

STUDY

Informal caregivers in the COVID-19 Crisis Findings of a nationwide survey in Germany

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I. Background

The coronavirus disease 2019 – abbreviation COVID-19 – was identified in late December 2019. It is caused by a previously unknown type of coronavirus, known as SARS-CoV-2. The outbreak was traced back to the Chinese city of Wuhan, subsequently spreading rapidly around the world, and was accordingly classified as a pandemic by the WHO in March 2020 (WHO, 2020).

The COVID-19 disease course varies considerably between “no symptoms” up to “very severe” and can result in death (RKI, 2020a). In patients who died of COVID-19, it has been shown that the virus often attacks the lungs but also other organs (Puelles et al., 2020).

Overall, current knowledge of COVID-19 or SARS-CoV-2 in relation to infection, course of the disease, therapy, prevention and psychosocial consequences of the protective measures designed to restrict the spread of the pandemic is still patchy and is developing very dynamically (RKI, 2020b; Tull et al., 2020). Care must therefore be taken in interpreting findings against the background of the knowledge currently available.

Germany is also affected by the COVID-19 pandemic. The official, laboratory-confirmed identification of Patient 0 is dated January 27, 2020. The patient was in the Munich area a few days previously where she infected other people (Böhmer et al., 2020). During the first half of 2020, the resulting wave of infection spread to different regions of Germany that were, and still are, affected to very different degrees; it is estimated to be the biggest social challenge ever faced in the history of the Federal Republic (Lohse, 2020). Up to midnight on May 29, 2020, the Robert Koch Institute registered 180,458 cases of COVID-19 in Germany and 8,450 COVID-19 related deaths (RKI, 2020c).

People with certain previously existing conditions have a greater risk of developing severe symptoms or dying of COVID-19, and are therefore classified as risk groups (Livingston & Bucher, 2020; Wu et al., 2020; Zhou et al., 2020). These include people who require care (Gerdner et al., 2020) and people with dementia (Brown et al., 2020). About 3.4 million people in Germany require care as defined in the German Social Security Code (SGB) XI. Around three-quarters of these are cared for at home (Federal Statistical Office, 2018). The majority is aged 80 and over. The proportion of people needing care in the general population is projected to continue to rise considerably over the next few years (Rothgang et al., 2016).

A number of conflicts has arisen in the context of attempts to protect this risk group. For example, older adults – particularly those who need care, or who live alone – may be particularly at risk in several ways, such as being stigmatized by corona measures, being particularly severely restricted in their opportunities for social participation, and overall, suffering additional damage to their health as a consequence of isolation and restrictions (Kessler et al., 2020; Hämpel et al., 2020). In particular, research into the psychosocial effects of the various distancing measures is urgently needed. Existing studies already indicate that quarantine measures imposed during epidemics may have negative consequences for mental and physical health, among other things (Brooks et al., 2020; Röhrs et al., 2020).

The pandemic thus also affects informal caregivers in their care work on different levels. They carry out a considerable proportion of the care work for care receivers in Germany; they are often older – at least when they are caring for older people – and thus in some cases, they themselves are members of the group at risk of a severe form of COVID-19 (Kent et al., 2020).

It was estimated that in 2012, about 4.7 million people in Germany were caring for a relative (Wetzstein et al., 2015). In general, informal caregivers are considered to be under physical and particularly mental stress, even in normal times. This effect is reinforced if the care receiver suffers from dementia (Pinquart & Sörensen, 2003, 2007; Bastawrous, 2013; Nowossadeck et al., 2016). Conflicts between their caring responsibilities and job are the source of additional stress for informal caregivers who are still working. In 2012, an estimated 2.6 million people were working in addition to their caring responsibilities (ZQP, 2016). Overall, therefore, informal caregivers are more at risk of experiencing negative stress in comparison to people without caring responsibilities. This can lead to their being subjected to excessive demands and when combined with other factors may result in fear, grief, frustration, and anger. Feelings of aggression in care situations may lead to violence, which potentially affects both informal caregivers and care receivers, particularly in the context of dementia (Eggert et al., 2018).

Against the background of the stress and risk factors for informal caregivers' health and wellbeing sketched above, we must assume that the COVID-19 pandemic and the associated protective measures result in significant additional burdens for informal caregivers that have not yet been systematically examined. It is therefore extremely important to gain knowledge about the challenges and stresses faced by informal caregivers due to the pandemic in spring 2020 in Germany, with a view to future support measures, including preventive measures, for relatives who will continue to be major care providers for the foreseeable future.

II. Methodology

The findings are based on a nationwide survey on the topic "Informal caregivers in the COVID-19 crisis", addressed to people who care for older care receivers in the family context. The base population of this study comprised people in Germany aged from 40 to 85, who have been providing care at least once a week, for at least six months, for a person with whom they have a personal relationship who fulfils the following criteria: (i) aged 60 or over, (ii) requiring care as defined in the German Social Security Code (SGB), i.e. the person has a recognized level of care requirement, and (iii) is cared for at home, i.e. is not resident in an old people's home or nursing home. The random sample of $n = 1,000$ people was drawn from an online panel with approx. 80,000 German speakers who were recruited entirely off-line. Only people belonging to the base population could participate.

The online survey was carried out from April 21 to May 2, 2020, a period when the contact restrictions imposed in late March 2020 still applied in all the Federal States in Germany (Saxony-Anhalt was the first state to ease contact restrictions on May 4, 2020.) Most of the answer scales used in the survey were four or five-stage scales, with the addition of a "don't know" category. The scales were not validated in advance, but they are based on established scales (Prüfer et al., 2003). The random sample was weighted in combinations of age, gender and educational level, in order to reflect as closely as possible the ideal of a representative random sample. The weighting was based on the German Ageing Survey 2014, a representative survey of 40 to 85-year-olds living in private households in Germany (Klaus & Engstler, 2016). The German Centre of Gerontology (DZA) kindly provided a special evaluation of the distribution of combinations of age, gender and educational level within this group. The highest weighting value is 1.51. The statistical error tolerance of the survey in the total sample is +/- 3 percentage points.

The above-mentioned online survey is at the core of the analyses. It was supplemented by the findings of a previously unpublished preliminary evaluation of reports written by informal caregivers about their experiences during the corona crisis in the context of the ZQP's "Sharing experience in the crisis" service.¹

III. Findings

Sample description

The majority (61 percent) of informal caregivers aged from 40 to 85 are women. About two-fifths of respondents are aged from 40 to 54 (41 percent), two-fifths are aged from 55 to 69 (38 percent) and one-fifth (21 percent) is aged from 70 to 85. Just under three-fifths (58 percent) of respondents are working, of whom about 70 percent work 30 or more hours per week. Two-thirds of the care receivers aged 60 or over supported by respondents are women; about half (46 percent) live alone and nearly a third (30 percent) live with the informal caregiver. A good tenth (11 percent) of the care receivers are classed as requiring care level 1, just over one-third in each case are classed as care levels 2 (37 percent) and 3 (36 percent). Another 12 percent are classed as care level 4 and 4 percent as care level 5 (Fig. 1).

Comparative distribution of care receivers aged 60 or over according to care level in the sample and those receiving ambulatory care

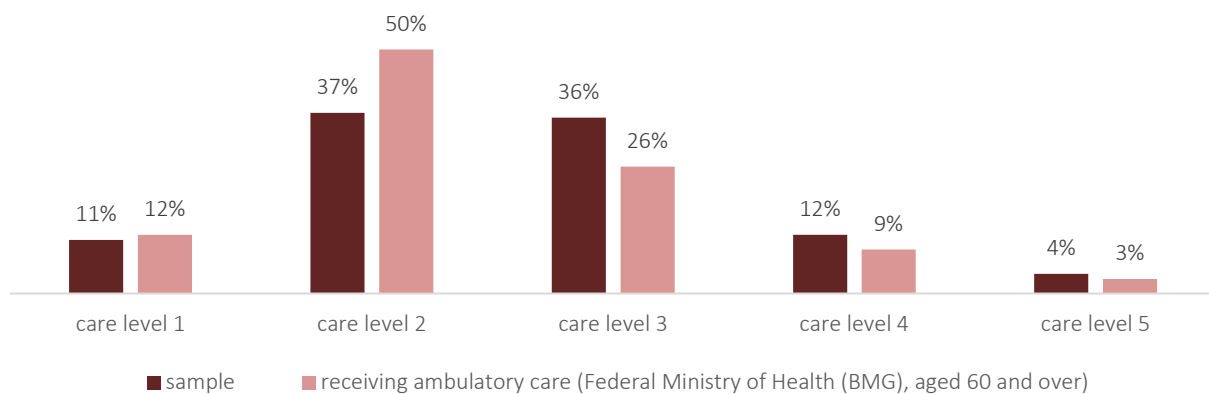


Figure 1: ZQP survey of informal caregivers in the COVID-19 crisis (n = 1.000); Federal Ministry of Health (BMG) (2020).

The distribution of care receivers according to the care level allocated shows relevant divergence from the Federal Ministry of Health (BMG) figures from end 2018 (BMG, 2020a) for care receivers allocated care levels 2 (higher in the BMG figures) and 3 (lower in the BMG figures); this may be partly due to the large decline in the proportion of transferred cases.²

¹ The ZQP has collected written reports by professional and informal caregivers since April 15, 2015 in the context of its "Sharing experiences in the crisis" service. Over 60 reports were received by May 31. These are currently being evaluated, after which the findings will be published.

