

No more visits: Informal care in nursing homes before the COVID-19 outbreak

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Abstract – *Since the COVID-19 crisis, visiting restrictions in nursing homes have been widely implemented. They may have affected the wellbeing of residents, notably by depriving them of care that would otherwise be provided by relatives and friends. There is little quantitative evidence on informal care receipt by nursing home residents in “normal times”. This study investigates the importance of informal care in nursing homes, the forms it takes, and the factors affecting its presence prior to the pandemic. Building upon these elements, we then discuss the likely implications of the COVID-19 restrictions. The analysis relies on a representative sample of the population in France aged 60+ years and living in a nursing home (N=3,223), taken from the 2016 CARE survey. Over 80% of residents receive informal care. Over 75% receive help with the activities of daily living (ADLs) or instrumental activities of daily living (IADLs), which is generally accompanied by moral support. Residents are mostly helped with administrative tasks (budget management, paperwork, administrative procedures) and activities related to mobility and the outside world (moving in and out of the nursing home, finding their way, shopping). The probability of receiving informal care highly depends on having close relatives (partner, children, siblings) who are alive, as well as the age and health status of the nursing home resident. Loss of informal care due to visiting restrictions may negatively affect the wellbeing of nursing home residents and lead to adverse health effects. Policymakers should factor in the role of informal caregivers when assessing the benefits and costs of visiting restrictions in nursing homes.*

Keywords – *nursing home, informal care, long-term care, COVID-19, population aging*

Résumé – Aide informelle en établissement : quel impact attendre des restrictions liées à la COVID-19 ?

Durant la pandémie de la COVID-19, des restrictions sur les visites en maisons de retraite ont été mises en œuvre. De telles mesures sont susceptibles d'affecter le bien-être des résidents, en les privant notamment de l'aide apportée par leurs proches. On dispose cependant de peu d'éléments quantitatifs sur l'aide fournie par les proches aux personnes en établissement. Cet article documente l'importance, les modalités et les déterminants de l'aide informelle en maison de retraite hors contexte épidémique, en s'appuyant sur un échantillon représentatif de la population française de plus de 60 ans vivant en établissement pour personnes âgées (N=3223) de l'enquête CARE (2016). Sur la base de ces éléments, l'article discute ensuite des implications des interdictions de visite dans le contexte de la COVID-19. Plus de 80 % des résidents reçoivent de l'aide informelle. Celle-ci porte sur les activités de la vie quotidienne (en particulier les tâches administratives et les activités en lien avec la mobilité) pour 3/4 des résidents, et s'accompagne alors généralement d'un soutien moral. Avoir des proches en vie, l'âge et l'état de santé sont des déterminants majeurs de la probabilité d'être aidé. L'interdiction des visites est susceptible d'affecter le bien-être des résidents et d'avoir des effets néfastes en termes de santé physique et mentale. Cette dimension est à prendre en compte dans l'évaluation des coûts et des bénéfices associés à la restriction des visites aux résidents.

Mots clés – Ehpad, aide informelle, soins de longue durée, COVID-19, vieillissement démographique

Data:

This research uses individual-level survey data. Access was granted by Réseau Quételet (reference: lil-1296: Enquête Capacité, Aides et Ressources des seniors (CARE institutions) – Volet seniors – 2016 (2016, Insee, Drees – Ministère de la Santé).

More details on data treatment can be found in the Supplementary Material to this article, provided online:

Jeanneau, Lucas; Roquebert, Quitterie and Marianne Tenand (2021): Data Appendix & Scripts to the article 'No more visits. Informal care in nursing homes prior to the outbreak of Covid-19'. Erasmus University Rotterdam (EUR). Online resource. <https://doi.org/10.25397/eur.16692631.v1>

Introduction

The ongoing COVID-19 crisis has shed light on a key aspect of life in a nursing home: visits from relatives. These visits form part of the routine for many nursing home residents, offering myriad benefits from moral support to concrete help. The protective measures implemented to contain the spread of the virus in nursing homes deprived residents and their relatives of the possibility to see each other. In France, on March 11, 2020, the Ministry of Health decided to put all external visits to nursing home residents on hold, implementing a lockdown for these individuals. This is before the general lockdown was implemented for all French citizens on March 17th. On April 20, 2020, visits could resume under strict conditions. On June 5, 2020, restrictions were further relaxed. Yet in summer 2021, physical contact between residents and their visitors, in-room visits, and leaving the institution were still strongly discouraged. As of September 2021, facilities were still allowed to enforce restrictive rules if COVID-19 cases were present in the nursing home (HAS, 2021). Similar rules have applied in many other countries (Salcher-Konrad *et al.*, 2021).

How have the restrictions on visits affected the daily life of nursing home residents? Qualitative studies have already shown that these restrictions increased residents' loneliness and deteriorated their wellbeing (Giebel *et al.*, 2020; Van Der Roest *et al.*, 2020; Verbeek *et al.*, 2020). There are several ways in which these visits, which were disrupted by the coronavirus outbreak, may contribute to the wellbeing of residents. This article will focus on one of these ways, namely the role that relatives and friends may play as informal caregivers. While the role of relatives for the community-dwelling elderly is well-documented, little is known on informal care for individuals living in nursing homes in normal times (i.e., outside the COVID-19 crisis).

Nursing home residents have long been considered as individuals with no family resources. Historically, social isolation was indeed a distinctive feature of nursing home entrants. This representation seems to persist today (Désesquelles and Brouard, 2003; Trépiéd, 2014). Nursing home admission is associated with the idea of caregivers within the family being relieved of their duties due to the presence of professional caregivers in the nursing home. In France, the definition of an informal caregiver provided in a law passed in 2015¹ does not specify whether the person being given the care lives at home or in an institution such as a nursing home. However, the definition of "*proche aidant indispensable*" (essential informal caregiver) only applies to individuals living in the community, somehow suggesting that informal care to nursing home residents is not equally essential.

