Rodrigues, R.** 2010. 'Informal Carers: Who Takes Care of Them?' *Policy Brief*. European Centre. Retrieved from: <http://citeseerx.ist.psu.edu/viewdoc/download;jsessionid=87F1626580FBFED33CAD0C61506B26F5?doi=10.1.1.627.6793&rep=rep1&type=pdf>.
- Huisman, M,** et al. 2011. 'Cohort profile: The longitudinal aging study Amsterdam.' *International Journal of Epidemiology*, 40: 868–876. DOI: <https://doi.org/10.1093/ije/dyq219>
- Koehly, LM,** et al. 2015. 'Caregiving networks-using a network approach to identify missed opportunities.' *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 70(1): 143–54. DOI: <https://doi.org/10.1093/geronb/gbu111>

- Koopmanschap, M**, et al. 2010. 'Determinants of health care expenditure in an aging society.' *Netspar Panel Papers*, 22: 11–103. Retrieved from: https://www.netspar.nl/assets/uploads/PP_22_WEB.pdf.
- Kromhout, M, Kornalijslijper, N and De Klerk, M**. 2018. Veranderde zorg en ondersteuning voor mensen met een beperking Landelijke evaluatie van de Hervorming Langdurige Zorg. SCP-publicatie 2018-17. Den Haag. ISBN 978 90 377 0875 2.
- Li, L**. 2005. 'Longitudinal changes in the amount of informal care among publicly paid home care recipients.' *Gerontologist*, 45(4): 465–473. DOI: <https://doi.org/10.1093/geront/45.4.465>
- Litwin, H**. 2004. 'Social networks, ethnicity and public home-care utilisation.' *Ageing and Society*, 24(6): 921–939. DOI: <https://doi.org/10.1017/S0144686X04002491>
- Litwin, H and Attias-Donfut, C**. 2009. 'The inter-relationship between formal and informal care: A study in France and Israel.' *Ageing and Society*, 29: 71–91. DOI: <https://doi.org/10.1017/S0144686X08007666>
- McMaughan Moudouni, DK**, et al. 2012. 'The relationship between formal and informal care among adult Medicaid personal care services recipients.' *Health Services Research*, 47(4): 1642–1659. DOI: <https://doi.org/10.1111/j.1475-6773.2012.01381.x>
- Min, JW and Barrio, C**. 2009. 'Cultural values and caregiver preference for Mexican-American and non-Latino White elders.' *Journal of Cross-Cultural Gerontology*, 24: 225–239. DOI: <https://doi.org/10.1007/s10823-008-9088-0>
- Ministry of Health Welfare and Sports (Netherlands)**. 2007. The PCB in perspective [Het pgb in perspectief]. Retrieved from: <https://zoek.officielebekendmakingen.nl/kst-26631-232.html>.
- Mudrazija, S, Thomeer, MB and Angel, JL**. 2015. 'Gender Differences in Institutional Long-Term Care Transitions.' *Women's Health Issues*, 25(5): 441–449. DOI: <https://doi.org/10.1016/j.whi.2015.04.010>
- Non, M**, et al. 2015. "Keuzeruimte in de langdurige zorg: Verandering in het Samenspel van Zorgpartijen en Cliënten". *CPB/SCP book*. Retrieved from: <https://www.cpb.nl/publicatie/keuzeruimte-in-de-langdurige-zorg>.
- Norton, E**. 2000. 'Long-term care.' *Handbook of Health Economics*, 1(part B): 955–994. Chapter 17. Elsevier. DOI: [https://doi.org/10.1016/S1574-0064\(00\)80030-X](https://doi.org/10.1016/S1574-0064(00)80030-X)
- OECD**. 2017. Health at a glance 2017. DOI: <https://doi.org/10.1787/19991312>
- OECD.Stat**. 2018. Health Expenditure and Financing, Long-Term Care [Dataset]. Retrieved from: <https://stats.oecd.org/>.
- Penning, M**. 2002. 'Hydra revisited: substituting formal for self- and informal in-home care among older adults with disabilities.' *Gerontologist*, 42(1): 4–16. DOI: <https://doi.org/10.1093/geront/42.1.4>
- Pickard, L**. 2012. 'Substitution between formal and informal care: A "natural experiment" in social policy in Britain between 1985 and 2000.' *Ageing and Society*, 32(7): 1147–1175. ISSN 0144-686X. DOI: <https://doi.org/10.1017/S0144686X11000833>
- Pinquart, M and Sörensen, S**. 2011. 'Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison.' *Psychology and Aging*, 26(1): 1–14. DOI: <https://doi.org/10.1037/a0021863>
- Plaisier, I, Broese Van Groenou, M and Deeg, DJH**. 2011. "VWS vraag 2011, Kwetsbare ouderen: Zorg of geen zorg?" Amsterdam: Vrije Universiteit Amsterdam.
- Portrait, F, Lindeboom, M and Deeg, D**. 2000. 'The use of long-term care services by the Dutch elderly.' *Health Economics*, 9: 513–531. DOI: [https://doi.org/10.1002/1099-1050\(200009\)9:6<513::AID-HEC534>3.0.CO;2-R](https://doi.org/10.1002/1099-1050(200009)9:6<513::AID-HEC534>3.0.CO;2-R)
- Schenk, N**, et al. 2014. 'Older adults' networks and public care receipt: Do partners and adult children substitute for unskilled public care?' *Ageing and Society*, 34(10): 1711–1729. DOI: <https://doi.org/10.1017/S0144686X13000469>
- Schomerus, G**, et al. 2013. 'Personality related factors as predictors of help-seeking for depression: A population-based study applying the Behavioral Model of Health Services Use.' *Social Psychiatry and Psychiatric Epidemiology*, 48(11): 1809–1817. DOI: <https://doi.org/10.1007/s00127-012-0643-1>
- SCP**. 2010. "Mantelzorg uit de doeken". Retrieved from: https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2010/Mantelzorg_uit_de_doeken.
- SCP**. 2013. "Informeel zorg in Nederland". Retrieved from: https://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2013/Informeel_zorg_in_Nederland.
- SCP**. 2019. "Mantelzorgers in het vizier". Retrieved from: <https://www.scp.nl/publicaties/publicaties/2019/11/08/mantelzorgers-in-het-vizier>.
- Shinkle, D**. 2010. "NCSL Legisbrief". *Growing groceries in food deserts*.
- Spillman, BC and Lubitz, J**. 2000. 'The effect of longevity on spending for acute and long-term care.' *The New England Journal of Medicine*, 342(19): 1409–1415. DOI: <https://doi.org/10.1080/13685530008500335>
- Spillman, BC and Pezzin, LE**. 2000. 'Potential and active family caregivers: Changing networks and the "sandwich generation".' *The Milbank Quarterly*, 78(3): 347–74: table. DOI: <https://doi.org/10.1111/1468-0009.00177>
- Tarricone, R and Tsouros, AD**. (Eds.) 2008. *Home care in Europe: The solid facts*. WHO Regional Office Europe.
- Tenand, M, Bakx, P and Van Doorslaer, E**. 2018. 'Equal long-term care for equal needs with universal and comprehensive coverage? An assessment using Dutch administrative data.' *Tinbergen Institute discussion paper 18-098/V*. Retrieved from: <https://www.tinbergen.nl/discussion-paper/2827/18-098-v-equal-long-term-care-for-equal-needs-with-universal-and-comprehensive-coverage-an-assessment-using-dutch-administrative-data>. DOI: <https://doi.org/10.2139/ssrn.3300848>
- Triantafillou, J**, et al. 2010. 'Informal care in the long-term care system European overview paper.' *Interlinks, EU Report Seventh Framework Programme, Athens/Vienna*, 1–67.