² Due to the transfer regulations in accordance with Section 140 SGB XI, everyone who, at the end of 2016, was classed in one of the original care stages (including stage 0) or who had applied for this was automatically assigned one of the five new care levels in 2017. The transferred cases accounted for 66 percent at the end of 2017 (BMG, 2020) and by the end of 2018 still accounted for 43 percent of all home care receivers. This reduction

47 percent of the care receivers included in this study also receive additional care from an ambulatory care service; this proportion is much higher than the proportion of 32 percent in the care figures for 2017. Possible causes are on the one hand, the increasing trend towards claiming ambulatory care in recent years, and on the other hand, the services provided by ambulatory care in accordance with the Social Security Code (SGB) V that are not included in the care figures.

Risk perception in the corona situation

Informal caregivers have widely varying perceptions of their own risk of infection and that of the person they care for: while only one-fifth of respondents are “moderately/extremely” concerned about becoming infected themselves, twice as many give this response in relation to the person they care for (Fig. 2).

Are you currently concerned that you yourself will become infected with the coronavirus or that the person you care for will become infected with the coronavirus?

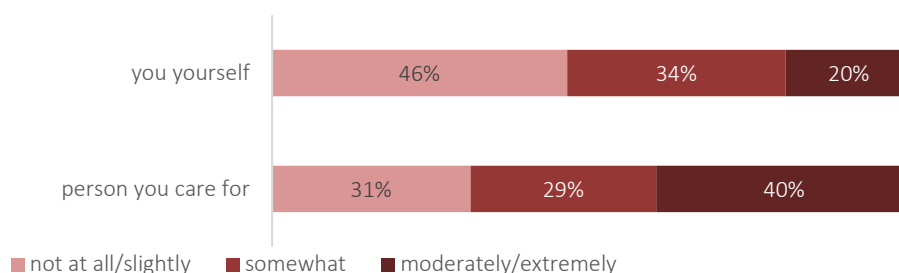


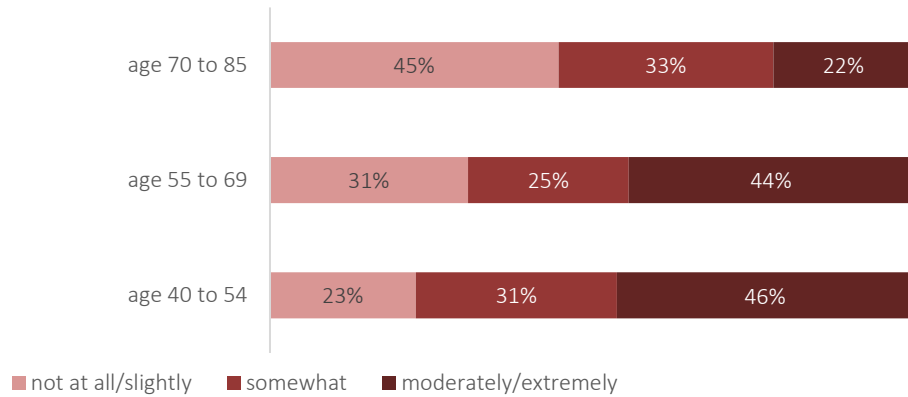
Figure 2: ZQP survey of informal caregivers in the COVID-19 crisis (n = 1.000).

The oldest respondents are much less concerned about an infection than younger informal caregivers (Fig. 3): 46 percent of respondents aged 40-54 and 44 percent of those aged 55-69 are “moderately/extremely” concerned. In contrast, in the 70-85 age group less than a quarter (22 percent) of respondents’ answers fell in these categories.³

in the proportion of transferred cases runs parallel to the new cases or cases classed at a higher level, resulting in considerable shifts in the distribution according to care levels (for example. the proportion of home care receivers with care level 2 aged 60 or over in the BMG figures declined from 53 percent at the end of 2017 to 50 percent at the end of 2018).

³ The effect size ϕ is subdivided in this and the following evaluations following Cohen (Cohen, 1988) in “small to medium effect” [$0,1 \leq \phi < 0,3$], “medium to large effect” [$0,3 \leq \phi < 0,5$] and “large effect” [$\phi \geq 0,5$].

Concern that the care receiver will become infected with the coronavirus, differentiated according to the informal caregiver's age

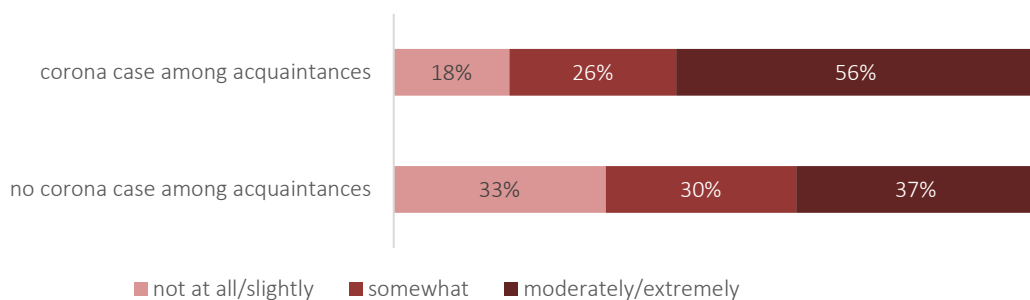


$\chi^2(4) = 48.33, p < 0.001, \phi = 0.22$ [small to medium effect]

Figure 3: ZQP survey of informal caregivers in the COVID-19 crisis (n = 999).

The proportion of “moderately/extremely” concerned informal caregivers among respondents who reported a Sars-CoV-2 case in their personal environment was also significantly higher (Fig. 4). If there was a corona case among their acquaintances (this was the case for 16 percent of respondents) the proportion of “moderately/extremely” concerned respondents was 56 percent, in contrast to 37 percent of other informal caregivers.

Concern that the person cared for may become infected with the coronavirus, differentiated according to whether a corona case occurred among their acquaintances



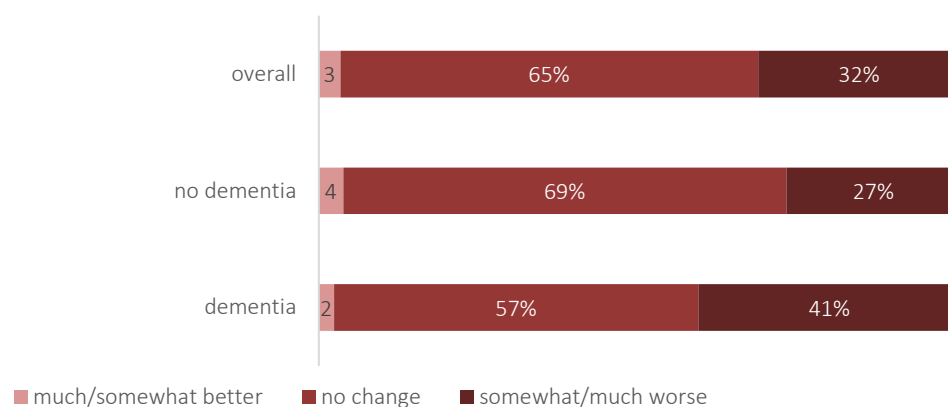
$\chi^2(2) = 22.15, p < 0.001, \phi = 0.15$ [small to medium effect]

Figure 4: ZQP survey of informal caregivers in the COVID-19 crisis (n = 999).

Changes in the care situation in the corona pandemic

As expected, respondents view the pandemic-related changes to their care situation rather critically. Nearly one-third (32 percent) of informal caregivers stated that the care situation has got “somewhat/much worse”. Only 3 percent spoke of an improvement (Fig. 5). Respondents who care for a person diagnosed with dementia (32 percent of cases) state with significantly higher frequency that the care situation has got worse (41 percent) than other informal caregivers (27 percent).

How has your personal care situation developed overall due to the corona situation in the last 4 to 8 weeks? Has your care situation since then...? [differentiated according to dementia diagnosis]



$\chi^2(4) = 23.34, p < 0.001, \phi = 0.16$ [small to medium effect]

Figure 5: ZQP survey of informal caregivers in the COVID-19 crisis (n = 970).

