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# Caregiving and care receiving across Europe in times of COVID-19

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## Caregiving and care receiving across Europe in times of COVID-19

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*Abstract:* The first wave of the COVID-19 pandemic hit the European countries at the beginning of 2020. This has become particularly problematic for those in need for personal care as related epidemiological control measures (physical distancing, stay-at-home requirements etc.) installed in almost all European countries strongly affected the possibility to provide care to others as well as to receive care from people outside the own household. Against this background, this paper focus on how caregivers and care recipients living at home (the non-institutionalized) dealt with the situation using preliminary data from the 8<sup>th</sup> wave of the Survey of Health, Ageing and Retirement in Europe (SHARE) until its suspension in March 2020 and the SHARE Corona Survey fielded from June to August 2020. Concretely, we analyzed the effects of the pandemic as well as accompanying public health measures on those giving as well as receiving personal care by exploring country differences on COVID-19-related changes. Our results show that giving personal care to parents has increased, while care to children, in turn, has decreased. Further, about one out of five care recipients had difficulties in obtaining personal care during the pandemic, which was mainly because carers could not come to the home of the care recipients. In addition, country differences played an important role in explaining perceived difficulties in receiving home care and hence are an important starting point for policy makers and social organizations.

*Zusammenfassung:* Die erste Welle der COVID-19-Pandemie traf die europäischen Länder zu Beginn des Jahres 2020. Dies war besonders problematisch für diejenigen, die persönliche Pflege benötigen, da in fast allen europäischen Ländern epidemiologische Kontrollmaßnahmen („Physical Distancing“, Kontaktbeschränkungen etc.) eingeführt wurden, welche die Möglichkeit der Pflege von Menschen außerhalb des eigenen Haushalts stark beeinträchtigten. Vor diesem Hintergrund beschäftigt sich dieses Papier insbesondere damit, wie Pflegepersonen und Pflegebedürftige, die zu Hause leben, diese schwierige Situation erlebt haben. Hierfür verwenden wir vorläufige Daten aus der achten Welle des Survey of Health, Ageing and Retirement in Europe (SHARE), die bis März 2020 durchgeführt werden konnte, sowie die von Juni bis August 2020 laufende SHARE Corona Umfrage. Konkret analysierten wir die Auswirkungen der Pandemie sowie die hiermit verbundenen Kontrollmaßnahmen im Bereich der öffentlichen Gesundheit auf Pflegende sowie Pflegebedürftige in den unterschiedlich stark betroffenen Ländern in Europa. Unsere Ergebnisse zeigen, dass die persönliche Pflege der Eltern seit Ausbruch von COVID-19 stark zugenommen hat, während die Betreuung der Kinder in gleicher Weise abgenommen hat. Darüber hinaus hatte etwa jede/r fünfte Pflegebedürftige Schwierigkeiten, während der Pandemie die notwendige persönliche Pflege zu erhalten. Dies war hauptsächlich darauf zurückzuführen, dass Pflegende nicht zu den Pflegebedürftigen nach Hause kommen konnten. Darüber hinaus spielten Länderunterschiede eine wichtige Rolle bei der Erklärung der wahrgenommenen Schwierigkeiten

hinsichtlich häuslicher Pflege und sind daher ein wichtiger Ausgangspunkt für politische Entscheidungsträger und soziale Organisationen.

*Keywords:* SHARE; COVID-19; public health measures; physical distancing; physical and mental health

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# 1. Background

The first wave of the COVID-19 pandemic, which hit the European countries at the beginning of 2020, has especially impacted those in need for care and those providing the care needed. While media attention mainly focused on the problematic and often dramatic situation in nursing homes, a major part of care in Europe is provided to people living at home (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011; Eurocarers, 2020; Genet, Boerma, Kroneman, Hutchinson, & Saltman, 2012). This home care is often provided by cohabitating family members, but also by family members from outside the household (mainly female children) or by paid service providers (Fischer & Geyer, 2020; Li & Song, 2019; Vlachantoni, Shaw, Evandrou, & Falkingham, 2015). In the context of the COVID-19 pandemic, physical distancing and other epidemic control measures (e.g. stay-at-home requirements, travel restrictions etc.) installed in almost all European countries have restricted individuals' access to both formal and informal support resources (Evandrou, Falkingham, Qin, & Vlachantoni, 2020; Lorenz-Dant, 2020; Park, 2020; Rothgang et al., 2020). Particularly, older people and individuals with chronic medical conditions, were advised to stay at home as much as possible, raising concerns about the provision of personal care. In addition to these accompanying or *indirect* effects of the pandemic, there are *direct* effects of the virus itself that might influence the provision of personal care. Thus, it is obvious that caregivers who provide personal care to family members outside the own household are of higher risk to get infected by COVID-19 themselves as they regularly travel to and meet with care recipients, accompany them to doctors and hospitals, and often also do grocery shopping for them. Fearing an infection as well as fearing to infect someone close, therefore, might also have an impact on the frequency and amount of providing informal care but also to make use of it (Giebel, Hanna, et al., 2020). Taken together, these direct and indirect effects of the pandemic can be assumed to a) increase the intensity and burden for caregivers and b) lead to a worsening of the situation for those who rely on personal care as less care will be provided and the remaining amount does not meet the needs of care recipients anymore. In this respect, it is crucial to examine how private care networks were affected by the pandemic and to which degree personal care could be provided to those who need it the most. Further, our knowledge of possible negative effects of the pandemic on physical and mental health of care recipients as well as caregiving family members is still limited. In particular, we lack reliable and internationally comparable evidence that can increase our knowledge about country differences regarding the challenges caregivers and care recipients are facing during the COVID-19 pandemic as well as with regard to the handling of the pandemic by national governments.

## 1.1 COVID-19 and the situation for informal caregivers

Informal care usually is done by one main caregiver who is supported by other family members and/or by additional formal care providers, the so-called support or care network (e.g. Andersson & Monin, 2018; CarersUK, 2020). During the pandemic, these additional family caregivers often reduced their contacts either voluntarily or forcedly to avoid transmission of the virus and/or to reduce their own risk of infection (Eggert, Teubner, Budnick, Gellert, & Kuhlmeier, 2020). This led to smaller care networks and hence to more responsibility for the main caregiver. Further, many informal caregivers usually receive support from formal care providers, who often had to close, reduce, or re-arrange services since the outbreak of the

pandemic (see COVID-19 Health System Response Monitor<sup>1</sup>). In Germany, for example, the provision of ambulant care was affected by staff shortage (Wolf-Ostermann et al., 2020). In addition, day care and night care centers had to close (Eggert et al., 2020) and rehabilitation centers and hospitals sent their patients home in order to free capacity for expected COVID-19 patients (Caritas, 2020). Also, many live-in migrant care workers returned to their home countries during the pandemic and were unable to cross European borders afterwards as many work without an official working contract (Leiblfinger et al., 2020; Safuta & Noack, 2020). As a consequence, many (single-country) studies report a substantial increase of carers helping people outside their own household and of the average time spent on caring (CarersUK, 2020; Greenberg, Wallick, & Brown, 2020; ONS, 2020; Rothgang et al., 2020). Concerning the situation of caregivers, Eggert et al. (2020) provide evidence that one out of three caregivers in Germany reported a worsening of the care situation after the outbreak of COVID-19. Evidence from several countries shows that large proportions of caregivers have experienced increased burden and stress related symptoms like trouble sleeping since the outbreak of the pandemic (e.g. Cagnin et al., 2020; CarersUK, 2020; Cohen, Russo, Campos, & Allegri, 2020; Rothgang et al., 2020). Further, informal caregivers frequently reported a worsened physical and mental health, such as being depressed or anxious as well as feeling more socially isolated and lonely (e.g. Bennett, Zhang, & Yeandle, 2020; Roach et al., 2020; Rothgang et al., 2020).

