

# Burdens of family caregivers during the Covid-19 pandemic in Germany. A qualitative study of social media posts

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## Research Article

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# Abstract

## Background

A large proportion of people in need of care in Germany are cared for at home by relatives. Caregiving is associated with various burdens for family caregivers. The Covid-19 pandemic and the protective measures to restrict public life such as social distancing and the closure of services and educational institutions, add further challenges. Little is known about how they are perceived by family caregivers. Based on an analysis of social media posts, the aim of the present study was to explore the additional strains family caregivers experience during the pandemic.

## Methods

The German-language versions of the social media sites Facebook, Twitter, and YouTube comments were systematically searched with regard to the pandemic-related burdens of family caregivers and examined using qualitative content analysis. The search was conducted from Nov 24, 2020 to Dec 8, 2020. A total of 237 social media posts were included in the data analysis.

## Results

Seven main categories with varying numbers of subcategories were identified: Care and support (lack of care and support services, care in case of illness or quarantine), deterioration of the condition of the person being cared for, psychological challenges, financial challenges, infection control, access to protective equipment (questions and problems regarding infection control measures), and acknowledgement of family caregivers (consideration of relatives of children or people with disabilities, unequal treatment, and consideration in the context of protective measures).

## Conclusions

Family caregivers are affected by additional burdens during the pandemic, which make it necessary to develop support and relief services tailored to this population group. The results of the present study can contribute to the development of respective diversity-sensitive support services.

## Introduction

In January 2020, the first case of SARS-CoV-2 was reported in Germany [1]. To contain the spread of the virus and to prevent the overburdening of the health care system, measures to restrict public life – similarly to most other countries in the world – were adopted by the federal and state governments in Germany in March 2020 [2–4]. They included contact restrictions, the closure of personal hygiene services such as hair and nail salons, and the closure of educational institutions. In response to declining numbers of new infections, Germany gradually relaxed protective measures in May and June 2020. Beginning in the late summer months of the year 2020, again a sharp increase of the number of new infections was reported. In response to this development, measures regarding the restriction of public life were again adopted by the federal and state governments in November

2020 [4]. By April 22, 2021, 3,217,710 people have been infected with SARS-CoV-2 in Germany since the beginning of the pandemic. A total of 80,893 people have died from Covid-19 as of that date [5].

The Covid-19 pandemic also poses numerous challenges for family caregivers. Approximately 2.5 million people in need of care in Germany are cared for by their relatives at home [6]. Caring for relatives is associated with a variety of burdens for caregivers comprising mental, physical and social consequences [7–9]. The pandemic and the protective measures implemented to restrict public life add further strains [10–13]. In Germany, e.g., these result from the closure of day care facilities as implemented in the spring of 2020 [2;13]. On the part of the federal and state governments, the "Second Act for the Protection of the Population in the Event of an Epidemic Situation of National Significance" passed on May 14, 2020, however, also implemented parallel relief measures for family caregivers, including, for example, an expansion of the care support allowance [4;14]. Little is known about how these measures are perceived by caregivers.

Due to their age and existing underlying diseases, a large proportion of caregivers belong to a group that itself requires special protection and is at high risk for a particularly severe course of Covid-19 [15]. Regardless of the measures to restrict public life, it can be assumed that burdens for caregiving relatives therefore also arise from fears of infecting care recipients or even themselves [16].

A study by the Berlin Center for Quality in Care examined the challenges of family caregivers between the ages of 40 and 85 during the Covid-19 pandemic via an online survey conducted in late April/early May 2020 [13;17]. One of the findings of the survey was that a large proportion of family caregivers were concerned about an Covid-19 infection of the person in need of care. About one-third of respondents reported that their caregiving situation had worsened since the pandemic. In a similar study by Rothgang et al. conducted in June-August 2020 [18], nearly 60% of informal caregivers surveyed reported that the care situation had changed and had become more time-consuming. For 71% of respondents, the pandemic had made it more difficult to balance caregiving and work, and 52% reported a deterioration in their own health and quality of life.

