Additional burdens of family caregivers during the COVID-19 pandemic: A qualitative analysis of social media in Germany

Jana Fieselmann BSc | Diana Wahidie MSc | Yüce Yilmaz-Aslan DrPH¹,²,³ | Patrick Brzoska DrPH¹

¹Faculty of Health, School of Medicine, Health Services Research, Witten/Herdecke University, Witten, Germany
²Department of Epidemiology and International Public Health, School of Public Health, Bielefeld University, Bielefeld, Germany
³Department of Nursing and Health Services Research, School of Public Health, Bielefeld University, Bielefeld, Germany

Correspondence
Patrick Brzoska, Health Services Research, Faculty of Health, School of Medicine, Witten/Herdecke University, Alfred-Herrhausen-Straße 50, D-58448 Witten, Germany.
Email: patrick.brzoska@uni-wh.de

Abstract
Caregiving is associated with various burdens for family caregivers. The COVID-19 pandemic and the protective measures implemented 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 German social media posts, the aim of this study was to explore the additional strains family caregivers experience during the pandemic. The websites of three social media services were searched using the respective search engines provided by the websites. Data from a 10-month period (March to December 2020) were identified and examined. A total of 237 publicly available posts were included in the analysis. Seven main categories were identified using a thematic approach: care and support, deterioration of the condition of the person being cared for, psychological challenges, financial challenges, infection control, access to protective equipment, and acknowledgement of family caregivers. Family caregivers are affected by additional burdens during the pandemic, which makes the development of support and relief services tailored to this population group necessary.

KEYWORDS
caregiver burden, disaster relief, COVID-19, family caregivers, SARS-CoV-2, social media

Key points
- Family caregivers are affected by a variety of additional challenges and burdens during the COVID-19 pandemic.
- Support and relief services tailored to the needs of family caregivers need to be developed.
- Services must take the heterogeneity of family caregivers into account.

1 | INTRODUCTION

In January 2020, the first case of SARS-CoV-2 was reported in Germany (Böhmer et al., 2020). 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 (Bundesministerium für Gesundheit, 2020; Buthe et al., 2020; Presse- und Informationsamt der Bundesregierung, 2020). 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. In late 2020 and late 2021 sharp increases of the number of new infections were reported. In response to this development, measures to restrict public life were again adopted by the federal and state governments (Bundesministerium für Gesundheit, 2020). By December 20, 2021, almost 7 million people were infected with SARS-CoV-2 in Germany since the beginning of the pandemic. Over 100,000 people have died from COVID-19 as of that date (Robert Koch-Institut [RKI], 2021).

The COVID-19 pandemic also poses numerous challenges for family caregivers, that is, relatives, friends, or neighbors who provide informal caregiving services to individuals with physical and/or cognitive impairment. These services are usually provided in the home of the person in need of care with the informal caregiver living within or outside the same household ( Zarit & Zarit, 2015). According to an analysis of data from 20 European countries, on average, about 34.4% of people provide care for a relative (United Nations, 2019; Verbakel et al., 2017). In Germany, approximately 3.3 million people in need of care are cared for by their relatives at home (Statistisches Bundesamt, 2019). Caring for relatives is associated with a variety of burdens for caregivers, comprising mental, physical, and social consequences (Johansen et al., 2018; Ribé et al., 2018; Schieron & Zegelin, 2021). The pandemic and the protective measures implemented to restrict public life added further strains (Cohen et al., 2020; Killen et al., 2020; Russell et al., 2020; Teubner et al., 2020). In Germany, for example, these resulted from the closure of day care facilities as implemented in the spring of 2020, so that family caregivers had to take over the care and accommodation themselves or to organize it otherwise (Buthe et al., 2020; Teubner et al., 2020). On the part of the federal and state governments in Germany, the “Second Act for the Protection of the Population in the Event of an Epidemic Situation of National Significance” passed on May 14, 2020, also implemented relief measures for family caregivers, including, for example, an expansion of the care support allowance (Bundesministerium für Gesundheit, 2020; German Federal Government, 2020). Little is known about how these measures were perceived by family caregivers and how well they are considered to address burdens experienced by them.

A large proportion of family caregivers in Germany and other countries are aged 50 years or older and also have some form of chronic illness (Centers for Disease Control and Prevention, 2020; Fagerström et al., 2020; Wetzstein et al., 2015; Woodrell et al., 2021). They, therefore, belong to a population group that itself requires special protection and is at high risk of a particularly severe course of COVID-19 (Parohan et al., 2020). Regardless of the measures implemented by the government 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 (Sousa et al., 2021). An online survey conducted among family caregivers in April and May 2020 found that 54% of the respondents reported being worried about contracting SARS-CoV-2 themselves and 69% reported being worried about infecting the person they provide care for (Teubner et al., 2020). Another 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 (Budnick et al., 2021; Teubner et al., 2020). One of the findings of the survey was that a large proportion of family caregivers were concerned about a COVID-19 infection of the care recipient. About one third of respondents reported that their caregiving situation had worsened since the beginning of the pandemic. In a similar study by Rothgang et al. conducted in June–August 2020 (Rothgang et al., 2020), 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.