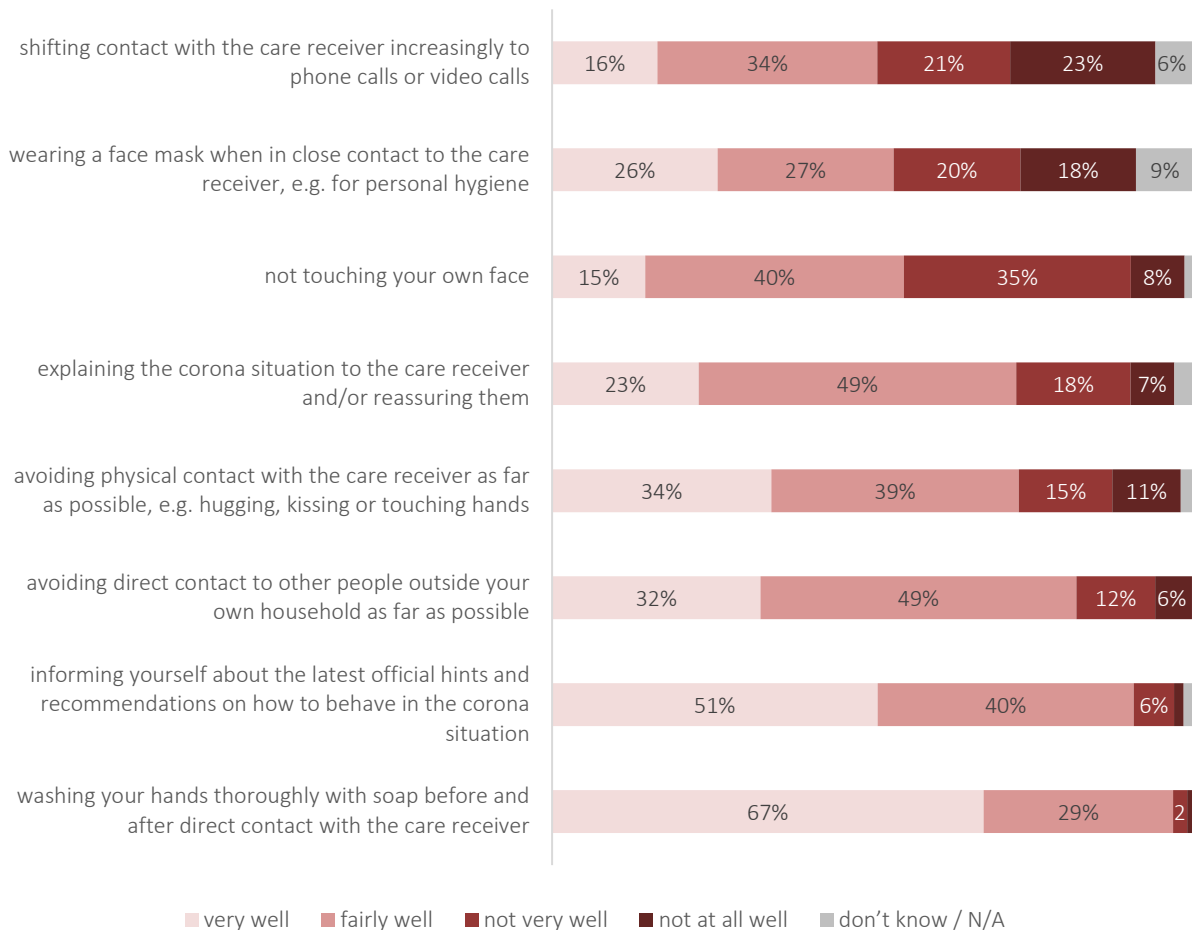
Overall, however, most respondents still described their own care situation during the COVID-19 pandemic rather positively. Four fifths of respondents stated that the care situation is “excellent” (18 percent) or “very good” (61 percent). Only one-fifth described the care situation as “poor” (16 percent) or “very poor” (4 percent).

The recommended safety measures may also influence the care situation. But how far do informal caregivers succeed in implementing these measures? Respondents see thorough hand washing before and after direct contact with the care receiver as the least problematic measure (Fig. 6). Almost all respondents (97 percent⁴) stated that this could be implemented “very well” (67 percent) or “fairly well” (29 percent). 43 percent stated that shifting contact with the care receiver to phone calls or video calls contact functioned “not at well” (23 percent) or “not very well” (21 percent).⁵ As described by many informal caregivers, wearing a face mask could be implemented “not very well” (20 percent) or “not at all well” (18 percent).

⁴ Due to differences in rounding off, the combined proportion is different from the sum of the rounded-off proportions of the individual categories.

⁵ For this question, only cases where the informal caregiver and the care receiver do not live in the same household were taken into account (n = 699). Due to differences in rounding off, the combined proportion is different from the sum of the rounded-off proportions of the individual categories.

Currently there are corona-related recommendations that informal caregivers should take seriously in their home care work. However, that isn't always easy in the bustle of everyday life. How well can you implement the following measures in your home care work?

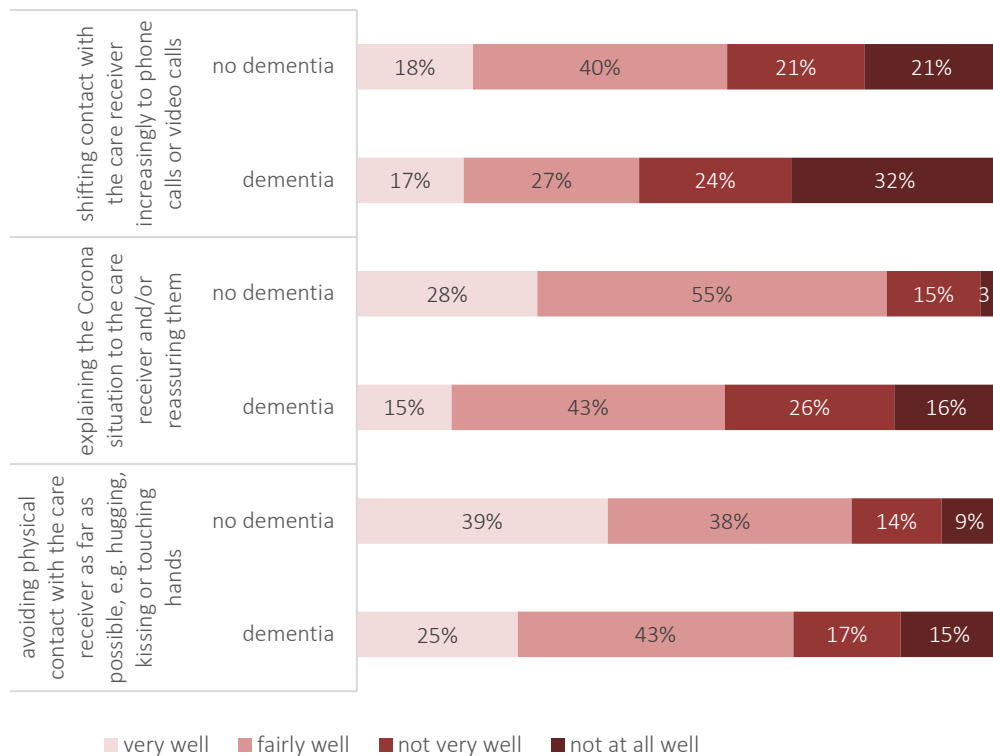


Case numbers for “Shifting contact with the care receiver increasingly to phone calls or video calls” only include cases where informal caregiver and care receiver do not live in the same household (n = 699); for other measures n = 1,000

Figure 6: ZQP survey of informal caregivers in the COVID-19 crisis.

Informal caregivers of people with a dementia diagnosis found the implementation of three measures significantly harder than other respondents (Fig. 7): More than two-fifths found it difficult to explain the pandemic situation to the care receiver (26 percent “not very well”; 16 percent “not at all well.” Almost one-third stated that avoiding physical contact with the care receiver as far as possible could be implemented “not very well” (17 percent) or “not at all well” (15 percent). More than half stated that shifting contact to a care receiver who does not live in the same household to phone calls or video calls was difficult to implement (24 percent “not very well”; 32 percent “not at all well”).

How well can you implement the following measures in home care? (differentiated according to dementia diagnosis]



Shifting contact to phone calls or video calls ($n = 648$; $\chi^2(3) = 13.19$, $p = 0.004$, $\phi = 0.14$ [small to medium effect]), explaining and reassuring ($n = 957$; $\chi^2(3) = 89.99$, $p < 0.001$, $\phi = 0.31$ [small to medium effect]), avoiding physical contact $n = 967$; $\chi^2(3) = 21.90$, $p < 0.001$, $\phi = 0.15$ [small to medium effect])

Figure 7: ZQP survey of informal caregivers in the COVID-19 crisis.

How do informal caregivers experience the situation at the emotional level? The care situation in the COVID-19 pandemic has proved to be an emotional challenge for many informal caregivers (Fig. 8). They report that feelings of helplessness (29 percent), emotionally stressful conflicts (24 percent), feelings of despair (22 percent) and feelings of anger and rage (20 percent) in the care situation “have increased”. Pleasant moments with the care receiver have also tended to decrease – as 23 percent of respondents reported – although 12 percent report an increase in such moments.

Now we turn to how the current corona situation affects your feelings in relation to the care situation. Taking the following possible answers, how would you describe the effects?