The present study complements and updates the findings from these quantitative survey studies from the Spring and Summer of 2020 with a qualitative analysis of social media posts from November/December 2020. The aim of the study is to draw on these posts to explore the perceived burdens of family caregivers during the Covid-19 pandemic and to identify particularly vulnerable groups. The results may help to inform relief and support strategies for this population group.

## Methods

### Data selection

The German-language versions of the three social media sites Facebook, Twitter, and the comments section of YouTube were examined with regard to the burdens of family caregivers during the Covid-19 pandemic. The sites were selected as they are the three of the most frequented networks in Germany. They were searched for the keywords "Corona", "Corona virus", "Covid-19", "SARS-CoV-2," "Corona crisis," "family caregivers" and "home care" in German language. Posts considered relevant to the research question were extracted into a text document. Data were retrieved until no further dimensions of burdens of family caregivers regarding the Covid-19 pandemic could be identified. The search was conducted from Nov 24, 2020 to Dec 8, 2020.

# Data analysis

A total of 237 social media posts were included in the data analysis. Of these posts, 120 were identified on Facebook, 108 on Twitter, and 9 on YouTube. The social media posts were analyzed inductively by means of structured qualitative content analysis [19]. In the process, text passages relevant to the research question were highlighted in the text document. Subsequently, the posts were coded one by one. Text excerpts that had similar coding were combined into a main category. The main categories were categorized into subcategories according to their content. Codes were developed based the categories.

## Ethical aspects

Public and freely accessible information from social media posts were used for the analysis that were also considered open data according to previous studies [20]. Furthermore, to ensure the anonymity of the users, the term "user" was used instead of the published user name of the contributor. In addition, the language of quotations was slightly modified to prevent the posts from being identified by search engines. Abbreviations and emojis were removed. The content of the posts was left unchanged.

## Results

The qualitative content analysis of the social media posts identified seven main categories and six subcategories of burdens experiences by family caregivers, which are presented in the following.

Care and support

### Lack of care and support services

Based on the analysis of the posts, it appears that the loss of support services for family caregivers, including the closure of day care and educational facilities, constitutes a significant burden:

"All of a sudden, our entire network broke away, day care was closed, neighborhood assistance was discontinued, and occupational therapy was canceled. [...]" [User #23.]

"Family caregivers are left alone. Day care facilities are not open during the Corona crisis and family caregivers are therefore left to fend for themselves. Many are now devastated after a good four weeks without support." [User #15]

In addition, the loss of support services for working family caregivers is also considered problematic regarding the compatibility of care and work:

"And how do you support the largest care provider in Germany, namely family caregivers? There is no support for working family caregivers who care and provide care at home, nor for those who work in system-relevant professions. Care at home and at work are currently the horror." [User #41]

"20 Days. How long has it been since day care facilities and sheltered workshops have closed? Many family caregivers have now already used up all their annual leave allowance thanks to Corona and the closure of the facilities and are on unpaid leave. [...]" [User #176]

In some cases, care and support services had also been cancelled by family caregivers and/or service providers as a means of protection against infection with SARS-Cov-2:

"We would like to take some time off to recharge our batteries. However, we have canceled the respite stay at the children's hospice, out of concern about Corona. That's our decision, you have to prioritize." [User #12]

"I canceled care in February due to Corona. Since then I have been taking over the care of my mother (...) completely on my own. In the meantime, I am at the end of my rope and can no longer get a care service, because there are no free capacities available for the foreseeable future. The short-term care was also canceled because of Corona; for months, I am responsible for everything on my own." [User #106]

## Care in case of illness or quarantine

In addition, the posts illustrate the caregivers' concern about how care can be provided in case of illness or quarantine:

"In the event of a parent's infection with Covid-19, there are currently no, really no(!), care options for their disabled children, no matter what age the parents and their children are. Relevant to the system? What solutions and perspectives are being worked out for these families?" [User #16]

In addition, users also report stress and lack of support services in the case of illness or quarantine:

"We got hit. My sister, who mainly cares for our grandma with dementia and does the shopping and cooking, tested positive for Corona. Fortunately, she has no symptoms. But organizing everything in a hurry is crazy. Informing the nursing service, which only comes to give pills, a neighbor spontaneously takes over the preventive care, but the family doctor does not want to come for the test." [User #120].