Several studies in sociology, geriatrics, and gerontology investigate the combination of professional care and informal support within care institutions. These studies show that relatives may become or remain informal caregivers to an older person after this person has entered a nursing home (Gaugler, 2005; Keating

¹ Act on Adapting Society to an Ageing Population, law no. 2015-1776 of December 28, 2015.

et al., 2001; Mallon, 2005; Trépiéd, 2014). Early models put forward the hypothesis of “caregiver specializations,” whereby professional workers provided specialist support such as nursing care and help with the activities of daily living, while informal caregivers provided moral support. However, both anecdotal evidence and qualitative literature show that informal caregivers also help with the activities of daily living, including personal care.

The COVID-19 pandemic may have a major influence on the daily life of nursing home residents, specifically by depriving them of regular and concrete informal care that cannot be provided remotely. How many residents were affected? Which types of residents were most likely to receive informal care and thus lose it due to the protective measures? Which types of tasks were performed by relatives and friends before they were not allowed in anymore?

The objective of this article is twofold. First, it provides a quantitative study on the informal care received by nursing home residents in France before the COVID-19 outbreak. Second, based on these findings, it discusses the potential impact of restrictions on visits for nursing home residents. We take advantage of the “Capacités, Aides et REssources des seniors” survey (CARE) (Capabilities, Help and Resources for Seniors), conducted in 2016. As it is representative of the 60+ institutionalized population and includes rich information on informal support, this survey allows us to describe in a quantitative way how important informal care within nursing homes. Furthermore, focusing on help with the activities of daily living, we analyze which personal characteristics are associated with the probability of receiving informal care.

The paper proceeds as follows. Section 2 provides information on the data used and descriptive statistics on the French nursing home residents. Section 3 documents the types of informal care received by residents, focusing on the tasks performed by informal caregivers. Section 4 sheds light on the determinants of the probability of receiving informal care. Section 5 discusses the implications of the findings in the context of the COVID-19 pandemic, as well as highlighting the limitations of our study and directions for future research. Section 6 provides a conclusion.

Data and study population

A representative survey of the population in nursing homes

For this study, we take advantage of the CARE survey (*Capacités, Aides et REssources des seniors*), a survey targeting French people aged 60 years and older that is divided into two sub-sections and documents their living conditions, their relationships with their relatives, the limitations they face, as well as the human, technical, and financial support they receive.

In particular, we make use of the CARE-Institutions (CARE-I) sub-section, which focuses on nursing home residents in 2016. The sampling procedure is carried out in such a way so as to ensure the sample is representative. A sample of permanent

residents is drawn from within selected facilities including non-medicalized nursing homes (EHPAs, établissement d'hébergement pour personnes âgées), nursing homes offering a high level of medical care (EHPADs, établissement d'hébergement pour personnes âgées dépendantes), and long-term care units in hospitals (USLDs, unités de soins de longue durée).² 3,262 respondents from 616 facilities participate in the survey.

Study population and sample

Our study population covers the 583,000 permanent nursing home residents present in France in 2016, representing 3.5% of the French population aged 60+. From the initial survey sample, we drop 39 observations for which information on difficulties with the activities of daily living is missing. Our baseline sample therefore consists of 3,223 individuals. Table 1 provides general descriptive statistics.

Table 1 – General descriptive statistics on nursing home residents in France

Variable	Mean	Standard deviation
Women	74.5%	
Age: [60;75]	11.5%	
Age: [75;85]	25.3%	
Age: [85;90]	28.6%	
Age: [90;95]	26.1%	
Age: >96	8.6%	
No diploma	27.2%	
Elementary school or middle school diploma	43.0%	
High school diploma or higher	10.9%	
No partner	87.5%	
Partner at home	6.6%	
Partner in institution	5.9%	
Number of children	1.8	1.7
No children	25.9%	
Closest child in the same city	21.2%	
Closest child not the in same city	53.0%	
Has siblings	44.2%	
IADL difficulties of any kind	96.7%	
Number of IADL difficulties	4.8	1.6
ADL difficulties of any kind	84.1%	
Number of ADL difficulties	3.6	2.2
Both ADL and IADL difficulties	40.7%	
Severely disabled	43.4%	

² We use the generic term "nursing home" to designate EHPAs, EHPADs and USLDs. See the Data Appendix for additional details on the scope of the survey.

Alzheimer's disease	35.2%	
Positive subjective health	64.7%	
Institution type: EHPAD	92.8%	
Institution type: USLD	6.2%	
Institution type: EHPA	1.0%	
For-profit institution	20.3%	
Not-for-profit institution	28.8%	
Public hospital institution	26.8%	
Public non-hospital institution	24.2%	
Institution size: <60 residents	13.8%	
Institution size: [60;99] residents	50.6%	
Institution size: >100 residents	30.0%	
Institution size: unknown	5.7%	
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N(sample)		3,223
N(population)		583,572
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Sample: Respondents of the CARE-I survey with no missing value on ADL and IADL difficulties. Statistics weighted by survey weights.

Notes: The number of IADL difficulties is computed assuming that all nursing home residents who live in an institution where residents do not autonomously perform meal preparation, grocery shopping, medication managing, and domestic chores, have difficulties in these activities. For binary variables, the standard deviation is not a relevant statistic and is not reported.

93% of nursing home residents live in an EHPAD, 6% live in a USLD and only 1% live in an EHPA. Almost 30% of residents live in private non-profit institutions and 20% live in for-profit institutions, while the rest live in public institutions, either a hospital (27%) or a not-for-profit nursing home (29%). Institution size varies, with 14% of residents living in an institution with less than 60 occupied beds, 51% in an institution counting with 60–100 occupied beds, and 30% with 100 other residents or more.