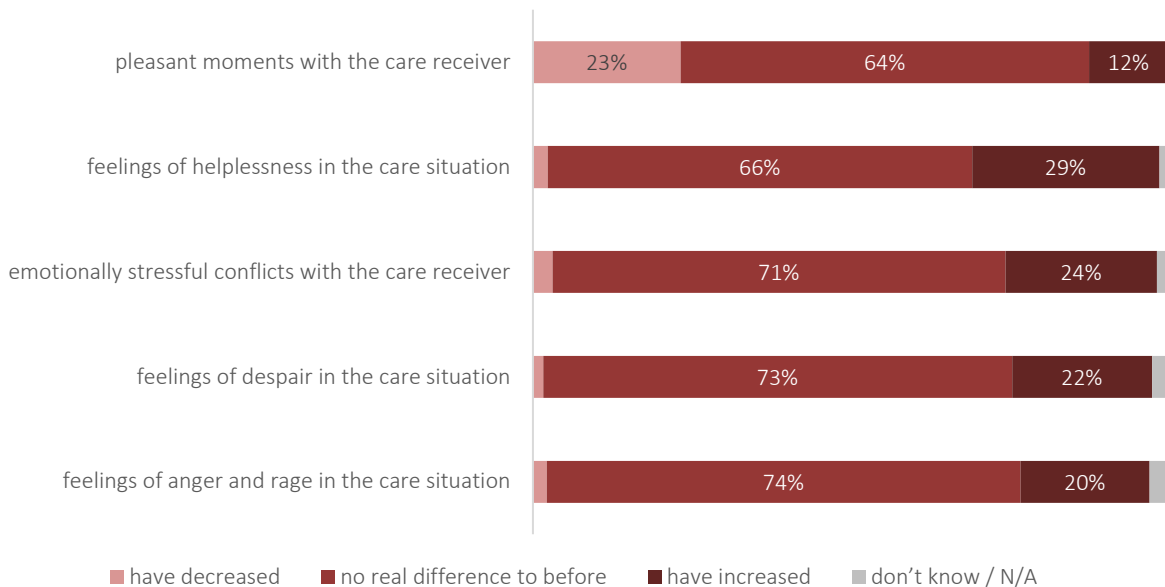
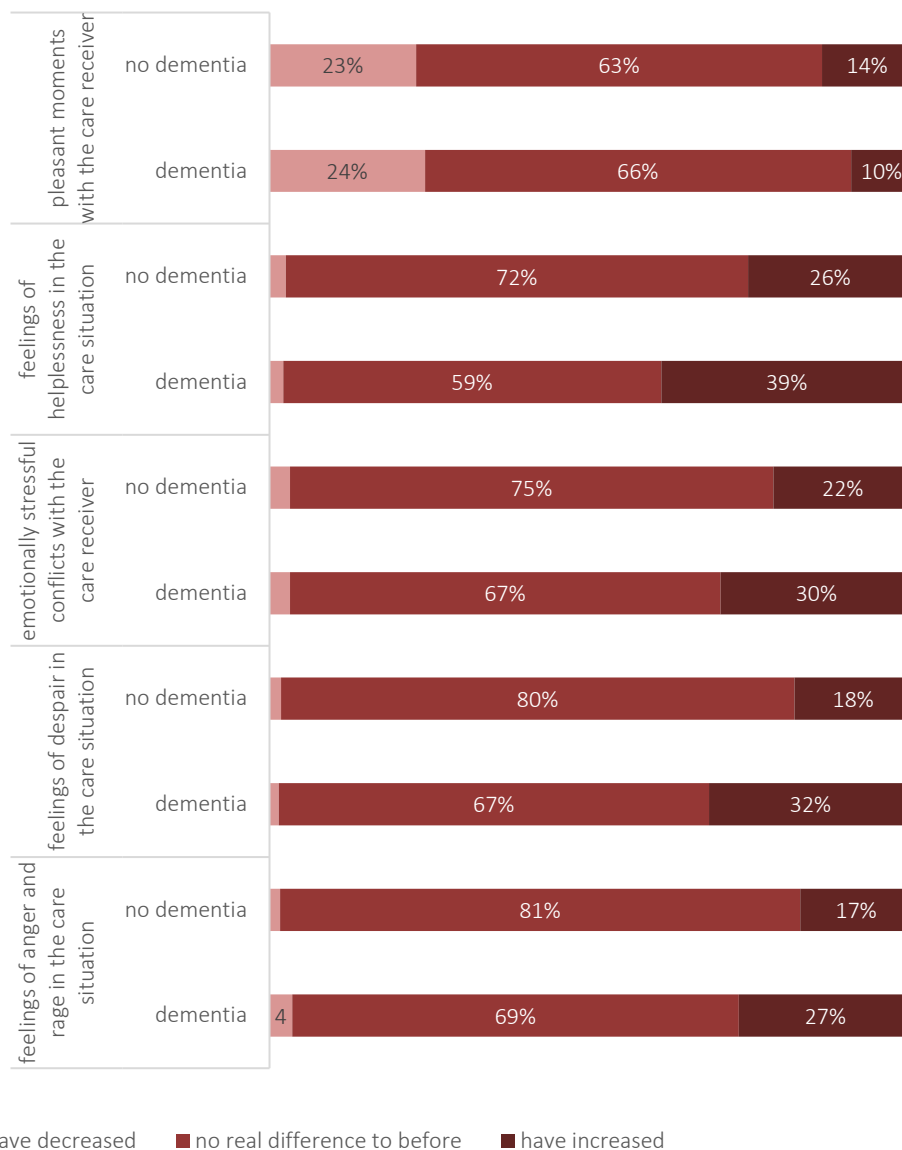


Figure 8: ZQP survey of informal caregivers in the COVID-19 crisis (n = 1.000).

Informal caregivers of people with a dementia diagnosis report even more frequently of an increase in negative feelings than other respondents (Fig. 9). The differences can be most clearly seen in feelings of despair (32 percent in contrast to 18 percent report an increase) and helplessness (39 percent in contrast to 26 percent) in the care situation. Anger and rage (27 percent in contrast to 17 percent) and emotionally stressful conflicts (30 percent in contrast to 22 percent) have also increased much more frequently among informal caregivers for people with dementia. In contrast, there are no significant differences in relation to the pleasant moments with the care receiver.

Effects of the current corona situation on feelings in relation to the care situation [differentiated depending on dementia diagnosis]



Pleasant moments (n = 981; not significant); helplessness (n = 968; $\chi^2(2) = 18.45$, $p < 0.001$, $\phi = 0.14$ [small to medium effect]); conflicts (n = 964; $\chi^2(2) = 7.88$, $p = 0.019$, $\phi = 0.09$ [insufficient effect]); despair (n = 956; $\chi^2(2) = 21.13$, $p < 0.001$, $\phi = 0.15$ [small to medium effect]), anger and rage (n = 952; $\chi^2(2) = 16.09$, $p < 0.001$, $\phi = 0.13$ [small to medium effect])

Figure 9: ZQP survey of informal caregivers in the COVID-19 crisis.

Challenges in the care situation

Particular challenges in the care situation may be possible causes of emotional stress. The most frequently mentioned items in this respect were increased burdens due to cancellation of nearby services and support structures (Fig. 10). For two-fifths of respondents (40 percent⁶), this “applies completely” (11 percent) or “applies somewhat” (28 percent). Just under one-third of respondents see the care receiver as finding the current care situation excessively stressful (6 percent “applies completely”, 25 percent “applies somewhat”) and one-quarter (4 percent plus 21 percent) find the situation excessively stressful themselves. Nearly one-quarter (4 percent plus 19 percent) of informal caregivers were concerned that they might not be able to cope with home care in future. Nearly one-quarter (4 percent plus 19 percent) of informal caregivers were concerned that they might not be able to cope with home care in future.

The following question deals with the special challenges in the care situation due to the corona situation. Please state to what extent the following statements apply to you and your care situation.

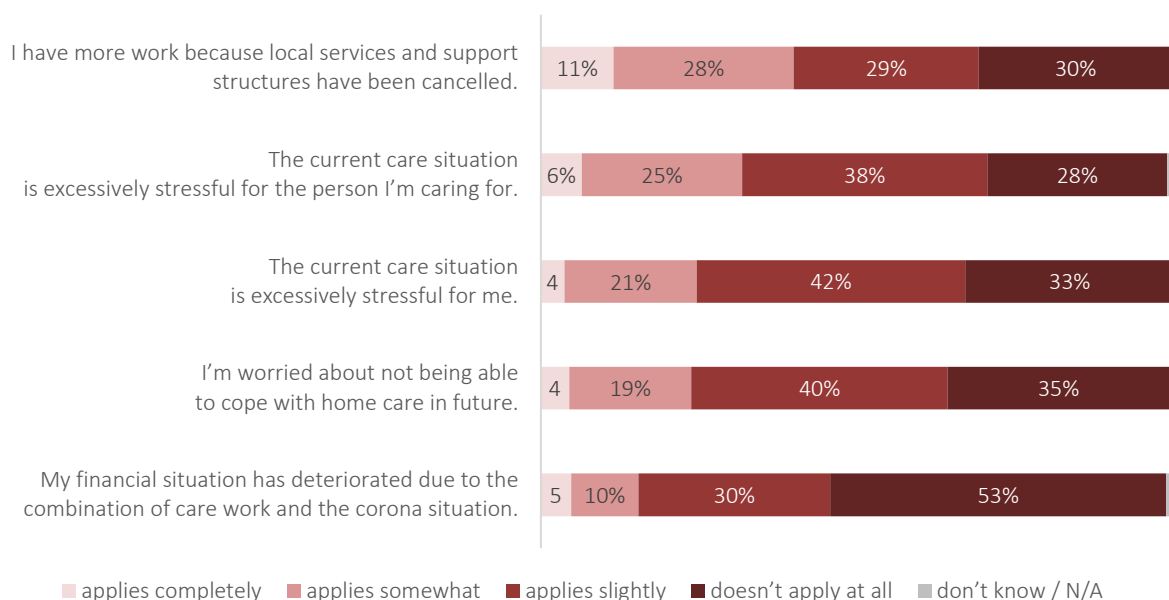


Figure 10: ZQP survey of informal caregivers in the COVID-19 crisis (n = 1.000).

A deterioration in the financial situation due to the combination of care work and the COVID-19 pandemic was mentioned least often as a challenge: On this point, only 15 percent of respondents stated that this “applies completely” (5 percent) or “applies somewhat” (10 percent).