## Deterioration of the condition of the care recipient

Some of the users report a deterioration in the physical and mental health of the care recipient during the pandemic. In some cases, the deterioration of the condition is associated with the closure of care and education facilities:

"A phase of dementia begins with local disorientation, respectively, it already lasts a little. But it becomes stronger in recent times and more difficult with regard to the Corona situation. [...]" [User #24]

"My son was in the special needs school for seven days from March until the summer vacations. That did not do him any good at all. He was like disconnected and introverted at times." [User #126]

## Psychological challenges

Psychological challenges emerge as a further burden for family caregivers during the Covid-19 pandemic. According to the social media users, these results, among other things, from isolation and the permanent burden of caregiving due to the loss of professional caregiving services:

"The overall situation as a family caregiver with someone with dementia to care for is becoming more challenging." [User #24]

"My daughter was home for three months! Then here I had a husband with dementia! I had to be careful that the two did not clash! Physically it was no problem, but mentally I am still exhausted, since then I had no chance to recover!" [User #181]

"Through something like that you can really have a paddy and get a depressed mood. But giving up is not an option, it has to go on." [User #136]

## Financial challenges

Furthermore, family caregivers reported being affected by financial challenges during the Covid-19 pandemic as part of the extra workload associated with caregiving:

"Day care has been closed for six months, the annual and caregiving leave allowance have been used up, now what? A loan to provide family caregiving? That is a debt, not knowing how long it will all take. Permanent care of a mother with dementia and an additional debt, why don't we get the money from day care? Hardcore care for six months. There is no end in sight, something is wrong." [User #104]

Family caregivers also face additional financial burdens due to SARS-CoV-2 testing required to care for a person:

"Great, you can voluntarily get tested for Corona for free. But if, for example, you need a test as a family caregiver in order to be able to have someone in need of care being looked after or something comparable, I pay €128. That raises some questions." [User #41]

## Infection control

The analysis further reveals that infection control in the home environment proves to be challenging for caregivers. On the one hand, this is explained by social media users by the fact that recommended measures of infection control, such as keeping a distance, cannot be implemented during caregiving. On the other hand, the protective equipment needed is not always available in the home environment. Furthermore, the care recipients come into contact with possible sources of infection, for example, through the work-related activities of their caregiving relatives or through the support of outpatient care services. Many of the care recipients are reported to be at high risk of a severe course of Covid-19 and many caregivers fear infecting the care recipients. In addition, infection control in public also places a burden on family caregivers:

"I am a family caregiver. And keeping a distance is not possible, especially as regards basic care. Even not if I turned the hallway into a sluice and applied everything I once learned in dealing with MRSA, provided I had the material." [User #24]

"You are a family caregiver and you are frustrated when the outpatient nurse on night duty tonight has a bad cold in the middle of the pandemic. But you know the only alternative is, you send her home and take over the night watch yourself." [User #12]

The analysis also reveals that not all care recipients can implement or tolerate recommended infection control measures:

"It is all really bad for us family caregivers right now. My husband just got picked up, for day care, he made such a fuss about the mask." [User #153]

# Access to protective equipment

The analysis of the posts revealed that during the Covid-19 pandemic, it may be difficult for family caregivers to obtain the protective equipment needed to provide day-to-day care:

"We family caregivers are struggling with limited supplies. For example, it is becoming steadily more difficult to get disposable gloves. In our case, a care recipient with a stoma, a permanent catheter and diaper due to bowel stump leakage and wound care. We need help." [User #84]

In addition, the users report, obtaining additional protective gear to improve infection control is problematic:

"Why can't family caregivers get FFP2 masks?" [User #6]

"We can't get masks anymore, they're all sold out." [User #95]

## Questions and problems regarding infection control measures

The analysis shows that users have unanswered questions with regard to the infection control measures implemented by the federal and state governments, for example, regarding occupational regulations related to SARS-CoV-2:

"I work professionally in a facility for people with disabilities. There are many Corona cases in this facility. The risk of falling into home and work quarantine is very high. Can my employer force me to go to work anyway? According to an internet search I can get an exemption; is anyone in a similar situation?" [User #131]