Regarding sociodemographic characteristics, around 80% of residents are aged between 75 and 95 years, with an average age of 86 years. Consistent with the higher life expectancy and higher prevalence of widowhood among women, around 75% of residents are females. About 10% of residents have a high school diploma (Baccalauréat) or have completed higher education; for over 60%, the highest diploma received is the elementary school diploma (Certificat d'études) or middle school diploma (Brevet d'Etudes Professionnelles or Certificate d'Aptitude Professionnelle). Finally, almost 30% of residents did not complete elementary school. This distribution reflects the fact that most residents grew up before high school education and higher education were made more accessible.

Health and functional status

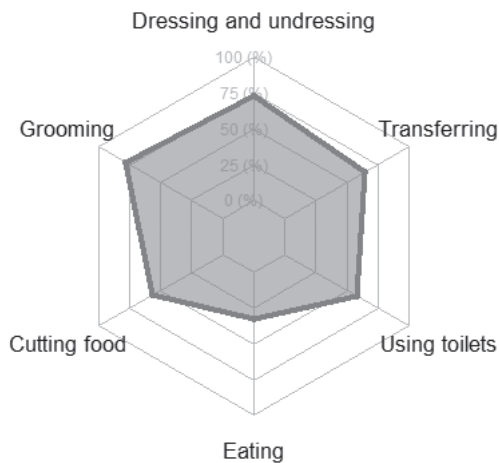
To assess the functional status of each resident, we primarily refer to their self-reported ability to perform a number of activities. Following the epidemiological literature (Katz, 1983), the CARE survey distinguishes between the activities of daily living (ADLs) and the instrumental activities of daily living (IADLs). ADLs

are essential tasks relating to self-care, including grooming, dressing and undressing, using the toilet, transferring (to and from bed), as well as cutting and eating food (that is already prepared). IADLs are more complex activities, requiring higher organizational capacity. In the CARE survey, they include grocery shopping, domestic chores, preparing meals, managing medication, moving around alone (in one’s room), using a phone, managing transportation, leaving the institution, finding one’s way, and managing administrative tasks.

CARE respondents are asked whether they perform each activity: (i) without difficulty, (ii) with some difficulty, (iii) with a lot of difficulty, or (iv) whether they are unable to perform the activity without assistance. We consider respondents as “restricted” for a given activity as soon as they report at least *some* difficulties in performing it (level (ii)).³

Figure 1 shows the proportion of residents who report ADL difficulties, by activity. For each ADL except eating food (that is already prepared), over half of residents report difficulties. Over 80% of residents report difficulties with grooming or dressing. Table 1 indicates that 86% of residents have a restriction in at least one ADL. These statistics reflect the fact that most residents require frequent assistance. Similarly, Figure 2 shows the proportion of residents who report IADL difficulties (for non-filtered IADLs). Although 40% of residents can move around in the facility (on the same floor as their room) and 33% can use a phone without difficulty, more than 80% have difficulties either with leaving the nursing home, using transportation, or finding their way once out of the institution. Virtually all residents have difficulties with at least one IADL (96%; Table 1).

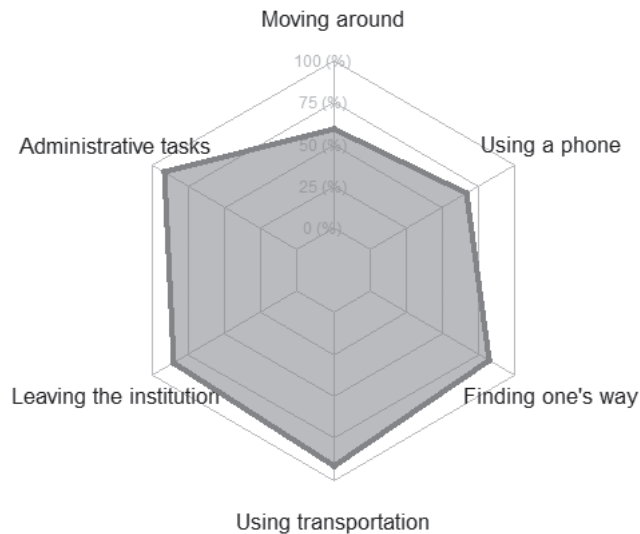
Figure 1 – Share of residents with ADL difficulties, by activity



Sample: CARE-I respondents with no missing value on ADL and IADL difficulties (N=3,223). Statistics weighted by survey weights.
 Analysis: 74% of nursing home residents have difficulty with dressing or undressing.

³ Some questions relating to IADLs were filtered in the questionnaire administered to residents. See the Data Appendix for more details.

Figure 2 – Share of residents with IADL difficulties, by activity



Sample: CARE-I respondents with no missing value on ADL and IADL difficulties (N=3,223). Statistics weighted by survey weights.
Analysis: Around 90% of nursing home residents have difficulties in managing administrative tasks.

We combined information on ADL and IADL difficulties to construct a 3-level disability scale, building upon epidemiological studies on the hierarchical structure of such difficulties (Barberger-Gateau *et al.*, 2000; Edjolo *et al.*, 2016). The least dependent are those respondents who do not report any ADL difficulties. The moderately dependent are those reporting both ADL and IADL difficulties. The severely dependent are those who cannot eat, use the toilet, or transfer to and from bed on their own. These 3 ADLs have been shown to be the last activities, chronologically speaking, to be affected in the disablement process, and the inability to perform them implies the need for very frequent human assistance. Only 12.5% of institutional care residents have no ADL difficulties, while 40% are moderately dependent, and almost 45% severely dependent.

In addition, we took subjective health into consideration, i.e., if the respondent reports a positive general health (“very good,” “good” or “rather good” vs “bad” or “very bad”). Finally, we included Alzheimer’s disease as a dummy variable.