These challenges, too, are more difficult for caregivers whose care recipient has a dementia diagnosis. In this group, the proportion of those who stated that the statement “I’m worried about not being able to cope with home care in future” either “applies completely” or “applies somewhat” was 35 percent, almost twice as high (16 percentage points difference) as among other informal caregivers where the figure was 19 percent. A considerable difference is also apparent for each of the statements “The current care situation is excessively stressful for me” (34 percent, 14 percentage points difference), “The current care situation is excessively stressful for the person I’m caring for” (38 percent, 9 percentage

⁶ Due to differences in rounding off, the combined proportion is different from the sum of the rounded-off proportions of the individual categories.

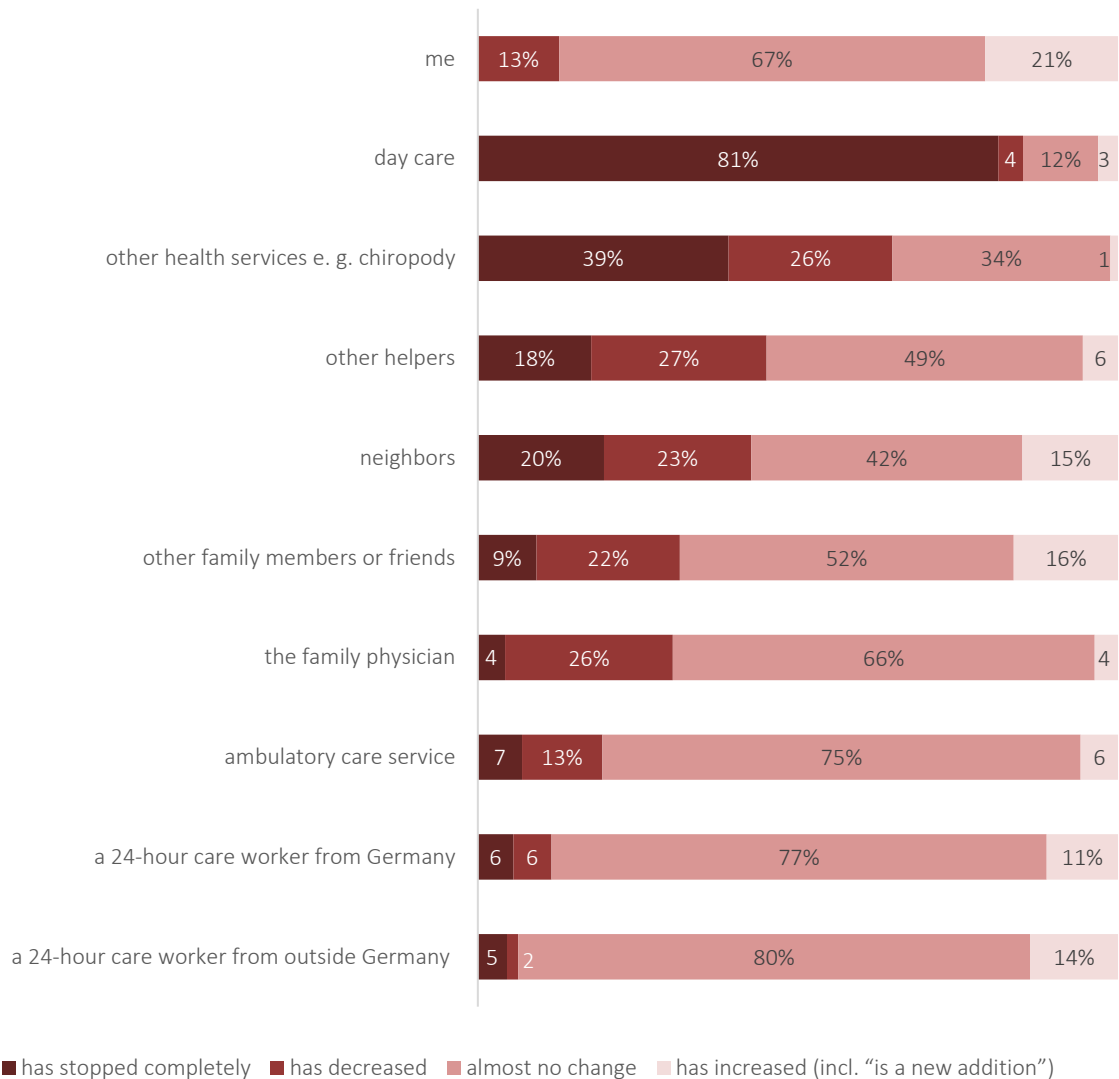
points difference) and “I have more work because local services and support structures were cancelled” (49 percent, 13 percentage points difference). With the exception of the deterioration in the financial situation (19 percent, 5 percentage points difference), all differences between groups with and without a dementia diagnosis are significant.

Development of local support services

To what extent have changes occurred in informal caregivers’ own involvement and the local support services previously used or have new tasks or services been added? Changes in this context may be due to statutory provisions, or to initiatives from supporting individuals or services, informal caregivers or care recipients. According to informal caregivers, the most dramatic cuts are to day care (Fig. 11) that was used by 105 care recipients: in 81 percent of cases it was cancelled completely and used less in another 4 percent. About two-thirds state that support by other healthcare service providers has “stopped completely” (39 percent) or “decreased” (26 percent). Neighbors’ support has “stopped completely” in 20 percent of cases and “decreased” in 23 percent.⁷

⁷ Neighbors usually provide active support in 528 cases.

There are different ways to receive care support. Please state in each case whether there has been a corona-related change for your care recipient. The support provided by ...



Number of cases: me (n = 1,000), day care (n = 105), other health services (n = 641), other helpers (n = 475), neighbors (n = 528), other family members or friends (n = 792), the family physician (n = 863), ambulatory care service (n = 470), 24-hour care worker from Germany (n = 56), 24-hour care worker from outside Germany (n = 89)

Figure 11: ZQP survey of informal caregivers in the COVID-19 crisis.

30 percent state that support from the family physician, who is involved in care provision in about two-thirds of cases, has "stopped completely" (4 percent) or "decreased" (26 percent). Levels of support by ambulatory care services have also changed: provision has "stopped completely" in 7 percent of cases and "decreased" in a further 13 percent.

Information on COVID-19

A large majority of informal caregivers feels well-informed about the topic of corona (Fig. 12). 87 percent feel that the provision of public information in Germany is good and 93 percent state that they can understand this information. Almost one-fifth of informal caregivers (18 percent) state that they have searched for corona information on home care at least once. A further 4 percent have made use of professional advice specifically on the corona situation, for example, at a care support center or other advisory service.

Currently there is a great deal of information about corona and new information is continually being added (e.g. from authorities or in newspapers or news broadcasts). How far do you agree with the following statements?

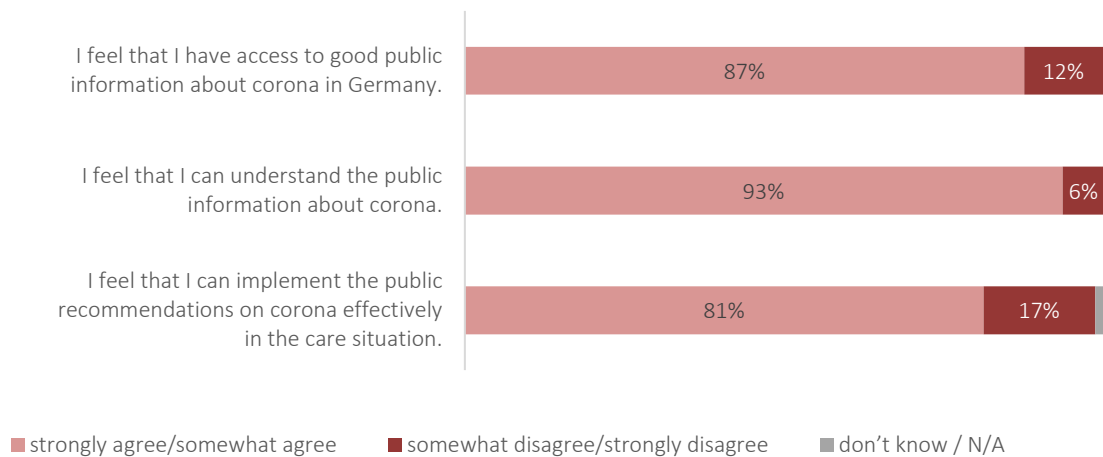


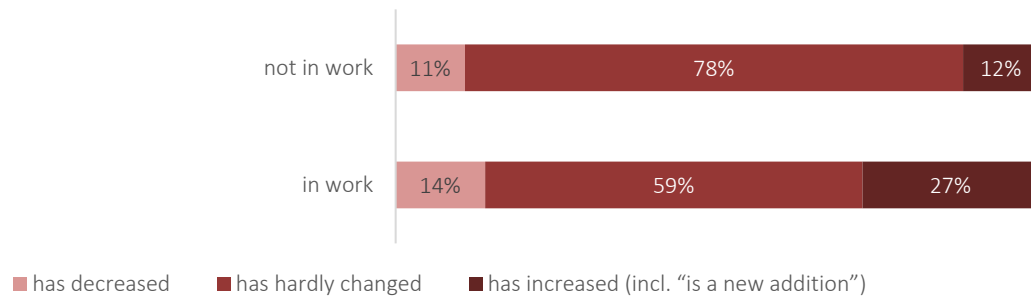
Figure 12: ZQP survey of informal caregivers in the COVID-19 crisis (n = 1.000).