## *1.2 COVID-19 and the situation for care recipients*

Compared to caregivers, evidence how the pandemic and its accompanying epidemic control measures affected care recipients is scarcer. For example, we currently still lack comprehensive knowledge whether care receivers had more unmet (health) care needs during the first wave of the pandemic. As older care receivers often have the greatest risk on their health from being infected with COVID-19, they typically are in higher need for health care. In addition, it is long known that meeting older people's care needs is crucial for maintaining their mental and physical wellbeing (Allen, Piette, & Mor, 2014). Compared with older adults receiving adequate care, those reporting unmet needs hence face greater challenges. Since the outbreak of the pandemic it can be assumed that such challenges have strongly increased. While evidence was mixed in the beginning regarding physical and mental health (Killgore, Cloonan, Taylor, Miller, & Dailey, 2020; but: Luchetti et al., 2020; ONS, 2020) more and more studies now are reporting higher depression and greater loneliness following the onset of the pandemic with respect to older adults (Killgore, Cloonan, Taylor, Lucas, & Dailey, 2020; Krendl & Perry, 2020; Wong et al., 2020) well as higher levels of stress, anxiety, and depression regarding people with health problems or dementia (Giebel, Cannon, et al., 2020; Giebel, Lord, et al., 2020; Wang et al., 2020). In this respect, other studies emphasized reduced opportunities for social interaction and made use of examples where caregivers reported that their relatives with dementia were frustrated as it was difficult for them to understand why they should not go out or had to reduce contacts (Roach et al., 2020). This coincides with observations that caregivers in many countries report a worsening of the care situation (e.g. Giebel, Cannon, et al., 2020; Rothgang et

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<sup>1</sup> The COVID-19 Health System Response Monitor, a joint undertaking of the WHO Regional Office for Europe, the European Commission, and the European Observatory on Health Systems and Policies, provides a comprehensive overview of policy measures also with regard to formal care (<https://www.covid19healthsystem.org>).

al., 2020). Therefore, it is likely that such a worsening will also be noticed by care recipients. In this respect, Comas-Herrera et al. (2020) presented indications that the quality of social care services to older adults decreased during the early stages of the pandemic. This can partly be attributed to government distancing guidelines and travel restrictions, which also affected care recipients who rely on the provision of care by people from outside their own household. A study of older adults in the UK during the early stages of lockdown found that public health measures disrupted individuals' access to medical care, including accessing medications and cancellation or delays of doctors' appointments and surgeries (Moss, 2020). Another British study found that around 40% of outpatient and 60% of inpatient care was cancelled by the National Health Service in spring 2020 and that 20% of the patients cancelled their doctor's visits by themselves (Benzeval et al., 2020). In contrast, there is also evidence that the majority of caregivers, particularly when providing personal care to people with more advanced health conditions like dementia, maintained their services (Cohen et al., 2020). Thus, it can be assumed as well that care recipients with severe chronic conditions will be prioritized by the health care system as a vulnerable and high-risk group. Finally, epidemic control measures affected informal caregivers and the care recipients alike, but the intensity and the duration of these measures (as well as its perception and adherence) differed across countries and hence might have exhibited effects in varying degrees. Therefore, it is crucial to relate country-specific conditions to both changes in caregiving behavior and unmet care needs of care recipients.

Against this background, we focus on how family caregivers and care recipients in Europe experienced and dealt with the situation during the first wave of the COVID-19 pandemic in spring/summer 2020. We contribute to the existing literature by restricting our analyses to personal caregiving and care receipt to and from outside the household. In this respect, we explicitly exclude more common forms of help and support (e.g. obtain necessities like food, medications or emergency household repairs) to analyze the direct and indirect effects of COVID-19 for care recipients who rely on personal care and caregivers who provide care to those in need, because these two groups are most directly and severely affected by the pandemic. With respect to caregivers, we want to give answers to the following research questions:

- 1) How were private care networks affected by the pandemic? Was there a change in the frequency of providing informal care to others outside the own household and if yes, were there differences by the type of relation between caregiver and care recipient?
- 2) Was caregiving associated with higher physical and mental health strains compared to non-caregivers?

When focusing on care recipients, we are interested in answering the following research questions:

- 3) Did care recipients report a worsening of their physical and mental health compared to non-care recipients?
- 4) Did care recipients indicate a worsening of their situation with respect to pursuing planned medical treatments compared to non-care recipients?

Our study makes several contributions to the literature. First, our results are based on a large, high quality survey derived from full probability samples and including 27 European countries plus Israel. The country-

comparative perspective enables us to better understand the effects and consequences of a global pandemic like COVID-19 and hence is superior to studies from single countries, which can only reflect a small part of the whole picture. Second, by extending survey data collected during the first phase of the pandemic with panel information collected before the outbreak of the pandemic, we are able to use the full wealth of information on the situation of people 50+ who have been hit most hard by COVID-19. In particular, we know details of their economic and health situation as well as on their care dependency that can feed our analyses. This provides us with crucial context information on households' situations before the outbreak of the pandemic and enables us to thoroughly investigate how COVID-19 has changed the situation of informal caregivers and care recipients and what are the consequences thereof. Finally, our results can increase our understanding with regard to what support is needed most by both informal carers and care recipients due to the direct and indirect effects of COVID-19. This is important for finding common responses to the short-, mid- and long-term consequences of the pandemic by policy makers and social organizations. The remainder of this paper is organized as follows: In section 2, we describe the data used for the analyses and our analysis strategy. Afterwards, we first explore changes in caregiving during the first phase of the pandemic (section 3.1) and then focus on care receiving and the problems care recipients faced in receiving the care they need in spring/summer 2020 (section 3.2). Finally, in section 4, we discuss our findings and their implications.

## **2. Data and Methods**

### *2.1 Data source*

The following analyses use Wave 8 (release 0) data from the Survey of Health, Ageing and Retirement in Europe (SHARE; Börsch-Supan et al., 2013) until its suspension in March 2020 (Börsch-Supan, 2020j) and the SHARE Corona Survey fielded from June to August 2020 (Börsch-Supan, 2020i). SHARE is a multidisciplinary panel study, providing information on health, socioeconomic status, and social and family networks of respondents aged 50 and over. From 2004, data were collected every two years in person (Computer Assisted Personal Interview; CAPI). By its eighth wave, SHARE included 27 European countries plus Israel. While all waves so far have been conducted face-to-face, the SHARE Corona Survey was done by telephone (Computer Assisted Telephone Interview; CATI) and covers the most important life domains for the target population and asks specific questions about infections and life during the lockdown. For most countries, the SHARE Corona Survey is based on the whole national SHARE panel sample, including both panel members who had not been interviewed before the suspension of fieldwork and panel members who had already been interviewed face-to-face in Wave 8. Only in two countries (the Netherlands and Sweden) a stratified sub-sample based on region of the panel households had to be selected due to funding. Our analyses are based on data from the SHARE Corona Survey for 51,983 respondents over 50 years.<sup>2</sup> The preliminary average individual retention rate based on eligible