Potential informal care: Presence of relatives

We posit that having a living partner or children is a major determinant of the probability of informal care receipt for individuals living in nursing homes—just as it is the case for older people living in the community (Colombo and Al, 2011). Among the French nursing home residents, 87% do not have a living partner, 6.5% have a partner who also lives in an institution, and the remaining 6.5% have a

community-dwelling partner.⁴ 75% have at least one living child. We observed that 24.1% of residents have neither a living child nor partner (with 12.3% having no living child, partner, brother, or sister)—thus, their potential supply of informal care from close family is limited. Meanwhile, 10.7% have both a living partner and at least one living child. Most individuals (63.4%) have at least one child but no partner, while having a partner but no child is extremely rare (1.8% of individuals). 44% of residents have a living sibling.

In-person contacts not only may play an important role in the wellbeing of nursing home residents but also offer windows of time in which relatives might provide informal care. Respondents were asked to report the frequency at which they met and spent time with either family members or friends in the 12 months prior to the survey. 73% of residents met a family member at least once a month, with 50% doing so at least once a week. 21% spent time with friends at least once a month but only 7% did so on a weekly basis.⁵ 12% of residents had not spent any time with either a friend or family member over the past 12 months. It is also worth noting that 56% of respondents declared that they had not established any friendship or “intimate relationship” with other residents, meaning that, for them, valuable social relationships lay entirely outside the nursing home.

Caregivers are primarily involved in ADL and IADL support

This section describes the informal care received by nursing home residents. We distinguish between three types of informal care (ADL or IADL support, moral support, financial support) and zoom in on the specific help provided for each ADL and IADL.

Three different types of informal support

A major strength of the CARE survey is the information about care provided. Respondents are asked whether each of their informal caregivers provide (i) help with performing the ADLs and IADLs, (ii) moral support (i.e., contact between the caregiver and respondent aimed at supporting the respondent’s wellbeing, without direct ADL/IADL support being provided), and/or (iii) financial support (e.g., contributions to the cost of the nursing home, payments of some purchases). Based on this information, we can derive whether respondents receive any ADL/IADL support, moral support, or financial support.⁶

⁴ See Data Appendix for the treatment of missing values.

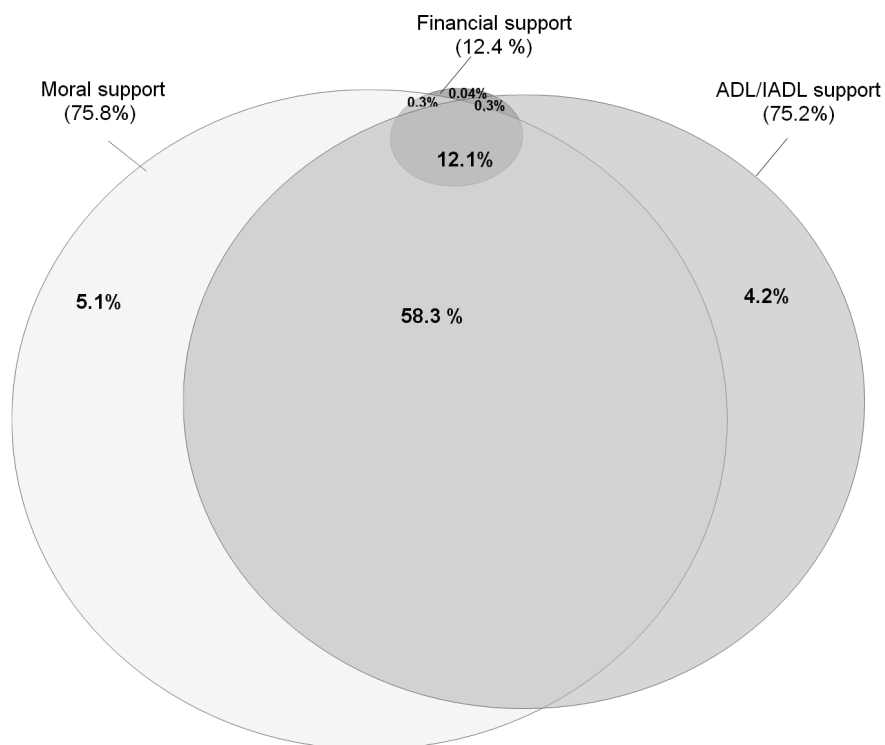
⁵ Less than 2% of residents report having no family, and 3% as having no friends.

⁶ Discrepancy may occur between the initial declaration of some respondents and the information they give about the care provided by each of their caregivers (e.g., the respondent declares not being helped for grooming, but later reports that their caregiver X does, in fact, helps with grooming). See Data Appendix for more details.

How common are these types of help?

ADL/IADL support and moral support are the most common types of care declared by nursing home residents (Figure 3). Around 75% of individuals declare that they receive ADL/IADL support from at least one caregiver, with almost 80% of them additionally receiving moral support. Financial support is relatively marginal, standing at 12.1% of those who receive informal care, and it is almost always associated with moral support and ADL/IADL support.

Figure 3 – Nursing home residents receiving informal care, by type



Sample: CARE-I respondents with no missing value on ADL and IADL difficulties (N=3,223). Statistics weighted by survey weights. 19.7% of nursing home residents do not receive informal care.

The relative frequency of these three types of care for nursing home residents is similar to what is observed with older people living the community (Besnard *et al.*, 2019; Roquebert, Fontaine, and Gramain, 2018). However, it is more common for elderly individuals living in the community to report receiving only ADL/IADL support or only moral support.