"As a professional who is caring for a high-risk patient and who cannot agree with the employer on time off, what can I do?" [User #89]

In addition, questions and issues arise among users regarding how to deal with SARS-CoV-2-related changes in the nursing situation, as well as concerning quarantine regulations in this context:

"We got a letter from the nursing service today: Out of service due to Corona. The nursing service requires a confirmation from us regarding the assignments cancelled due to Corona, to be submitted to the responsible authority. What does that mean exactly and what do I sign? Is this associated with any disadvantages for me?" [User #100]

"On Thursday I had contact with an infected person. [...] What do I do now? Okay, I have to go into quarantine. But I am taking care of my husband, plus, I have assistants coming to support me and therapists. Do I send them home for two weeks and lock myself in with my husband? Or is it just about avoiding contact with therapy and assistants? I do not know what to do right now. [User #140]

Similarly, questions arise about how to deal with a SARS-CoV-2-related increase in home care expenses as well as support services which were not properly provided by service providers:

"What about when the 20 working days per case and the support allowance are used up but the care recipient still needs to receive care?" [User #171]

"I have also given all the personal assistance and nursing staff, which I had painstakingly assembled, time off to minimize the risk of infection. I can still use overtime and remaining vacation time, but what if they are used up? We do not know how long this condition will last." [User #53]

Acknowledgement of family caregivers

## **Considering relatives of children or of people with disabilities**

Users complain that the term 'family caregiver' is often associated with caring for an elderly person only, and that family caregivers of sick children, younger people, or people with disabilities seem to go unnoticed in the Covid-19 pandemic. The fact that they also have a different set of needs with respect to support would complicate matters further:

"What about caring for (mentally) disabled relatives who, for example, cannot go to the sheltered workshop during Corona and need to be permanently cared for at home? Or people with disabilities who have to go back to their parents temporarily because of the risk of infections in special living arrangements?" [User #169]

"Please also consider the caregivers of impaired children. This is often ignored and their needs are often not the same [as for caregivers of older people]. These parents are often forgotten, unfortunately." [User #173]

## **Unequal treatment**

Furthermore, users perceive an unequal treatment of family caregivers as compared to other stakeholders:

"Everyone is looking at professional caregivers. What are family caregivers doing to protect their dependent parents, partners, siblings, children? They are almost completely on their own." [User #3]

"For car, airplane and steel companies worth billions, there is short-time allowance and additional billions on top, which are waved through in no time. For family caregivers only some 'pseudo-assistance' is available and bureaucracy on top and please wait until this is graciously approved at some point." [User #58]

## **Consideration in the context of protective measures**

The limited consideration of family caregivers in the Covid-19-related measures implemented and planned by federal and state governments is also perceived as burdensome by the social media users:

"Why are family caregivers who provide around-the-clock home care not mentioned or considered anywhere? For many, all offers of help have gone away, which means more effort. In addition, the isolation reinforces the situation and you continue to ignore us? Where is the Corona bonus for family caregivers?" [User #51]

"It cannot go on like this! Finally, make sure that family caregivers also get supported, they are the largest care service in Germany. Some helpless advice and consoling people until the end of pandemic is over is not productive." [User #1]

## **Discussion**

By analyzing social media posts, this study investigated the subjectively perceived burdens experienced by family caregivers during the Covid-19 pandemic in Germany. The analysis revealed that since the beginning of the pandemic, family caregivers have been permanently confronted with a variety of strains, some of which have

intensified in the course of the pandemic. These strains can be allocated to seven main categories, and add to the strains that exist independently of the pandemic and are caused by providing care itself. To cope with the care-related strains and challenges, which in turn can lead to psychological impairment and illness [7–9], a large proportion of family caregivers usually turns to formal care and support services for relief, such as support provided by day care and short-term care facilities [21;22]. As a result of the measures taken by the federal and state governments to contain the Covid-19 pandemic, these relief options have been shut down in many cases. This led to changes in the nursing care situation and to an increase in the care-related burden for family caregivers. Rothgang et al. came to similar conclusions in an online survey of informal caregivers; according to this survey, 57% of respondents stated that their daily care-related burden had increased since the beginning of the pandemic [18]. Comparable findings are reported by studies from other countries [12;23;24].