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<sup>2</sup> We decided to exclude Austria from our analyses, because fieldwork could only start there beginning of August when most other countries nearly finished the SHARE Corona Survey. At this point in time, however, the lockdown

respondents participating in Wave 8 was 79 percent, ranging from 58 percent (Luxembourg) to 96 percent (Romania). 18,398 respondents conducted only the SHARE Corona telephone interview after the outbreak of the pandemic, but could not be successfully approached in person before the suspension of the Wave 8 fieldwork. These data have been carefully augmented with information from previous waves where appropriate (Börsch-Supan, 2020a, 2020b, 2020c, 2020d, 2020e, 2020f, 2020g, 2020h). The SHARE data are unanimous based on full probability samples (Bergmann, Bethmann, & De Luca, 2019; Bergmann, Kneip, De Luca, & Scherpenzeel, 2019), providing internationally comparable data that can add important insights to recent studies, which are frequently restricted to the national level. Both the methodological rigor and the cross-country harmonization of SHARE are necessary prerequisites to properly investigate the direct and indirect effects of a global pandemic like COVID-19 and hence support evidence-based policy-making. In this respect, our results offer a unique perspective that allows to compare how the high-risk group of older respondents coped with the crisis, how the national health care and social systems responded to the pandemic, and which lessons should be drawn from the variability between countries for the future.

## 2.2 Measures

*Caregiving and care receiving:* In our analyses, we focused on informal (i.e. non-professional, unpaid) caregiving and care receiving, excluding more common forms of help or support to obtain necessities like food or medications (for the latter see, e.g., Kaschowitz & Brandt, 2017). Caregiving was measured by the following question: “Since the outbreak of Corona, did you provide personal care to others outside your home?”, followed by a request to indicate the frequency and the recipient of the caregiving activities (if applicable): “How often did you provide personal care to the following people from outside your home compared to before the outbreak of Corona; less often, about the same, or more often?”. The list of recipients included own children, own parents, other relatives, and other non-relatives like neighbors, friends, or colleagues. Care receiving was asked the following way: “Did you regularly receive home care before the outbreak of Corona?”. In contrast to caregiving, there were no follow-up questions on the frequency or on the provider of personal care. Instead, we used the respondents’ answers on possible difficulties in receiving personal care for our analyses: “Since the outbreak of Corona, did you face more difficulties in getting the amount of home care that you need?”.

*COVID-19-related health outcomes:* To explore the direct and indirect effects of the pandemic, we included several indicators that measured changes in respondent’s physical and mental health since the outbreak of the COVID-19 crisis. In this respect, we generated dichotomized variables that indicate a worsening of respondents’ self-rated health as well as worsening indications of depression, anxiousness, sleeping problems, and loneliness. In addition, we included a measure that indicates whether the respondent was directly affected by COVID-19, using a set of questions on a) having experienced symptoms, b) having been

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measures had already been lifted again and thus answers from Austria are not directly comparable to those from other countries.

tested<sup>3</sup> for COVID-19, and c) having been hospitalized. For analyzing the associations with care receiving, we further included two dichotomized variables measuring problems regarding a continuation of medical treatments since the outbreak of the pandemic: first, whether a medical treatment was cancelled by the respondents themselves because of being afraid to become infected and, second, whether a planned medical treatment was postponed or denied by the doctor or medical facility.<sup>4</sup>

Covariates that potentially confound the relationship with caregiving and care receiving were selected according to existing knowledge regarding their predictors (see, e.g., Litwin, Stoeckel, & Roll, 2014; Sacco, König, Westerlund, & Platts, 2020; Wajnberg et al., 2016) and included the following:

*Socio-demographics:* We included the respondent's sex (0: male, 1: female) and her/his age at interview. Further, we coded the level of education attained based on the International Standard Classification of Education 1997 (ISCED-97). Respondents were then grouped into three categories (see, e.g., Avendano, Jürges, & Mackenbach, 2009): primary education (ISCED-97 score: 0-2), secondary education (ISCED-97 score: 3), and post-secondary education (ISCED-97 score: 4-6).

*Living conditions:* From the coverscreen we used information on the respondent's household composition (0: living with a partner, 1: living alone) and the type of her/his living area (0: rural area, 1: urban area like large town or big city). Further, we measured the respondent's economic status by a question that asks the degree to which respondents could make ends meet (0: with great/some difficulty, 1: fairly easily/easily) and included a measure whether the respondent was employed (including self-employment) or not.

*Physical health before the pandemic:* To control respondent's physical health before the pandemic, we used indicators from the previous SHARE waves that have been conducted before the outbreak of COVID-19. In this respect, we used the reversed 5-point scale on respondents' self-rated health (0: poor, 1: fair, 2: good, 3: very good, 4: excellent). Further, we used three disability measures to measure (a) difficulties in basic activities of daily living (ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), such as dressing, walking, bathing/showering, or using the toilet (0: no limitations, 1:  $\geq 1$  limitation), (b) difficulties in instrumental activities of daily living (IADL; Lawton & Brody, 1969), such as using a map, preparing a meal, shopping for groceries, or making telephone calls (0: no limitations, 1:  $\geq 1$  limitation), and (c) long-standing activity limitations based on the Global Activity Limitation Index (GALI; van Oyen, Van der Heyden, Perenboom, & Jagger, 2006) that refers to general health problems in activities people usually do (0: not limited, 1: somewhat/severely limited).

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<sup>3</sup> We did not distinguish between a positive and a negative test result and considered both cases as being affected.

<sup>4</sup> The second indicator was based on the following two questions: "Did you have a medical appointment scheduled, which the doctor or medical facility decided to postpone due to Corona?" and "Did you ask for an appointment for a medical treatment since the outbreak of Corona and did not get one?"