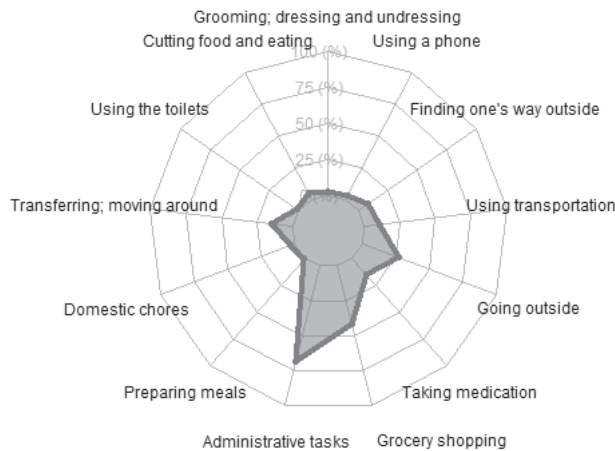
The remainder of our study focuses on informal ADL/IADL support, for two reasons. First, this is a major component of care provided to individuals living in care institutions. Second, such care generally requires the effective presence of

the caregiver, contrary to moral and financial support that might be more easily provided remotely. ADL/IADL support is thus the type of informal care that is most likely to have been radically affected by the visiting restrictions during the COVID-19 pandemic.

Relatives focus on administrative tasks and mobility-related activities

Respondents were invited to list the ADLs and IADLs for which they regularly receive help from an informal caregiver.⁷ The results are presented in Figure 4.

Figure 4 – Share of residents receiving informal ADL/IADL support, by activity



Sample: CARE-I respondents with no missing values on ADL and IADL difficulties (N=3,223). Statistics weighted by survey weights.
 Analysis: More than 25% of nursing home residents receive informal help when travelling outside the institution.

Help with transferring to and from bed is the most frequently declared for ADLs. Informal care is more common for IADLs: 72% of individuals declare being helped for administrative tasks—including budget management and paperwork—and around 45% for grocery shopping. Relatives also play a role regarding mobility and access to the outside: 16% are helped to move within the institution, 29% receive help to go out of the institution, and 8% are helped to find their way outside.

The role of relatives is thus concentrated on certain IADLs related to administrative tasks and mobility; for ADLs, on the other hand, little support is provided. This probably relates to the fact that professionals are already present to help with ADLs, as well as some IADLs relating to personal care and domestic chores—tasks that generally require more technical skills. Relatives tend to get involved in tasks that are not necessarily part of professional care workers’ duties, suggesting a form of dual specialization within ADL and IADL support.

⁷ As mentioned before, some questions relating to IADLs were filtered in the questionnaire administered to residents. These filtered variables are treated separately in the subsequent analysis.

Children and partners as main sources of informal care for ADLs/IADLs

We have categorized the family situation of nursing home residents into three groups: (i) individuals with a partner (whether they have children or not), (ii) individuals without a partner and with children, (iii) individuals without a partner or children. In terms of how this relates to receiving informal care, around 84% of those with a partner, or with children and no partner, report receiving this care, while the figure stands at only 54% of those who do not have a partner or children.

Table 2 – Informal care receipt, depending on the presence of a partner and children

	<i>Has a partner</i>	<i>Has children but no partner</i>	<i>Has neither children nor a partner</i>
Helped by partner or child	76.5%	77.7%	0.0%
Helped by sibling or parent	1.7%	1.1%	13.1%
Helped by other family member	4.3%	6.3%	28.1%
Helped by friend or other resident	1.9%	2.2%	5.7%
Helped by somebody else	2.4%	1.2%	6.7%
No informal care for ADLs/IADLs	18.0%	18.4%	54.2%

Sample: CARE-I respondents with no missing value on ADL and IADL difficulties (N=3,223). Statistics weighted by survey weights.

Notes: Only caregivers providing help with ADLs/IADLs are taken into account. Each column gives a sum greater than 100%, as individuals may be helped by different categories of informal caregiver. Analysis: 76.5% of individuals with a living partner receive informal care for ADLs/IADLs from their partner or children.

Table 2 shows the share of nursing home residents receiving care from (i) a partner or child, (ii) siblings or parents, (iii) other family members, (iv) friends or other residents, (v) somebody else, or (vi) no one. It shows that most individuals who either have a partner, or children but no partner, receive care from these people. When individuals do not have a partner or children, they mainly receive care from extended family (13% from siblings or parents, 28% from other family members). Overall, informal care from friends, other residents, or other caregivers is not frequent, even for individuals who do not have partner or children. In the absence of close relatives, more than half of this group does not receive any informal care for ADLs/IADLs.

The determinants of receiving informal care in nursing homes

To shed light on the factors that are associated with the receipt of informal care for ADLs/IADLs, we turn to an econometric analysis, which allows us to deploy “all other things being equal” reasoning, and therefore to disentangle the roles played by various factors.

We fit a multivariate Probit model on a binary outcome equal to 1 when the respondent receives informal care with ADL/IADL, or 0 otherwise. The average marginal effect (AME) of each regressor shows the change in outcome associated with a marginal (or one-unit) change in this regressor while all other regressors are held constant. Regressors include (i) sociodemographic characteristics, (ii) functional and health indicators, (iii) measures of potential informal care supply and (iv) the status of the institution (for-profit vs not-for-profit).

We stratify our sample according to the presence of potential informal caregivers. Table 3 presents the results of the Probit estimation on the full sample (Column 1) as well as on the subsamples of individuals with a partner (Column 2), without a partner and with children (Column 3), and with neither partner nor children (Column 4).