Over four-fifths (81 percent) of respondents feel that they can implement the corona-related recommendations effectively. This positive impression is also maintained among informal caregivers who have already searched for information on home care in the corona situation: 75 percent of these feel that they can implement the information effectively.

Balancing care and work in the corona situation

A significantly bigger proportion of informal caregivers who are in work (27 percent) than those not in work (12 percent) stated that they give the person they care for more support due to the corona pandemic (Fig. 13).

The support that I give, due to the corona situation [differentiated according to 'in work', yes/no]



$\chi^2(2) = 43.16, p < 0.001, \phi = 0.21$ [small to medium effect]

Figure 13: ZQP survey of informal caregivers in the COVID-19 crisis (n = 994).

Informal caregivers who are in employment also face changes in their work in some cases. Over one-quarter (28 percent) of this group state that they currently work exclusively, or to a greater extent, at home or from home (Fig. 14) and 18 percent state that they are fully or partly released from work or are on furlough.

You have to reconcile the care situation with your work. Which of the following possibilities applies to you? [multiple answers possible; employees]

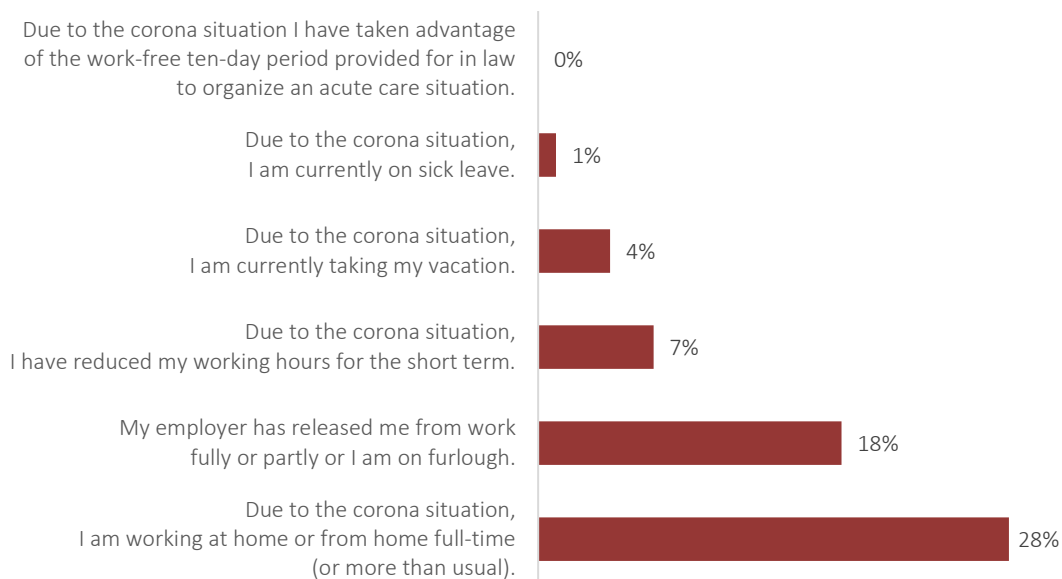
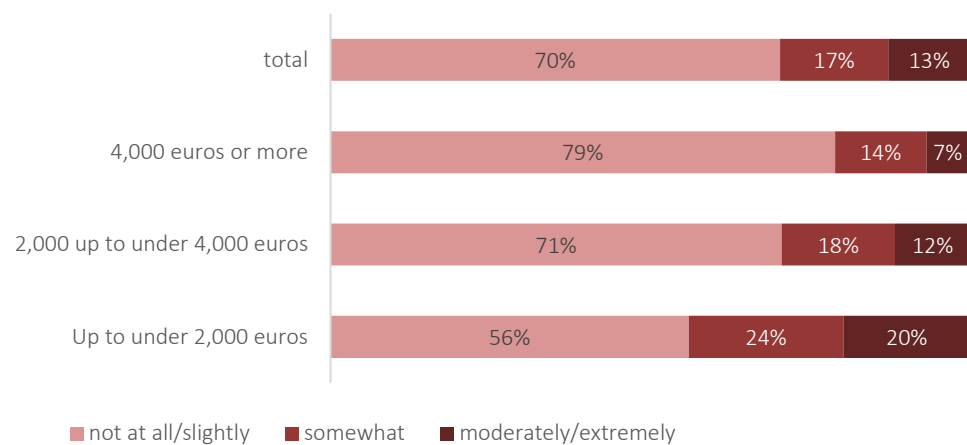


Figure 14: ZQP survey of informal caregivers in the COVID-19 crisis (n = 520).

It is striking that none of the respondents took advantage of the work-free ten-day period provided for in law.

Over two-thirds (70 percent) are “not at all/slightly” concerned about the future of their employment, while in contrast, 13 percent are “moderately /extremely” concerned (Fig. 15). Significant differences can be seen according to monthly net household income: while in the group with a monthly net household income of up to 2,000 euros, a total of 44 percent are “moderately/extremely” concerned (20 percent) or “somewhat” concerned (24 percent), the proportion in the group with a monthly net household income of 4,000 euros or more was less than half as big (7 percent “moderately/extremely” concerned; 14 percent “somewhat”).

Are you concerned about the future of your employment due to the corona situation? [people in employment; differentiated according to monthly net household income]

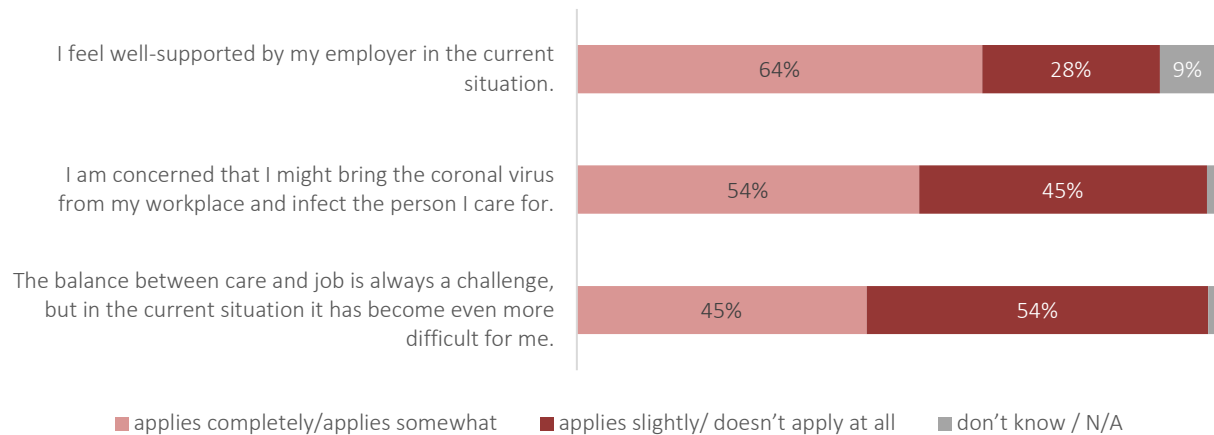


$\chi^2(4) = 14.56, p = 0.006, \phi = 0.17$ [small to medium effect]

Figure 15: ZQP survey of informal caregivers in the COVID-19 crisis (n = 521).

Almost two-thirds of informal caregivers who are employed (64 percent) feel well-supported by their employer during the COVID-19 pandemic (Fig. 16). The majority of employed informal caregivers (54 percent) also state that the balance between job and care has “not at all/slightly” changed in the current situation. In contrast, just under half (45 percent) state that it has become more difficult. Informal caregivers of people with a dementia diagnosis stated this particularly often (56 percent in contrast to 40 percent of other informal caregivers) (Fig. 17). The majority of all respondents (54 percent) is concerned about bringing the virus from their workplace and infecting the person they care for.

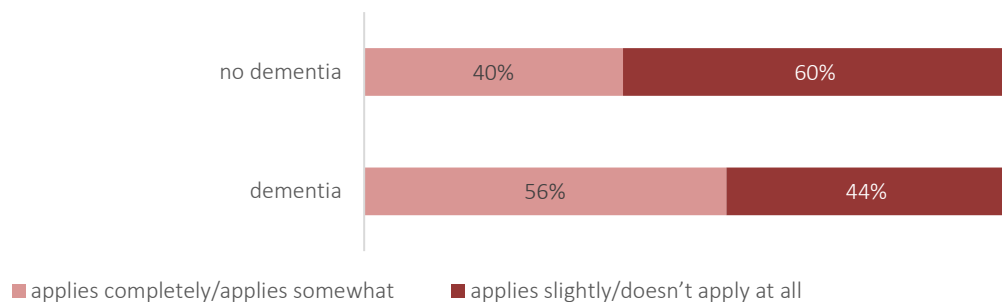
Another question on the balance between care and job in the corona situation. How far do the following statements apply to you?



Number of cases: balance is more difficult (n = 578); concern about bringing the virus to care recipient (n = 578); supported by employer (n = 520)

Figure 16: ZQP survey of informal caregivers in the COVID-19 crisis.

Balancing care and job is always a challenge, but in the current situation it has become even more difficult for me.



$\chi^2(1) = 13.13, p < 0.001, \phi = 0.15$ [small to medium effect]

Figure 17: ZQP survey of informal caregivers in the COVID-19 crisis (n = 568).