### *2.3 Analysis strategy*

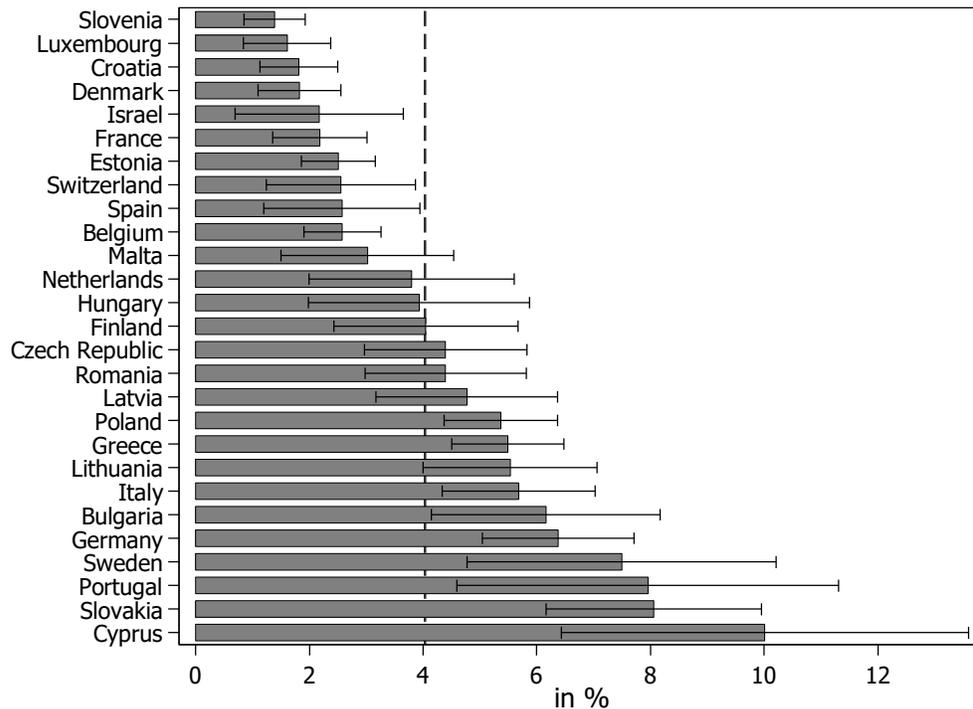
We restrict our analyses to caregiving and care receiving to and from someone outside the own household, because other than personal care within the same household we expect that care activities outside the own household were more severely affected by the pandemic and accompanying public health measures, such as physical distancing or stay-at-home requirements. To address our research questions, we first descriptively looked at country differences regarding the prevalence of providing and receiving personal care since the outbreak of the COVID-19 crisis. Afterwards, we investigated differences in relevant health-related outcomes between caregivers and care recipients on the one side and respondents who did not provide care to or receive home care from someone outside the own household on the other side. Here, we were particularly interested in differences with regard to a worsening of physical and mental health as well as the degree of affectedness by COVID-19. In this respect, we used comparisons of adjusted predictions, controlling for a large set of individual respondents characteristics. In particular, we controlled for respondents' sex, age, level of education, household composition (i.e. living alone or with a partner), area of living (rural vs. urban), subjective economic status, and whether the respondent was (self-) employed before the pandemic. Further, we controlled for respondents self-rated health and limitations in (instrumental) activities of daily living (ADL, IADL), as well as in activities people usually do (GALI) due to long-standing health problems before the pandemic. Finally, country dummies were included to control for regional differences. With this approach we were able to compare two hypothetical populations (e.g. non-caregivers and caregivers) that have identical values on all independent variables included in the model. The logic is similar to that of a matching study: Because the only difference between the two populations is the provision/receipt of care, caregiving/care receiving can be attributed with much more confidence as the cause of differences in the probabilities of reporting physical and mental health strains (see Williams, 2012).

## **3. Analyses**

### *3.1 Caregiving during the pandemic*

We started our analyses by having a look at the overall prevalence of caregiving across Europe during the first phase of the pandemic. On average, four percent of all respondents (n=1710) indicated that they provided personal care (excluding general help to obtain necessities like food or medications) to someone outside the own household since the outbreak of the pandemic. Figure 1 shows rather large differences between countries. While Slovenia brought up the rear with only 1.4 percent, in Cyprus respondents provided care about seven times more often (10.0 percent). In addition, it was noticeable that due to the small sample size, standard errors were quite large in some countries. Further, there was no clear pattern visible with respect to region, but except from Germany and Sweden, only countries from South-Eastern Europe exhibited a prevalence of providing personal care significantly above the average.

Figure 1: Percent of respondents providing personal care to others outside the own household since the outbreak of the pandemic



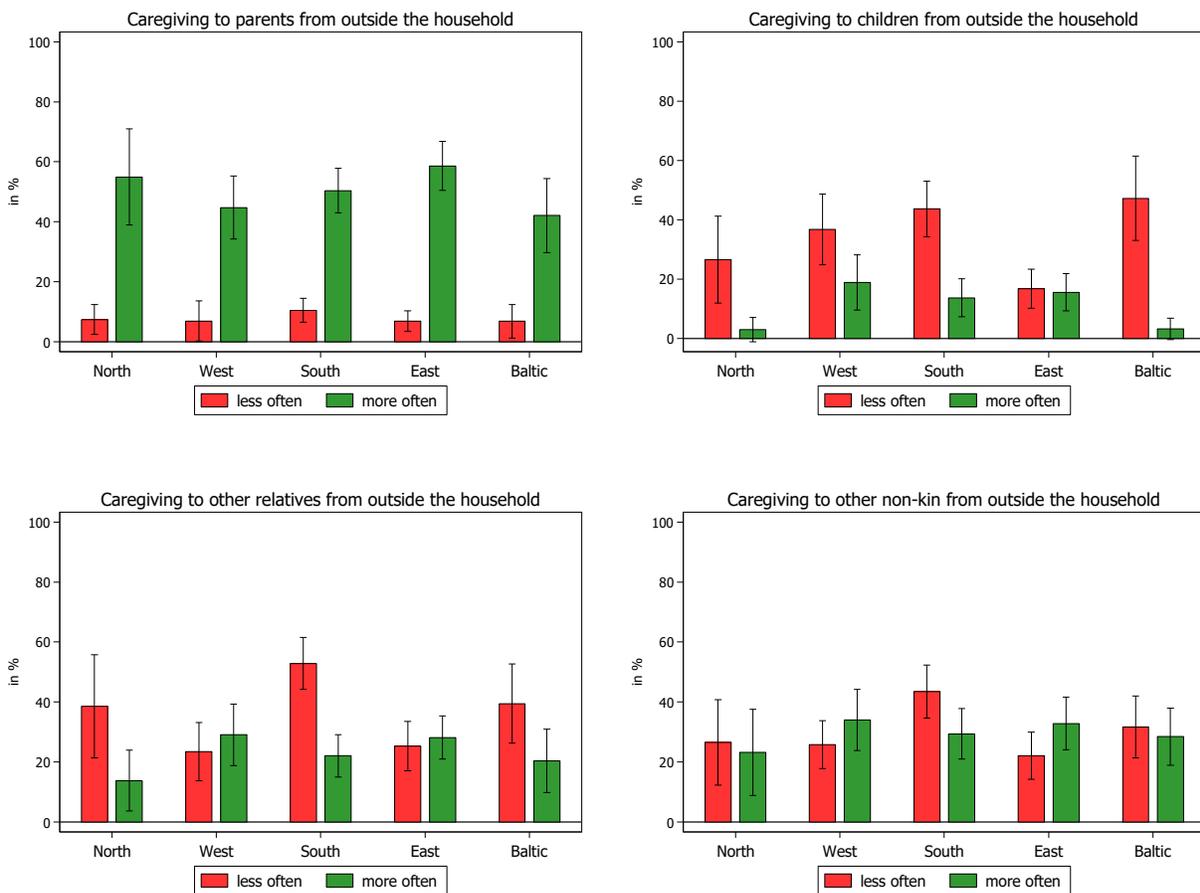
Data: SHARE COVID-19 Survey Release 0.0.1 beta (n=1710; weighted) with 95% confidence intervals.

What cannot be seen in Figure 1 is whether the frequency of providing personal care changed due to COVID-19 and whether this differed with respect to the care relationship. In the following, we therefore differentiated between different recipients who received personal care from someone outside the own household when investigating the changes in providing care (see Figure 2). Most striking in this respect was the huge increase of children providing care to their parents, which can be seen in the upper left graph of Figure 2. This increase was consistent across the different regions in Europe<sup>5</sup>: Between 42 percent (Baltic States) and 58 percent (Eastern Europe) of all parental caregivers declared that they increased the provision of personal care to their parents since the outbreak of the pandemic, i.e., on average, more than every second parental caregiver reported an increase. In contrast, only about eight to nine percent indicated that they decreased the personal care given to their parents. The rest, on average about 40 percent, neither increased nor decreased their caregiving activities to parents since the outbreak of the pandemic. The picture considerably changed with regard to parents providing personal care to their children (see upper right graph of Figure 2). Here, about one third of all caregivers providing personal care to their children reported a decrease, while only about 12 percent reported an increase. Thus, with the exception of Eastern European States, decreases in the provision of care from parents to their children

<sup>5</sup> There are different classifications in grouping European countries, representing different geographical regions, welfare state regimes and behavioral patterns (for an overview, see Avendano et al., 2009). In the following, we distinguished between Northern European States (SE, DK, FI), Western European States (DE, NL, FR, CH, BE, LU), Southern European States (ES, IT, GR, IL, PT, SI, HR, CY, MT), Eastern European States (CZ, PL, HU, BG, RO, SK), and the Baltic States (EE, LT, LV).

clearly outweighed the increases. Finally, with respect to other relatives and other non-kin, our findings were more balanced (see lower two graphs of Figure 2). In both cases, the overall share of caregivers who decreased their respective caregiving activities was larger than the share who indicated an increase (39% vs. 24% with respect to other relatives, 32% vs. 30% with respect to other non-kin). This was mainly due to the countries in Southern Europe, where decreases most clearly outweighed increases in providing personal care.