Table 3 – Determinants of probability of informal care receipt for ADLs/IADLs

	Dependent variable: Receives informal care			
	<i>All</i>	<i>Partner</i>	<i>Children, no partner</i>	<i>No partner, no children</i>
	(1)	(2)	(3)	(4)
Sociodemographic characteristics:				
Age: [60–75]	-0.17544*** (0.02971)	-0.05253 (0.07736)	-0.23453*** (0.04410)	-0.15265*** (0.05291)
Age: [75–85]	-0.04867** (0.01955)	-0.03477 (0.04342)	-0.05382** (0.02303)	-0.03209 (0.04953)
<i>Reference = Age: [85–90]</i>				
Age: [91–95]	0.04903*** (0.01834)	-0.05682 (0.05467)	0.06415*** (0.01934)	0.04567 (0.05192)
Age: [95+]	0.04151 (0.02587)	-0.02877 (0.09563)	-0.00824 (0.03036)	0.23437*** (0.06589)
Woman	0.03051* (0.01702)	0.00721 (0.03376)	0.05787** (0.02291)	-0.02903 (0.03919)
No diploma	0.00512 (0.01594)	0.04466 (0.03943)	0.01074 (0.01826)	-0.06450 (0.03978)
<i>Reference = Elementary/middle school diploma</i>				
High school diploma (Baccalauréat)	-0.02992 (0.02390)	-0.02382 (0.05401)	-0.00666 (0.02744)	-0.07952 (0.05592)
Disability and health:				
No ADL difficulties	-0.17428*** (0.02423)	-0.24531*** (0.07471)	-0.16476*** (0.03141)	-0.17284*** (0.04678)
<i>Reference = ADL and IADL difficulties but not severely dependent</i>				
Severely dependent	-0.03373** (0.01589)	-0.00100 (0.04075)	-0.03897** (0.01834)	-0.02794 (0.03964)

Positive subjective health	-0.00319 (0.01515)	0.00088 (0.03660)	-0.01864 (0.01686)	0.04397 (0.03918)
Alzheimer's disease	0.00409 (0.01555)	0.05528 (0.03561)	-0.01386 (0.01787)	0.01810 (0.04096)
Family situation:				
<i>Reference = Partner in institution</i>				
Alone	-0.00727 (0.02975)			
Partner at home	0.13373*** (0.02936)	0.06252 (0.04033)		
No child alive	-0.24338*** (0.01974)	-0.11097** (0.05390)		
Closest child in the same city	0.10480*** (0.01762)	0.11877*** (0.03203)	0.08080*** (0.01594)	
<i>Reference = Closest child not in the same city</i>				
Brother or sister alive	0.07169*** (0.01408)	0.08718*** (0.03364)	0.03543** (0.01622)	0.15974*** (0.03556)
Institution type:				
For-profit institution	0.03482** (0.01700)	0.02964 (0.03758)	0.02941 (0.01878)	0.05737 (0.04669)
Observations	3,223	402	2,036	785
Log Likelihood	-1,509.32300	-139.60160	-824.38330	-514.25530
Akaike Inf. Crit.	3,054.64600	313.20320	1,678.76700	1,056.51100

Samples:

- (1) full sample
- (2) individuals with partner, with or without children
- (3) individuals without partner, with children
- (4) individuals without partner and without children

Notes: * $p < 0.1$; ** $p < 0.05$; *** $p < 0.01$. Standard errors clustered at the institution level.

Estimations of Probit models. Average marginal effects are presented. Informal care is defined specifically as help with ADLs or IADLs.

In the full sample (Column 1), we observe a strong effect of variables capturing the potential supply of informal care: having a partner, children, and siblings, and how close to the respondent they live. Stronger effects are found for the presence of children and partner. Having a child in the same city, compared to having a child who does not live in the same city, increases the probability of receiving informal care by 10 percentage points (pp), while having no child decreases it by 24 pp. Having a partner at home (thus plausibly in relatively good health) compared to having a partner in an institution or having no partner increases the chance of receiving informal care by 13 pp. This confirms our interest in stratifying the analysis according to marital status and presence of children. The presence of siblings significantly increases the probability of receiving informal care—an effect that presents itself regardless of the presence of a partner or children.

In the full sample, the second group of variables affecting the probability of receiving informal care are age, sex, and functional status. Older individuals and women have a higher probability of receiving this care, with other variables having an equal effect. Compared to individuals with both ADL and IADL difficulties but who are not severely disabled, individuals without ADL difficulties are less likely to declare informal care. Severely disabled individuals, however, have a slightly *lower* probability (3 pp) of receiving informal care, possibly demonstrating that their relatives are no longer able to provide it, given the skills that such care would require. Interestingly, when used as a control for the severity of ADL/IADL difficulties, dementia is not associated with a higher probability of receiving ADL/IADL support.

Finally, individuals in for-profit institutions have a higher probability of receiving informal care. This might be because for-profit institutions have a different informal support policy and generally have a lower staff-to-resident ratio (Reynaud, 2020). Alternatively, it might reflect unobserved differences between residents in different types of nursing home. For example, individuals in for-profit nursing homes tend to have larger families as well as greater economic and social resources (Trépiéd, 2014).

Turning to the subsample estimates, we observe that for individuals with a partner (Column 2), the presence of informal care is much less sensitive to the determinants we have considered. Apart from the positive effect of having close relatives (children, siblings) or a partner in good health (proxied by having a partner at home), only the disability level is found to affect the probability of receiving informal care. Despite the small sample (402 observations), point estimates suggest marginal effects close to zero with small standard errors. Thus, our estimates suggest that receiving care from relatives—with the partner generally giving the most informal care—depends little on the care recipients' personal characteristics.

Among individuals with children but without a partner (Column 3), age and health correlates to the presence of informal care, like in the full sample. These effects are also observed for individuals without partner or children (Column 4), except for severely disabled individuals who do not have a lower probability in declaring the presence of informal care. Moreover, this last subgroup is the only one in which education level affects the probability of declaring informal care: individuals with no diploma have a slightly lower probability in this regard. For those individuals with no potential caregivers within the nuclear family, informal caregiving might depend more on social capital, which correlates positively to education level.

Overall, individuals who are the most likely to receive informal care are those with existing close relatives (partner, children, siblings). Age and functional status are also associated with informal care, with older and disabled individuals more likely to declare its presence.