IV. Discussion

The study aimed to describe the challenges faced by informal caregivers due to the COVID-19 pandemic in Germany in spring 2020. The survey addressed people aged between 40 and 85 who care for, or help to care for, at least one person aged over 60 with whom they have a personal relationship at least once a week. While there are currently few studies in Germany of the challenges the SARS-CoV-2 pandemic poses for care work (Hower et al., 2020), this is the first survey to present findings on this topic from the viewpoint of informal caregivers of older care receivers (aged 60+).

The discussion of the findings focuses on three core areas of challenge derived from the analysis of the data.⁸

Area of challenge 1: psychosocial stresses faced by informal caregivers

The SARS-CoV-2 pandemic faces people around the world with particular, in some cases far-reaching, health-related, mental, social, and economic challenges (Tull et al., 2020). The contact restrictions and quarantine measures up to and including isolation that heavily influenced people's lives in Germany in spring 2020 are associated with considerable psychosocial consequences and risks for physical and mental health (Wang et al., 2017; Brooks et al., 2020; Röhr et al., 2020). Informal caregivers face this general state as a population group that is already considered to be stressed and thus at risk in terms of health, in particular in relation to their mental health, opportunities for social participation, and poverty (Bastawrous, 2013; Wetzstein et al., 2016).

In addition to the generally demanding care situation, demands and stresses in the personal care constellation risk being intensified in the pandemic. The findings of the nationwide survey in German shown here suggest that the corona pandemic is causing concern among many informal caregivers in relation to their relatives' infection risk, challenges in the care situation – for example, due to the cancellation of many care services – and to a lesser extent, about their financial future. They are also concerned about the person they care for, for example, about their health and caring for them safely – and they support them in dealing with the pandemic, and taking measures to reduce the risk of infection. These concerns were also mentioned by informal caregivers in the context of the ZQP's "Sharing experience in the crisis" service. The findings of this survey bolster these individual reports with quantitative estimates. Thoughts like these are particularly prevalent in the sample among people aged 40 to 54: 46 percent of informal caregivers in this group are moderately or extremely concerned that the person they care for will become sick with COVID-19. This concern is lowest in the 70 to 85 age group: 22 percent of this group are moderately or extremely concerned. 33 percent of them, however, report that they are somewhat concerned. Previous findings also show a corresponding age-related difference in risk perception (Bruine de Bruin, 2020). In addition, the evaluation of this study points to a clear difference between the subgroups "Corona case among acquaintances" and "No corona case among acquaintances". Among those who have a personal experience of the pandemic through an acquaintance, the "moderately/extremely" high risk perception of infection of the person they care for is much greater: 56 percent state this. Only 37 percent of the group with no infections among their acquaintances report such a high level of risk perception.

Against the background described above, informal caregivers were also asked about their feelings in

⁸ Please note that the combined proportions given here may be different from the sum of the rounded-off proportions of the individual categories, due to rounding-off differences.

relation to the care situation and the care relationship. Over the whole sample, it appears that on the one hand, most respondents see no negative changes to the care relationship or their feelings due to the new situation. These findings recall the fact that taking on care tasks is not associated in principle with stress and problems, but can also be accompanied by feelings of life satisfaction, happiness and meaningfulness (Kuuppelomäki et al., 2004; van Campen et al., 2013). On the other hand, between 20 and 30 percent of informal caregivers report deteriorations across the range of questions. It is particularly striking that informal caregivers of a person with dementia report significantly more frequently about an increase of stressful feelings and conflicts: Feelings of helplessness have increased for 39 percent of these respondents, feelings of despair for 32 percent, conflicts with the care receiver for 30 percent and feelings of anger and rage in the care situation for 27 percent. That informal caregivers of people with dementia are particularly affected is consistent with existing studies: Cognitive problems – independent of a particular situation such as a pandemic – increase the average perceived stress in family care situations (Nowossadeck et al., 2016). For people with dementia, the stress caused by measures to reduce the risk of infection is due in part to changes to everyday routines, the requirement to follow systematic hygiene rules, restrictions to their freedom of movement, reduction of support and participation services, and health provision – and these probably also cause additional stress for their informal caregivers (Brown et al., 2020).

Informal caregivers' reports of an increase in despair, anger and rage in the care situation, emotionally stressful conflicts, care situations that are considered excessively demanding in some cases, and concerns about jobs and finances due to the pandemic, indicate additional health risks for care receivers and caregivers in the setting examined: namely an increase in aggression and possible violence (Elman et al. 2020). This should be viewed in the context of the fact that anger, aggression and violence are generally no exception in informal or partly informal care in Germany (Eggert et al. 2018). International research findings on risk factors for occurrences of violence in the informal care context are mixed. However, it appears that among other things, low income and a care situation that is perceived as very stressful, for example when linked to dementia, increase the likelihood of an informal caregiver using violence in the care situation. At the same time, the risk of experiencing violence is greater for older people with poor cognitive status (McDonald, 2019).

Area of challenge 2: care and support situation during the corona pandemic

This study is the first to deliver insights into how informal caregivers in Germany assess their personal care and support situation in the COVID-19 pandemic context. Just under one-third of all respondents overall report a deterioration in the care situation. Again, the significance of dementia as a factor is clear in this context: if a care receiver has dementia, informal caregivers' perception of a general deterioration in the situation is 14 percentage points higher than among informal caregivers of care receivers without dementia. The finding that informal caregivers perceive a deterioration in the home care situation in the pandemic context was to be expected. After all, infection prevention measures such as closing social or health-related infrastructure, or the avoidance of such institutions for fear of infection, may considerably increase stress factors for informal caregivers (Kent et al., 2020).

The study confirms a reduction in the use of support resources in the home care situation during the pandemic. This reduction is considerable in relation to daycare, family physician visits, and health or other service providers such as chiropodists. A lapse or reduction in support by ambulatory care services was mentioned comparatively rarely – nevertheless, it was reported by one-fifth of respondents who

had involved a care service before the crisis. To that extent, this study also confirms current estimates that ambulatory care services were at least partly destabilized during the first wave of SARS-CoV-2 infections (Universität Bremen, 2020). Reduction in assistance by neighbors, family members or friends, which was quite often reported, seems equally significant. These groups are often important resources in the home care constellation (ZQP 2013). Informal caregivers' personal reports (ZQP's "Sharing experience in the crisis" service) also refer to the loss of neighborly support that can be activated at short notice as being particularly painful. The informal caregivers' reports point to the problems caused by the decimation of support resources for partly informal care situations in relation to the pandemic. The three most often-mentioned particular challenges in the home care situation due to the COVID-19 situation, in relation to all respondents, are: 1. Increased stress due to loss of local services and support structures (40 percent "applies completely" or "applies somewhat"), 2. The current care situation is excessively stressful for the care receiver (31 percent "applies completely" or "applies somewhat"), 3. The current care situation is excessively stressful for the informal caregiver (24 percent "applies completely" or "applies somewhat"). In this context too, informal caregivers of people with dementia more frequently report challenges in all categories of question.

Informal caregivers also take on responsibility for core safety-relevant and risky care aspects, such as medication (Eggert et al., 2019) and hygiene (ZQP, 2018). The COVID-19 pandemic has probably raised awareness for the importance of hygiene rules and infection protection when dealing with the care receiver, at least temporarily; however, the amount of information and the practical requirements are considerable (ZQP, 2020). It seems to be difficult to implement the recommendations correctly in everyday practice. One reason is, for example, that the initially controversial discussion about the correct use of a face mask, and in some cases, the limited availability of hygiene materials for informal caregivers, can be seen as problematic – as shown by these study findings and the experience reports (ZQP's "Sharing experience in the crisis" service). These study findings give a differentiated picture of the ease of implementation of recommendations to prevent COVID-19 infection in (partly) informal care situations. When interpreting the figures, it is important to keep in mind that they show respondents' own estimate of the situation. How far the actual situation matches these reports cannot be clarified in this study. Respondents' answers give the following picture: 44 percent of informal caregivers state that they succeed "not very well" or "not at all well" in not touching their own face. 38 percent find it difficult to wear a face mask, for example when attending to the care receiver's personal hygiene. Avoiding physical contact as far as possible, and explaining the exceptional situation to the care receiver, were seen on average as less challenging. 25 percent of respondents in each of these two cases reported that this worked "not very well" or "not at all well". These two prevention requirements in particular showed once again that significantly more informal caregivers of people with dementia assessed these aspects as difficult. The difficulty of explaining new, complex problems to people with dementia, and reducing physical contact with them, is obvious. The situation is compounded by a serious conflict of aims facing informal caregivers: infection protection on the one hand and on the other, fulfilling the care receiver's needs for emotional and tactile communication.

Answers to the question of shifting contact with the care receiver increasingly to phone calls or video calls point to a similar problem. In the group of those who do not live in the same household as the care receiver, about one-half (51 percent) find this to be fairly successful. A total of 43 percent state that this worked "not very well" or "not at all well". However, negative answers here are much more frequent when dementia is present in the care situation. In that case, 56 percent state that using

telecommunications is accordingly more difficult.

Avoiding direct contact to people outside their own household seems to work very well or fairly well for 82 percent of respondents. As many as 97 percent of respondents state that the rule about washing one's hands thoroughly before and after every contact with the care receiver is very easy or fairly easy to implement.