Figure 2: Change in frequency of caregiving to someone outside the own household by type of care relation



Data: SHARE COVID-19 Survey Release 0.0.1 beta (weighted) with 95% confidence intervals.

Note: Caregiving to parents (n=891), caregiving to children (n=659), caregiving to other relatives (n=768), caregiving to other non-kin (n=844).

Based on these findings, we were also interested in whether caregiving in general and the strongly increased personal care activities of children to their parents in particular was associated with higher physical and mental health strains compared to non-caregivers and those respondents who have not increased their parental caregiving activities, respectively. To answer this question, we first compared all caregivers towards all non-caregivers in our sample (columns 2 and 3 in Table 1), while controlling for a

broad range of relevant individual characteristics including health conditions that are known to differ between caregivers and non-caregivers (e.g. Sacco et al., 2020; Wajnberg et al., 2016) and otherwise possibly would have biased our results. Table 1 thus presents adjusted predictions that are controlled for the covariates presented in section 2.2. With this approach we were able to compare two hypothetical populations (e.g. non-caregivers and caregivers) that have identical values on all independent variables included in the model.

When comparing the entries of column 2 (labelled “Non-caregivers”) with those of column 3 (“Caregivers”), we can see that caregivers partially indicated more mental health strains compared to non-caregivers. Since the outbreak of the pandemic, caregivers felt significantly more often depressed or sad (+3 percentage points) and in particular more often anxious or nervous (+6 percentage points) than non-caregivers. In addition, they slightly more often had to struggle with sleeping problems (not significant) and did not feel lonely more often. Further, general physical health seemed to be unaffected since the outbreak of the pandemic. Thus, the share of caregivers who indicated a worsening in general health was very similar to the share of non-caregivers. In this respect, it has to be stated that the overall prevalence of respondents indicating a worsening in health was low (about 7-8%, respectively). Finally, with regard to direct effects of COVID-19 it can be seen that only slightly (not significant) more caregivers reported that they personally had been affected by the virus compared to non-caregivers. However, any further developments should be followed closely, because increasing affectedness of caregivers will have strong implications for those who rely on the provision of personal care and at the same time are amongst the highest risk group (Fischer & Geyer, 2020).

Table 1: Adjusted predictions of health-related outcomes by caregiving and changes in parental caregiving

	Non-caregivers (in %)	Caregivers (in %)	Parental caregivers, personal care →/↓ (in %)	Parental caregivers, personal care ↑ (in %)
Worsened health	8	7	6	5
Affected by Covid-19	7	9	14	13
Felt sad/depressed more often	16	19*	13	28***
Felt anxious/nervous more often	21	27**	22	37***
Had trouble sleeping more often	8	10	10	12
Felt lonely more often	12	12	12	11
N	49969	1710	439	452

Data: SHARE COVID-19 Survey Release 0.0.1 beta, SHARE Wave 8 release 0, and SHARE Release 7-1-0 (weighted).

Entries are adjusted predictions, controlling for sex, age, level of education, household composition, area of living, economic status, (self-) employment, self-rated health, ADL, IADL, and GALI before the pandemic, and respondent’s country.

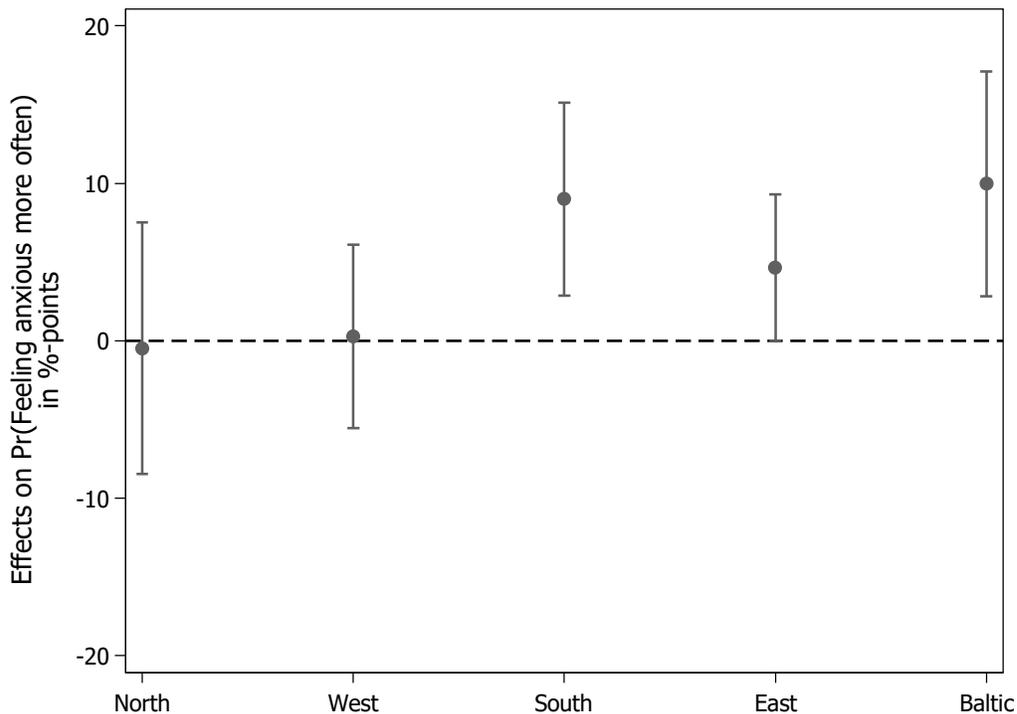
Significance level: \*: p<.05, \*\*: p<.01, \*\*\*: p<.001 (significances based on average marginal effects (AMEs) refer to respective previous column).

When exploring whether parental caregivers who increased their provision of personal care differed from parental caregivers who did not increase (i.e. either decrease or maintain) the frequency of providing personal care to their parents, we saw similar patterns: While general physical health again did not differ much, parental caregivers who increased the frequency of providing personal care reported much more mental health strains. The differences are most pronounced with respect to feeling sad/depressed and

anxious/nervous more often since the outbreak of the pandemic. More than twice as many parental caregivers who reported an increase of their care activities indicated that they felt sad or depressed more often since the outbreak of the pandemic, compared to those parental caregivers with the same amount or a decrease of their caregiving activities (+15 percentage points or nearly one out of three). With respect to feeling anxious or nervous more often the difference was also substantial. Here, about 37% of parental caregivers with an increase in personal care indicated that they felt anxious or nervous more often, compared to only 22% of parental caregivers who did not increase their caregiving activities. With regard to sleeping problems and direct affectedness by the virus, the differences were much smaller (+2 percentage points each) and not significant.