Discussion

Informal care in nursing homes and the expected impact of restrictions related to COVID-19

Our empirical investigation sheds light on the consequences of restrictions on visits in nursing homes. Individuals who are the most likely to suffer from visiting restrictions are those who are older and with some health limitations, who have a living partner, living children, or living siblings. Since most residents receive ADL/IADL support from relatives outside the nursing home, their absence implies that residents may have been limited in the accomplishment of some tasks during the pandemic. These tasks mainly encompass administrative tasks and mobility-related activities. Without visits, administrative tasks might have been postponed, passed onto professional caregivers or performed by caregivers remotely. Regarding mobility, it is likely that even without visiting restrictions, mobility outside of the institution would have been limited by the restrictions applying to the general population or by the general health context. Visiting restrictions would have then, more specifically, been likely to affect mobility within the institution or in its close vicinity (e.g., walks outside). Yet even small-scale mobility is critical at old age, as it is a matter of “use it or lose it” (Hultsch *et al.*, 1999; Rantanen, 2013). Sarcopenia, frailty, and loss of balance may be accentuated by a reduction in physical activity (see, e.g., Piastra *et al.*, 2018) and may in turn lead to more severe activity restrictions (Cambois, Robine and Romieu, 2005) and thus higher long-term care costs, but also to adverse health events and higher healthcare costs (Sicsic and Rapp, 2019).

Finally, ADL/IADL support is, in normal times, associated with moral support. The visiting restrictions question the ways relatives have been able to provide this latter form of support to residents while not being able to come to the nursing home in person. Let alone the fundamental rights of nursing home residents regarding their immediate quality of life, the benefits of visiting restrictions (in terms of a lower COVID-19 infection risk) should be assessed against their costs, in terms of the deteriorating physical and mental health that could be induced by the lack of moral and mobility support usually provided by visitors. Local and pilot initiatives during the COVID-19 crisis have shown that visits from relatives can be organized using strict guidelines, thus allowing family connections to be maintained while efficiently limiting contagion risk (Verbeek *et al.*, 2020).

Limitations

Our analysis has four types of limitations. The first relates to data. Most of the information depends on nursing home residents' own declarations, in particular to identify caregivers and the nature of care they provide. It is possible that some caregivers or tasks were forgotten. Furthermore, given the poor health and cognitive difficulties of many nursing home residents, 65% of respondents were assisted by a proxy respondent during the survey; 57.5% of these were relatives and 42.5%

were professional workers (Drees, 2019). It is difficult to predict how the presence of a proxy may affect declarations of receiving informal care.

Second, from a methodological viewpoint, we did not rely on data collected while visiting restrictions were in place. We have no information on which specific activities were prevented, for how long and for how many nursing home residents, beyond what the national measures stated. Surveying nursing home residents during a pandemic is challenging precisely because of the protective measures. Given this methodological challenge, we believe that improving our knowledge about the living situation of nursing home residents prior to the COVID-19 outbreak is an essential way of understanding and mitigating the adverse consequences of pandemics and epidemics on this population in general, beyond the specific example of COVID-19.

Finally, our study is limited in its scope, and as such we hope to pave the way for further investigation. Our aim was not to assess how informal care affects the wellbeing of residents or their mental and physical health in normal times, however such an exercise would be useful to estimate how these outcomes were affected by the visiting restrictions. Furthermore, we only focused on informal care, leaving aside both professional care and care provided by volunteers. The latter may play an important role in providing care for socially isolated residents and may also have been negatively affected by the visiting restrictions. Future research is warranted on the effect of the visiting restrictions on professional caregivers, their workload, and whether the nature of the tasks they perform changed in the absence of informal caregivers and volunteers. Such analyses would contribute further to understanding how the visiting restrictions affected the level and the quality of care received by nursing home residents, as well as their quality of life.

Conclusion

This paper describes the characteristics of informal care in French nursing homes in “normal times,” i.e., before the COVID-19 outbreak. 75% of residents receive some form of help from relatives, who are primarily involved in ADL/IADL support, in particular administrative tasks (budget management, paperwork, administrative procedures) and activities related to mobility and the outside world (moving in and out of the institution, finding their way, shopping). Receiving such help is almost always associated with receiving moral support. Individuals who are the most likely to receive informal care are those with close relatives who are still alive (partner, children, siblings), when other control variables such as disability, health, age, gender, and education are held constant. Age and health status are important factors affecting the presence of informal care, with younger and less disabled individuals being less likely to declare receiving such care. Overall, this paper highlights the role of relatives for nursing home residents. Such evidence questions the implications of visiting restrictions during the COVID-19 crisis for nursing home residents.

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Appendix

[This version: October 30th, 2021]

This Appendix contains information on the data used in the empirical analyses and the data treatment decisions that were made. In addition, it provides a description of the scripts containing the code for outputting the results presented in the article.

Additional details on the CARE-Institutions survey

We first provide additional information regarding the CARE-Institutions survey, in connection to our research question and analyses.

Sampling procedure and questionnaires

The sampling was carried out in two steps. First, a sample of long-term care institutions was drawn and surveyed, and the list of residents in these institutions retrieved. Second, a sample of permanent residents was drawn from within each institution.

A facility-level questionnaire (*Questionnaire Etablissements*) was used to collect general information about the institution and some personal information about the residents surveyed (e.g., public long-term care transfers received). A second questionnaire, containing most of the variables we used in our analysis, was administered to the selected residents or to proxy respondents (*Questionnaire Seniors*).

3,262 respondents from 616 institutions participated in the survey. Due to the compulsory nature of the survey the response rate was high (88% at the institution level and 86% at the respondent level).

Scope of the survey

Long-term care institutions include non-medicalized nursing homes (EHPAs, établissement d'hébergement pour personnes âgées), nursing homes offering a high level of medical care (EHPADs, établissement d'hébergement pour personnes âgées dépendantes), and long-term care units in hospitals (USLDs, unités de soins de longue durée).