One of the key preconditions for success in implementing health recommendations in the COVID-19 context is being able to keep up with the - at times very dynamic - state of information, filter out confusing or wrong information and apply the correct information in practice (Paakari & Okan, 2020). 51 percent of respondents stated that they succeed very well in keeping regularly informed of the most recent official instructions and recommendations on how to behave in the pandemic. 40 percent of respondents state that they succeed fairly well in this. Overall, opinions of the availability of reliable, comprehensible information on the topic of corona are positive: Only 12 percent of respondents have the impression that provision of sound information in Germany, for example, from the authorities or in newspapers and news broadcasts, is not very good or not at all good. 6 percent state that they have difficulty in understanding the information. The situation is less favorable in relation to implementing recommendations to prevent infection. In this context, 17 percent of all respondents state that they are not able to implement them effectively. In the rather small subgroup of the sample (n = 179) who have already specifically searched for concrete recommendations for home care in the COVID-19 context, 25 percent consider the information they found to be difficult to implement. The overall rather positive description of the subjective information situation matches similar current findings related to the pandemic (Orkan et al., 2020). At the same time, it must be stated that health competence is estimated to be rather problematic in Germany as a whole (Schaeffer et al., 2019; Sörensen et al., 2015).

Area of challenge 3: balancing work and care

The third area of challenge throws a light on the effects of the corona pandemic in spring 2020 and the situation of informal caregivers who are in work. The group of informal caregivers who work has increased noticeably in recent years and will probably continue to increase in future (ZQP, 2016; Eggert et al., 2018). The necessity of improving the overall balance between care and work emerges, for example, through existing scientific indications of stress factors and relief factors that informal caregivers experience in relation to their jobs. Thus, conflicts at the workplace related to this balance are clearly a considerable stress factor for informal caregivers, while positive experiences at work can potentially relieve stress (Pinquart, 2016).

This study shows that at the time when the survey was carried out, around 28 percent of working informal caregivers were working more than usual or entirely from home due to the corona situation. Informal caregivers with a university entrance qualification or a degree have above-average opportunities to "benefit" from this option. These findings are to a great extent consistent with the state of knowledge on working from home of the whole working population in Germany in the current crisis (Blom et al., 2020). The opportunity to work from home may be particularly important for some respondents, because over half report that they are at least somewhat concerned about bringing the SARS-CoV-2 virus from their workplace and infecting the person they care for at home. The reduction of their presence in the workplace and avoiding the journey to work reduce the risk of infection. Apart from this aspect, no further quantifiable statements about reduced or increased stress in relation to working from home can be made here. However, it seems likely that the effects of working at home in

the corona situation may either reduce or increase stress. Thus, working informal caregivers may experience more stress when they have to continue working for their company and at the same time, support services such as daycare institutions or volunteer support are no longer available. At the same time, concentrating on work is probably much more difficult at home when there is currently a demanding care situation in the same household and maybe even children who also need attention.

The study findings show that the situation caused by the COVID-19 pandemic is particularly challenging overall for many working caregivers. 13 percent report that they are moderately or extremely concerned about the future of their job due to the corona situation. As many as 20 percent of the group with a gross monthly income of under 2,000 euros state this. 45 percent of respondents state that the current situation made the balance between work and care even more difficult. However, most of those in this situation feel well-supported by their employer – 64 percent state this. The importance of paying attention to the concerns of informal caregivers in company culture has already been pointed to in a range of publications – particularly when they care for people with dementia (ZQP, 2016; Eggert et al., 2018). Informal caregivers for people with dementia face particular difficulty in balancing care and work, because as the disease progresses, symptoms occur such as agitated behavior, restless nights and the tendency to run away or set off towards an imaginary destination (Pinquart, 2016). The increasingly demanding care situation clearly also leads to about one-third of working informal caregivers of people with dementia reducing their working hours or giving up their job in the course of their care work (Schäufele et al., 2016). The specific dementia dimension on this point is also reflected in this study: More working people caring for a person with dementia state that the balance has become even more difficult in the COVID-19 crisis – namely 56 percent, while only 40 percent make this statement in the group where no dementia is present.

The debate should also consider that informal caregivers' participation in the labor force is known to decrease the longer the caring period lasts (ZQP, 2016). Against the background of the pandemic's anticipated progression with no end in sight, increasing numbers of informal caregivers may leave the labor force if they can no longer balance the stresses of home care with their working life in the long term. With this aspect in mind, policies to provide ways to better balance care and work for informal caregivers should also be discussed.

V. Limitations

Although this study gives valuable indications about the situation of informal caregivers during the corona pandemic, methodological limitations must be taken into account when interpreting the findings to derive possible conclusions. Although the base population was recruited offline, the survey comprised a weighted online survey that may, for this reason, not give an undistorted picture of the whole population of informal caregivers in Germany. It is possible that some informal caregivers who are under particular stress, or who do not have access to web-enabled devices, did not take part in the survey.

The pandemic in Germany has shown considerable regional variations. This study can, however, give no robust differentiations for regions or hotspots.

Four men and one woman among the respondents stated that they themselves were verifiably sick with COVID-19 when the survey was carried out, which does not permit robust conclusions about care processes and the situation of informal caregivers who become sick with COVID-19. In addition, only two respondents stated that the care receiver who features in the study was sick. However, 16 percent of respondents stated that they know someone among their acquaintances who is or was infected with the new coronavirus. It is difficult to assess the reliability of these statements. On the one hand, the findings could be influenced by knowingly or unknowingly false answers. It is possible, for example, that an infection or sickness occurred but was not reported, because it was either not noticed, or not identified as COVID-19. Socially desirable responding may also play a role in questions of infections or sickness (Wolter, 2012). Based on the 180,458 confirmed cases of COVID-19 infection in Germany on 30 May 2020, the rate was about 0.2 percent of the population (RKI, 2020c).

The survey did not use validated scales. Although this procedure is usual for ad-hoc surveys, and many of the questions were oriented on validated instruments, assessments of psychosocial stresses can only be interpreted as initial indications. Clinically relevant screening of the stress reactions, such as acute stress disorder or depression, is not possible using these data. In addition, the findings were mostly presented descriptively; this report is not intended to provide causal conclusions and statistical corrections of the interplay of all features examined, and the findings must therefore be seen as provisional interpretations.

With these limitations in mind, the authors reach the following conclusions.

VI. Conclusions

The findings of this survey shed light on the far-reaching health, mental, social, and economic challenges facing informal caregivers of people with and without dementia due to SARS-CoV-2 pandemic. The findings enable us to draw conclusions in the areas of the psychosocial stresses informal caregivers face, the care and support situation during the corona pandemic and the balance between work and care.

Psychosocial stresses faced by informal caregivers

- Despite the, in some cases, considerable increase in stresses due to the combination of the care situation and restrictions linked to the corona pandemic, informal caregivers provide *essential* care; the German health and care system is based to a great extent on this family support. The service that informal caregivers provide for society must be appropriately honored and effectively supported.
- In order to avoid or reduce the psychosocial stresses suffered by informal caregivers, support structures must be expanded both for the services informal caregivers provide and for their mental health. All institutions that are in contact with informal caregivers (e.g. care support centers, family physicians, care services) should continue to publicize existing provision in relation to psychosocial issues.
- The survey shows that people with care-dependent relatives with dementia are often faced with particular challenges due to the COVID-19 pandemic. Services that provide appropriate support or

relief for this group are therefore particularly important and should continue to be available during crises, as far as possible.

- Respondents reported an increase in conflicts in the home care situation as well as feelings of anger and despair. This can lead to aggression and violence in the care situation. Therefore, services related to prevention of violence in the home care context are important.

Care and support situation during the corona pandemic

- It was reported that the home care situation deteriorated due to the SARS-CoV-2 pandemic, with the main caregiver bearing a particularly heavy burden. Among other things, the discontinuation of neighborly support that can be called on at short notice seems significant. Increased stresses due to cancelled services and aid structures in the neighborhood were often mentioned. To maintain such neighborhood services for care receivers and informal caregivers in future, we recommend supporting ambulatory services and other providers in maintaining these services in a crisis more reliably and with as little health risk as possible. In this context, health protection for staff and clients needs to be improved, for example, by stocking sufficient hygiene supplies, appropriate testing capacity and regular hygiene training for staff in care organizations.
- Telemedicine services can make a contribution, for example by maintaining the contact to the family physician for care receivers and their informal caregivers. Nevertheless, obstacles were reported particularly in the field of telephone/videotelephone contact, which suggests that telemedical or telecare infrastructure in the wider sense needs to be extended in a way tailored to the target group. To address this issue, the risks of social inequality and the age structure of those affected, that are revealed by the current limitations of digital solutions in the fields of home care and communication, must be considered.
- The availability of reliable, comprehensible information on the topic of corona was positively evaluated by the informal caregivers surveyed. Therefore we recommend continuing to carry out measures to disseminate information by the federal and state governments, among others, based on the current strategy and to develop it further, taking into account user preferences of differentiated target groups and the findability of secure, comprehensible information specifically for informal caregivers. This may promote the implementation of hygiene methods in home care, for example, or the use of available health services and support provision.

Balance between work and care

- To take adequate account of informal caregivers' concern about infecting the person they care for, opportunities for flexible work organization should be urgently explored by employers and informal caregivers – wherever this is not already taking place – to find individual, efficient solutions that work for both sides.
- The work-care balance is a particular challenge for informal caregivers of people with dementia, and the COVID-19 crisis has made this even more difficult, as the findings presented here show. This points (among other things) to the fact that for these care arrangements in particular, care services and help structures in the neighborhood must be maintained as fully, and made as safe to use, as possible.

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