To investigate country differences, we calculated the country-specific average marginal effects of caregiving on the adjusted predictions of feeling anxious or nervous more often since the outbreak of the pandemic. Figure 3 clearly shows that caregivers in Southern European countries had a significant higher probability to report anxiety more often compared to non-caregivers. The same is true for the Baltic States. Eastern European countries were only slightly below a significant level and no effect could be found in Northern and Western European countries. This illustrated that there were country differences with regard to effects of the pandemic on caregivers' mental health, which should be taken into account.

Figure 3: Average marginal effects (AMEs) of caregiving on the adjusted prediction of feeling anxious/nervous more often since the outbreak of the pandemic by geographical regions

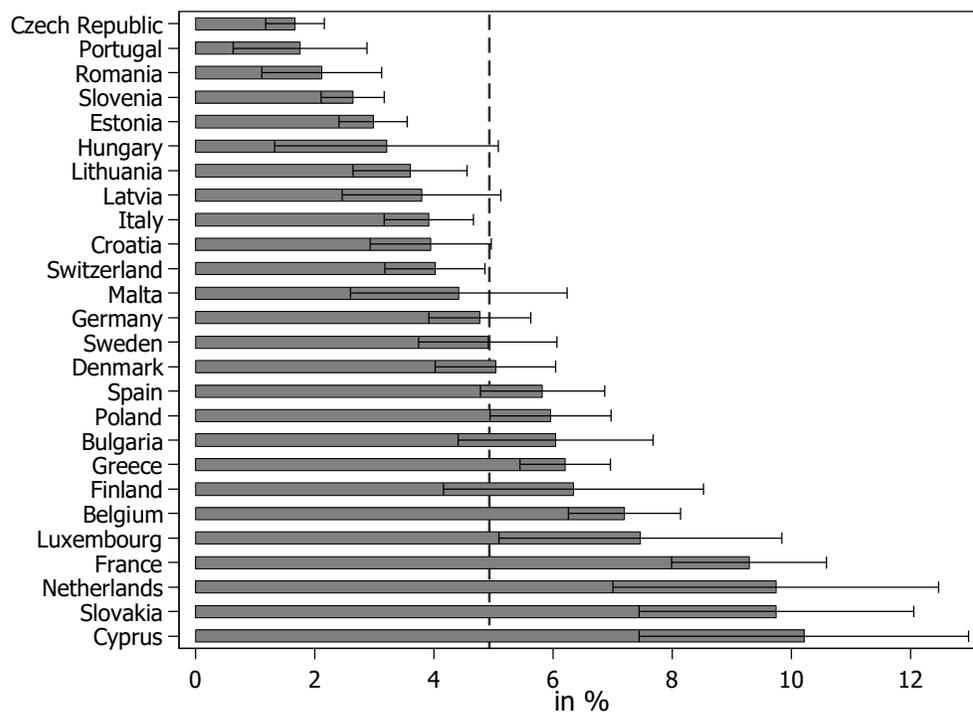


Data: SHARE COVID-19 Survey Release 0.0.1 beta, SHARE Wave 8 Release 0, and SHARE Release 7-1-0 (weighted). Displayed are average marginal effects, controlling for sex, age, level of education, household composition, area of living, economic status, (self-) employment, self-rated health, ADL, IADL, and GALI before the pandemic. Significance level: \*:  $p < .05$ , \*\*:  $p < .01$ , \*\*\*:  $p < .001$ .

### 3.2 Care receiving during the pandemic

When turning to care recipients, we started again with looking at the prevalence of care receiving across countries participating in SHARE (see Figure 4). Overall, about five percent of all respondents in our sample (n=3315) received home care, although it has to be noted that Israel had to be excluded for this overview due to a much higher value. A possible reason for this might be the use of the term “home care” in the generic version of the SHARE Corona questionnaire, which potentially mixed up the receipt of informal and formal care. However, a careful inspection of the different translations with the responsible country operators did not reveal any systematic differences across countries. Further, the following analyses regarding the associations of care receiving were not substantially affected by this issue.

Figure 4: Percent of respondents receiving home care by others from outside the own household since the outbreak of the pandemic



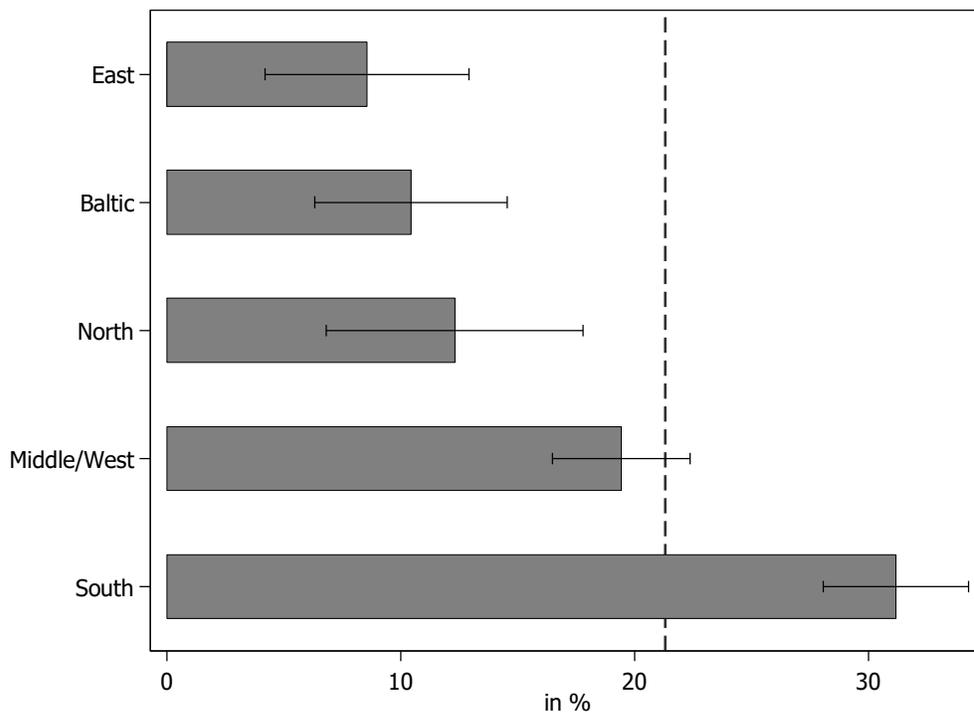
Data: SHARE COVID-19 Survey Release 0.0.1 beta (n=3315; weighted) with 95% confidence intervals.

Figure 4 again shows large differences between countries. The Czech Republic had the lowest number of care recipients (about 2%), while again Cyprus was the frontrunner with more than ten percent. When geographically grouping countries, it was noticeable that Western European countries exhibited a larger share of care recipients. While it can be argued that the age distribution in the national samples affected the countries' ordering, this explanation could be ruled out. Thus, the Czech Republic and Portugal both had rather old samples (69 and 70 years, respectively), but at the same time showed the lowest percentage

of care recipients. In addition, Slovakia and Cyprus had much younger samples (both about 65 years) but both exhibited a much higher share of respondents receiving care.