The results of the present study also show that family caregivers face additional psychological stress during the pandemic. This is consistent with the results of another online survey, in which family caregivers reported feelings of helplessness, emotionally stressful conflicts, and despair [13]. In addition to the already existing strains on family caregivers, there are additional burdens and challenges caused by the pandemic as the present study points out. These include the poor availability of protective equipment, such as disinfectants. Although availability has improved over the course of the pandemic, about one-sixth of family caregivers reported continuing to lack necessary protective materials in previous studies [18]. In addition, family caregivers perceive unequal treatment compared to other groups with regard to implemented and planned infection control measures. Furthermore, the poor consideration of the needs of family caregivers of children and other population groups is criticized. Likewise, family caregivers perceive too little acknowledgement and consideration on the part of policymakers. These results are also consistent with previous quantitative surveys [18].

Support measures aiming to reduce burdens for family caregivers during the pandemic must address the very shortcoming pointed out by the users comprising measures assisting caregivers in home care activities by allowing them to seek support from the formal nursing care system, reducing administrative and financial burdens, increasing regulatory flexibility as well as mental and physical health promotion. This can include an increase in the number of days caregivers can seek leave from their work, flexibility in working hours including extensive possibilities to work from home, better access to protective equipment including SARS-CoV-2 test kits and (telehealth) counseling services [25–27].

To our knowledge, this is the first study in Germany to examine the burden of family caregiving from the perspective of social media users. A limitation of this study is that only three frequently used social media platforms were used as data sources. Social media users are in the age group of 14 to 49 years [28;29]. According to routine data most family caregivers, in contrast, are between 50 to 70 years old [30]. Accordingly, the user profile is not representative of the entire population of informal caregivers in Germany. Instead, the present study explores the perceptions of a special subgroups of family caregivers and it is unclear to what extent the results are transferable to other population groups. In addition, the present study did not stratify by age, possible existing disabilities, and the severity of impairment of the person being cared for, as well as by socioeconomic characteristics, because this information was not available for the analysis. It is therefore unclear to what extent the burdens identified are applicable to the group of family caregivers in general. In addition, the coding of the social media posts selected for analysis took place by only one author (JF), which means that postings were interpreted subjectively and possible other aspects of meaning were potentially excluded. Accordingly, the coding process and the assignment of posts to main categories and subcategories may be biased by the author's

individual perspective. However, the identified codes, categories, and subcategories were reviewed and interpreted collectively by all authors. Furthermore, only posts until August 12, 2020 were considered. Since it can be assumed that the perception changed in the course of the pandemic, possibly, other relevant dimensions have not been considered due to the time frame of the study. Future research should determine how opinions expressed in social media posts evolved after August 12, 2020.

## Conclusions

The results of this study provide insights into the burdens of family caregivers in Germany during the Covid-19 pandemic, which can be clustered into various categories, some of which are specific to the pandemic. Support and relief services must adequately address the diversity of these strains, and therefore must include the promotion of mental health, providing protective materials, as well as information needs that arise for family caregivers. The results of the present study can contribute to the development of appropriate diversity-sensitive support services for this population group.

## Abbreviations

COVID-19: Coronavirus disease

SARS: Severe acute respiratory syndrome

SARS-CoV-2: Severe acute respiratory syndrome coronavirus 2

## Declarations

### *Ethics approval and consent to participate*

For this study, data from social media sites were used. Since these are open forums, users' posts were considered publicly available secondary data. As described in the methods section, several steps were followed to ensure anonymity of the data. Considering the recommendations for secondary data analysis, no further ethical review was required for this analysis.

### *Consent for publication*

Not applicable.

### *Availability of data and materials*

All posts used for the analysis are available from the corresponding author upon request.

### *Competing interests*

The authors declare that there are no competing interests.

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### ***Authors' contributions***

JF was responsible for the design of the study, for the data collection as well as for the analysis and interpretation of the data. YYA and PB participated in the development of the study design and together with DW contributed to the interpretation of the data and to writing the manuscript. All authors have read and approved the final manuscript.

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