In English, EHPA stands for “accommodation for older people”; these institutions host individuals with no or limited activity restrictions (GIR 5 and 6, on the disability scale used by the French administration). Professional workers perform tasks relating to room and board, personal hygiene, medication management, and social interaction. Residents may benefit from paramedical care and medical surveillance by external professionals. EHPAD stands for “accommodation for dependent older people”; these institutions host individuals with activity

restrictions (GIR 1 to 4). Residents are provided with medical surveillance, nursing care, and personal care. Finally, USLD stands for “long-term health units”, which are hospital units dedicated to hosting dependent individuals with very high medical care needs. EHPAs, EHPADs and USLDs cater exclusively to individuals aged 60+.

Residents of intermediate housing facilities (*résidences services* et *residences autonomes*, formerly known as *foyers logements*) were surveyed in the CARE-Ménages survey and not the CARE-Institutions survey.

Filters on IADL-related questions

In the facility-level questionnaire, residents were asked whether they could independently: (i) go grocery shopping, (ii) perform domestic chores, (iii) prepare meals, (iv) manage medication, and (v) move around. Within institutions in which one or several activities were typically not allowed for residents, respondents were not asked questions about those restricted activities.

Data treatment

Version of the survey

The curator of the survey (Drees) may release updates to the survey. Our analysis relies on version v2_190822.

Statistical software

The analysis was executed using software R, version 4.0.2.

Missing values

We only had to disregard 39 observations, for which information on activity restrictions was missing. Our baseline sample counts 3,223 respondents.

When the respondent did not answer the question “Do you have a partner?” we counted this answer as “no living partner.” 4.8% of those who responded they had a partner did not report where the partner lived. We then assumed that the partner lived in the community, rather than in an institution. Along the same lines, we considered that those who did not answer the question “Do you have any children (including adopted children)?” had no living children.

Declaration of ADL/IADL caregivers

Discrepancy may occur between the initial declaration of some respondents and the preceding information they offered about the care provided by each of their caregivers (e.g., the respondent declares not being helped for grooming, but later reports that caregiver X helps with grooming). The curator of the survey (Drees) used information provided for each caregiver to construct and release corrected versions of the respondent-level dummy variables for informal care receipt for

each ADL and IADL (variables RAAIDENT_R1 to RAAIDENT_R13). We created a dummy variable indicating ADL/IADL support if the respondent is helped for at least one ADL or IADL (i.e., at least one of dummies RAAIDENT_R1 to RAAIDENT_R13 is equal to 1).

In the same vein, two corrected variables, AIDENTFI_C and AIDENTSOU_C, were released; they indicate whether the respondent receives any financial or moral support respectively, based on both their initial declaration and the further information provided about each of their caregivers. We used these corrected variables to document how common financial support and moral support are.

Relationship between respondent and caregiver(s)

Detailed information on the caregivers reported by the (proxy) respondents is contained in a dataset at the caregiver level. It contains a variable, LIENSENAID, that provides the relationship between the respondent and their informal caregiver (e.g., their partner, their sibling, etc.). This variable is used to retrieve the proportion of individuals who receive ADL/IADL support from different categories of relatives, defined as follows:

- Helped by child or partner
- Helped by siblings or parents
- Helped by other relative (grandchild, daughter- or son-in-law, mother- or father-in-law, niece, nephew, aunt, uncle, cousin, other relative)
- Helped by friend or another member of the institution who is not a professional caregiver (assumed to be another resident)
- Helped by someone else (i.e., not a family member or friend; or someone whose relationship with the respondent is unknown).

The data reveal an inconsistency: a small number of individuals with no children nor partner—as recorded in the survey—receive help from children or a partner (less than 2%). To categorize these caregivers, we have assumed that respondents were helped by another family member.

Furthermore, there is a small discrepancy between the number of individuals receiving informal care for ADLs or IADLs based on the LIENSENAID variable, and that computed based the respondent-level variables provided in the survey (dummies RAAIDENT_R1 to RAAIDENT_R13, see above). This discrepancy is small, and mainly visible for the subgroup of individuals who have no living partner or children: with our baseline definition, 56% of them do not receive informal care for ADLs or IADLs, but the figure becomes 54% when calculating this proportion using LIENSENAID.

Scripts

The code is split into several scripts.

- **0.Data.R**

It loads two datasets from the CARE survey that will be used in the analyses:

- carei_sen_seniors_v2_190822.dta (dataset at the respondent level)
- carei_sen_aidants_v2_190822.dta (dataset at the informal caregiver level)
- carei_sen_enfants_v2_190822.dta (dataset at the children level)

From the respondent dataset—the first dataset in the list above—we proceed to drop the 39 observations which had no response to the questions about activity restrictions.

- **1.Variables.R**

This code creates the variables used to produce the main descriptive statistics and econometric analysis.

It runs after 0.Data.R.

- **2.DS.R**

This code outputs the general descriptive statistics displayed in Table 1 of the article, as well as the weighted proportions of individuals with ADL difficulties (Figure 1), the weighted proportions of individuals with IADL difficulties (Figure 2), and the weighted proportions of individuals who are helped with both ADLs and IADLs (Figure 4).

It runs after 0.Data.R and 1.Variables.R.

- **3.Spider_charts.R**

This code outputs Figure 1, Figure 2, and Figure 4, based on statistics computed in 2.DS.R.

It runs after 0.Data.R and 1.Variables.R and 2.DS.R.

- **4.Venn.R**

This code computes the proportion of individuals receiving combinations of different informal care types, and it outputs Figure 3.

It runs after 0.Data.R.

- **5.Caregivers.R**

This code links respondent-level information with caregiver-level information to retrieve the relationship between the two individuals. It computes the probability of receiving care from certain types of relatives, depending on the presence of a partner or children.

It runs after 0.Data.R.



- ***6.Extensive_margin.R***

This code produces estimates from the econometric analyses (determinants of the probability to receive informal care), for the entire sample and by the sub-samples defined by the presence of a partner and/or children. It outputs Table 3.

It runs after 0.Data.R and 1.Variables.R.