Next, we investigated how the utilization of (home) care was perceived by those receiving care to answer the question if COVID-19 negatively affected the receipt of personal care in Europe. In this respect, Figure 5 shows the share of care recipients reporting that they faced difficulties in receiving care by geographical regions. We did not differentiate between countries here as the sample size for receiving home care in some countries was very low and might have jeopardized results. Overall, about 21 percent of all care recipients reported difficulties in receiving care. This share was by far the highest in Southern European countries: More than every third care recipient in these countries reported difficulties in receiving care since the outbreak of the pandemic, while it was less than one out of ten in Eastern Europe. This mirrors partly the severity of the situation in the different parts of Europe in summer 2020 with substantially more deaths due to COVID-19 in Southern (esp. Italy and Spain) and Western Europe (esp. Belgium, France, and the Netherlands) compared to Eastern Europe and the Baltic States (Hale et al., 2020; Sabat et al., 2020).

Figure 5: Percent of care recipients facing difficulties in receiving home care since the outbreak of the pandemic by geographical regions



Data: SHARE COVID-19 Survey Release 0.0.1 beta (n=3315; weighted) with 95% confidence intervals.

In addition, the condition of the national health care system at the beginning of the pandemic as well as the scope and availability of long-term care services (e.g. measured by the proportion of the Gross

Domestic Product (GDP) devoted to public health care) was expected to have an impact here. Thus, Greece had to make great cuts in the provision of long-term care expenditures due to the financial crisis (Kentikelenis, Karanikolos, Reeves, McKee, & Stuckler, 2014) that, in turn, could explain the large share of care recipients perceiving difficulties in receiving care. Further, Southern European countries with its stronger ties regarding relationships and family, which frequently account for a large part of personal care, were more affected by epidemiological control measures like physical distancing, limitations of contacts, or travel restrictions (Sabat et al., 2020). This, in turn, complicated the receipt of personal care from someone outside the household.

Based on these findings, we were further interested whether care receiving in general as well as the perception of difficulties herein was associated with physical and mental health problems or with restrictions in the health care system. To answer this question, we first compared all care recipients towards all non-care recipients in our sample, while again controlling for relevant individual characteristics, including health conditions and country dummies. Table 2 reveals that care receiving actually was associated with a worsened health: Compared to non-care recipients, care recipients indicated a significantly worsened general physical health (+2 percentage points). In addition, significantly more care recipients reported that they personally had been affected by the virus (i.e. having had symptoms, having been tested, or having been hospitalized). The same was true for most of our indicators regarding mental health strains: Care recipients significantly more often reported that they felt sad/depressed, anxious/nervous, and lonely (all +2 percentage points, respectively). With regard to sleeping problems and respondents' affectedness by the virus, there was no significant difference. The same was the case for respondents' access to appropriate medical treatment: Treatments and appointments have not been cancelled by care recipients themselves or postponed/denied by medical facilities more often than with respect to non-care recipients.

Table 2: Adjusted predictions of health-related outcomes by care receiving and difficulties in receiving care

	Non-care recipients (in %)	Care recipients (in %)	Care recipients without difficulties in receiving care (in %)	Care-recipients with difficulties in receiving care (in %)
<i>Physical and mental health</i>				
Worsened health	8	10*	18	21
Affected by Covid-19	7	10**	9	8
Felt sad/depresses more often	16	18*	23	26
Felt anxious/nervous more often	22	24*	24	29*
Had trouble sleeping more often	8	9	11	12
Felt lonely more often	11	13*	21	24
<i>Access to medical treatments</i>				
Medical treatment cancelled by respondent	12	12	14	20**
Medical treatment postponed/denied	28	28	29	32
N	48364	3315	2588	707

Data: SHARE COVID-19 Survey Release 0.0.1 beta, SHARE Wave 8 Release 0, and SHARE Release 7-1-0 (weighted).

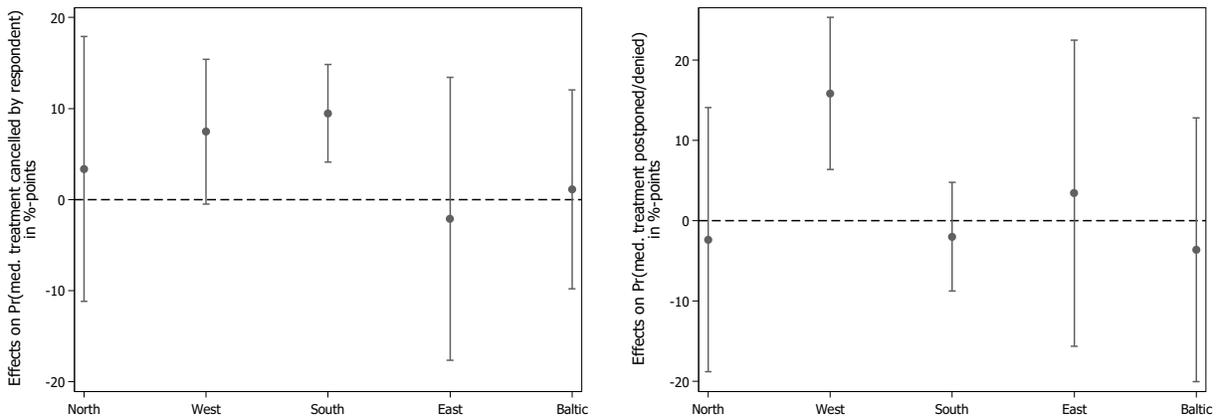
Entries are adjusted predictions, controlling for sex, age, level of education, household composition, area of living, economic status, self-rated health, ADL, IADL, and GALI before the pandemic, and respondent's country.

Significance level: \*: p<.05, \*\*: p<.01, \*\*\*: p<.001 (significances based on average marginal effects (AMEs) refer to respective previous column).

When turning to differences between care recipients with and without perceiving problems in receiving care the picture was somewhat different: Now, general health no longer differed significantly between the two comparison groups, i.e. a worsened physical health was not significantly correlated with indicating difficulties in receiving care, although the absolute difference was even slightly larger than before. Moreover, mental health strains, at least partly, were still related to perceiving difficulties in care receiving: Those care recipients who reported difficulties in receiving care significantly more often felt anxious or nervous (+5 percentage points) compared to care recipients who did not. In contrast, care recipients who reported difficulties in receiving care more often felt sad/depressed, lonely, and had sleeping problems more frequently compared to care recipient without such difficulties, but none of these indicators reached a significant level. In addition, affectedness was higher for care recipients perceiving difficulties in receiving care (+5 percentage points), but again the difference was not significant due to the small sample size. In contrast, care recipients who indicated difficulties in receiving care significantly more often reported that they cancelled a medical treatment by themselves (+6 percentage points). Interestingly, there was no significant difference between care recipients with and without indicating difficulties in receiving care with regard to postponing or denying medical treatments by a doctor or a medical facility.

To explore whether these latter differences vary across countries, we calculated country-specific average marginal effects of the difficulties in receiving care (see Figure 6), both for reporting medical treatments that have been cancelled by care recipients themselves (left graph) and that have been postponed or denied by medical facilities instead (right graph). In this respect, the left part of Figure 6 shows that the significant difference of cancelling medical treatments by care recipients themselves, which has been reported in Table 2, was mainly driven by Southern European (and to a lesser degree by Western European) countries. Additionally, the share of care recipients who have been cancelled a medical appointment by their doctor or medical facility was highest in Western European countries. This confirmed, for example, the situation in Belgium, where care professionals have been advised to prioritise their care and to assess whether the care is essential or can be postponed (COVID-19 Health System Response Monitor). Although the standard errors for these effects were rather high, our findings illustrate that the COVID-19 pandemic had different direct and indirect consequences for care recipients across Europe, dependent on the interaction between the severity of the pandemic as well as the (technical and personal) equipment of the national health care system.