- Twigg, J.** 1989. 'Models of carers: How do social care agencies conceptualise their relationship with informal carers.' *Journal of Social Policy*, 18(1). DOI: <https://doi.org/10.1017/S0047279400017207>
- Twigg, J** and **Atkin, K.** 1994. *Carers Perceived: Policy and Practice in Informal Care*. Buckingham: Open University Press.
- Van den Berg, B, Brouwer, WBF** and **Koopmanschap, MA.** 2004. 'Economic valuation of informal care. An overview of methods and applications.' *European Journal of Health Economics*, 5(1): 36–45. DOI: <https://doi.org/10.1007/s10198-003-0189-y>
- Van Houtven, CH** and **Norton, EC.** 2004. 'Informal care and health care use of older adults.' *Journal of Health Economics*, 23(6): 1159–1180. DOI: <https://doi.org/10.1016/j.jhealeco.2004.04.008>
- Walker, A, Pratt, C** and **Eddy, L.** 1995. 'Informal caregiving to aging family members: A critical review.' *Family Relations*, 44(4): 402–411. DOI: <https://doi.org/10.2307/584996>
- WHO.** 2020. Universal health coverage. Retrieved from: https://www.who.int/healthsystems/universal_health_coverage/en/.
- Wu, CY,** et al. 2014. 'Determinants of long-term care services among the elderly: A population-based study in Taiwan.' *PloS One*, 9(2). DOI: <https://doi.org/10.1371/journal.pone.0089213>
- Yoo, BK,** et al. 2004. 'Impacts of informal caregiver availability on long-term care expenditures in OECD countries.' *Health Services Research*, 39: 1971–1992. DOI: <https://doi.org/10.1111/j.1475-6773.2004.00328.x>

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