Figure 6: Average marginal effects (AMEs) of difficulties in receiving care on the adjusted prediction of cancelling medical treatments by the care-recipient (left) or the medical facility (right) since the outbreak of the pandemic by geographical regions



Data: SHARE COVID-19 Survey Release 0.0.1 beta, SHARE Wave 8 Release 0, and SHARE Release 7-1-0 (weighted). Displayed are average marginal effects, controlling for sex, age, level of education, household composition, area of living, economic status, self-rated health, ADL, IADL, and GALL before the pandemic. Significance level: \*:  $p < .05$ , \*\*:  $p < .01$ , \*\*\*:  $p < .001$ .

#### 4. Discussion

Informal caregivers as well as care receivers both have been hit hard by the outbreak of the COVID-19 epidemic. While a large number of people in Europe already before the pandemic provided substantial amounts of unpaid care to relatives and friends with long-term care needs, COVID-19 drastically increased many of the inherent problems of national health care systems in general and of long-term care in particular (Lorenz-Dant & Comas-Herrera, 2021). The spread of the virus together with physical distancing and further COVID-19-related public health measures affected the life of those providing care to others as well as those receiving care from people outside the own household to an unprecedented extent. Against this background, we focused in this paper on how caregivers and care recipients living at home (the non-institutionalized) dealt with the situation across Europe. By applying adjusted predictions that controlled for a broad range of relevant individual and contextual characteristics, we were able to present reliable results regarding the association between caregiving and care receiving on the one side and changes in physical and mental health due to the direct and indirect effects of the pandemic on the other side.

With respect to informal caregiving, our findings first showed that COVID-19 had a substantial impact on private care networks of caregivers and the persons being cared. During the first phase of the pandemic in spring 2020, the provision of personal care to parents outside the own household strongly increased across Europe, while it decreased for other relatives and non-kin, and in particular for children. One reason for the increase regarding parents in need for care was the reduced availability of paid services and care support due to the COVID-19 public health measures that had to be compensated by family care. The strong decrease for children on the other hand can be seen as the reverse of the same coin and indicates

a strong shift of informal care from the younger to the older generation that (despite certain exceptions) is, on average, more vulnerable and relies more strongly on informal care of their children than the other way round. In addition, our findings clearly showed that caregivers (compared to non-caregivers) more often felt depressed and anxious as a consequence of the pandemic and its accompanying public health measures. This finding was even more pronounced for parental caregivers who increased their caregiving activities since the outbreak of the pandemic. In this population nearly 30 percent indicated a feeling of depression and nearly 40 percent of anxiety more frequently. Both values were roughly about two times as high as with respect to caregivers who did not increase their care activities towards their parents. These numbers give cause for concern. It clearly shows the extent of burden caregivers were exposed to with respect to non-intended effects of the epidemiological control measures and, at the same time, suggests a great need within this population for interventions effectively reducing burden as well as symptoms of anxiousness or depression. This holds in particular for Southern European countries, for which we found the strongest negative effects. In contrast, caregivers' physical health remained rather stable during the period of investigation. From this, one could conclude that the direct effects of the virus itself were less pronounced for caregivers. Whether this observation will still hold in the long run and with further waves of the pandemic has to be seen and should be monitored closely. In any case, our findings point out that caregivers need compensation for the burden of providing care during the pandemic. Currently, however, they should do even more to protect those who rely on their help. Social organizations have long called for improvements of the caregivers' situation, including an actual increase of both their reputation and their payment. This now seems more reasonable than ever and should be recognized also by (health) policy makers.

With respect to care receiving, our results showed that the pandemic also negatively affected the health of (home) care recipient. In particular, care recipients (compared to non-care recipients) rated their general physical health significantly more worse and felt significantly more depressed, anxious, and lonely – although the differences in the adjusted predictions were smaller in absolute size than for caregivers. In addition, care recipients, overall, did not indicate a worsening of their situation with respect to pursuing planned medical treatments compared to non-care recipients. However, when differentiating between care recipients with and without difficulties in receiving the care they need, we saw that those perceiving difficulties reported substantially more cancellations of medical treatments by themselves due to their fear of a COVID-19 infection. Instead, the difference regarding postponements and cancellations by medical facilities between those care recipients indicating versus not indicating difficulties in receiving care was smaller and not significant. This suggests that the reporting of difficulties in receiving care was, overall, stronger related to subjectively fearing an infection in connection with a medical treatment than objective shortages in the health care system, even though only a small proportion of respondents had actually been infected with COVID-19. This finding, however, varied across countries, with higher shares of care recipients cancelling medical treatments by themselves in Southern European countries, which have been stronger affected by the pandemic, and higher shares of care recipients having been postponed or denied a medical treatment by their doctor or a medical facility in Western European countries, most likely due to shortages in the national health care system. Independent from its cause it has to be seen whether cancelling necessary medical and therapeutic treatments during the first phase of the pandemic will result in negative long-term consequences on health – and if yes, to what degree. Further, it is noteworthy that,

overall, one out of five care recipients reported difficulties in receiving the care they need. In Southern and several Western European countries, which have been hit hardest with respect to the number of confirmed deaths due to COVID-19, this number was even higher. On average, these care recipients also reported slightly more physical and mental health strains with a significantly higher level of anxiousness as the most explicit result. This corresponds with our findings regarding caregivers. It hence seems that the first COVID-19 phase in spring 2020 can best be characterized by an increase in anxiety of both caregivers and care recipients. However, there is concern that indications for depression will also further increase the longer epidemic control measures like physical distancing or stay-at-home requirements persist (Giebel et al., 2021).

The main limitations of this study are the, overall, rather low number of caregivers and, even more severe, care recipients in a presumably good health that allowed them to participate in the survey. We tried to circumvent this problem by geographically grouping countries to measure the varying direct and indirect effects of the pandemic on caregivers and care recipients across Europe. However, we are aware that more detailed typologies are needed that capture the institutional and cultural differences but also the different government responses to the COVID-19 crisis to fully explain the consequences of this global pandemic on caregiving and care receiving. Further, with the data at hand we lack a comprehensive understanding of the underlying causes why mental health declined for caregivers as well as for those who intensified their caregiving activities during the first phase of the pandemic: Was it the mere burden of caregiving in an unprecedented situation, in which increased care needs and reduced availability of paid services and informal support had to be compensated by informal family care? Or have been worries about care-dependent relatives the main driver for the strong increase of mental health strains? More research is needed here, also to explore the interaction of these explanations with the severity of the pandemic that differs between countries and hence is expected to exhibit different consequences across countries. In this respect, our study was only a first step in answering these complex questions and should be complemented with a multilevel approach that takes these considerations more comprehensively into account. Finally, we should consider that even though we are in the middle of a second phase of the pandemic, our findings here refer to spring/summer 2020 and the first COVID-19 phase. The changing experience with COVID-19 but also the changed mindset how we now look at the pandemic makes it more difficult to evaluate the results against the background of the first COVID-19 phase. Although the current situation is similar in some aspects, it differs a lot with respect to the overall perception of the crisis as well as the long-lasting epidemic control measures and its restrictions. Thus, the second phase of the pandemic is expected to put even more pressure on the persons under investigation. In this respect, it will be extremely valuable to compare our results with data from a second SHARE Corona Survey, which actually is planned for early summer 2021. This will provide valuable information to more comprehensively evaluate the consequences of the COVID-19 epidemic across Europe.

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