This study complements the findings from these quantitative survey studies from the spring and summer of 2020 with a qualitative analysis of social media posts from March to 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. Accordingly, it focused on the following research question: “What additional burdens do family caregivers experience during the COVID-19 pandemic?” The findings may contribute to rising awareness about the situation of family caregivers as well as to devising adequate support measures during the ongoing COVID-19 pandemic as well as future public health crises. Insights into the early phases of the pandemic are all the more important as the strategies employed are prototypical to address scenarios of rising infection incidence, which also have been observed in many countries in subsequent phases of the pandemic.

2 | METHODS

2.1 | 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. Facebook, Twitter, and YouTube were selected as they are three of the most frequented social networks in Germany (Beisch & Schäfer, 2020). They were searched for the key strings ‘(Corona OR COVID OR SARS-CoV-2) AND (“family caregivers” OR “home care”)’ in German language using their respective search engines/search functionality. The search in Facebook and Twitter included only publicly accessible posts. The Facebook groups were, for example, groups dedicated to the exchange between family caregivers. Posts in closed groups were not included. The YouTube search included comments from news channels, associations, and channels maintained by federal ministries. 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.
Inclusion criteria were posts written in German, posts reporting on challenges of caregiving relatives during the COVID-19 pandemic, and posts containing at least one of the aforementioned search term combinations. The search was conducted from November 24, 2020 to December 8, 2020. The contributions were translated verbatim from German into English by the first author (JF) and verified by the other authors with respect to accuracy; no changes were made to the content of the contributions.

2.2 | 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 using an interpretive thematic approach (Hsieh & Shannon, 2005). 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 on the categories. YYA and PB were responsible for the design of the study; JF was responsible for the data collection as well as for the analysis and interpretation of the data. The categories and codes were reviewed and interpreted by all authors and disagreements between authors were resolved through internal discussions.

2.3 | Ethical aspects

Public and freely accessible information from social media posts was used for the analysis, which were also considered open data according to previous studies (Hookway, 2008). Furthermore, to ensure the anonymity of the users, the term “user” was used instead of the respective published user names. 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.

3 | RESULTS

The analysis of the social media posts identified seven main categories of burdens experienced by family caregivers (see Table 1 for a definition of the categories and for the number of postings identified for each category): care and support, deterioration of the condition of the person being cared for, psychological challenges, financial challenges, infection control, access to protective equipment, and acknowledgement of family caregivers. They are presented in the following sections.

3.1 | Care and support

Based on the analysis of the posts, it becomes evident 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. Particularly, caregivers describe difficulties in ensuring the provision of care while still working full time. A further burden prevalent in working from home arrangements concerns the disruption of work by care activities:

“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 a 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 canceled 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 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]

In addition, the posts illustrate the caregivers’ concern about how care can be provided in case of illness or quarantine. Individuals perceive a lack of solutions and support services for situations in which they themselves are not able to provide care, e.g. in case of illness or quarantine:

“In the event of a parent’s infection with COVID-19, there are currently no, really not(!), 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]

“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]

### 3.2 | 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]

### 3.3 | Psychological challenges

Psychological challenges emerge as a further burden for family caregivers during the COVID-19 pandemic. According to the social media users, these emerge, among others, from social isolation and the permanent burden of caregiving because of the loss of professional caregiving services. In addition, rehabilitation services as well as support services provided by other facilities were put on hold because of the pandemic, resulting in an immediate loss of opportunities of support and relief available to family caregivers:

“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]
3.4 | Financial challenges

Furthermore, family caregivers reported being affected by financial challenges during the COVID-19 pandemic resulting from the extra workload associated with caregiving as well as from the increased demand for materials needed for care such as medical masks and disinfectants:

“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]

3.5 | Infection control

The analysis further reveals that infection control in the home environment also proves to be challenging for caregivers. On the one hand, social media users explain this 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, measures of infection control in public spaces also place a burden on family caregivers, resulting in feelings of uncertainty:

“I am a family caregiver. And keeping a distance is not possible, especially as regards [to] 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]

3.6 | Access to protective equipment

The analysis of the posts revealed that during the 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]

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. They are uncertain about how to behave appropriately and complain about having no possibilities to ask questions or to find solutions for problems they encounter:

“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 with support services which were not properly maintained 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]

3.7 | Acknowledgement of family caregivers

Users complain that the term “family caregiver” is often associated with caring for an elderly person 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 distinct from needs of older people, for example, with respect to the attendance of educational institutions or work in sheltered workshops, 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]

Furthermore, users perceive an unequal treatment of family caregivers as compared to other stakeholders with respect to aid and support measures provided by the federal government. Whereas stakeholders in the economy sector as well as professional caregivers would be considered, family caregivers were often not:

“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]

“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]

4 | DISCUSSION

By analyzing social media posts, this study investigated the subjectively perceived burdens experienced by family caregivers during the COVID-19 pandemic in Germany and explored how an emerging public health crisis may affect home care arrangements. The analysis revealed that family caregivers have been confronted with a variety of strains since the beginning of the pandemic. These strains can be summarized to seven main categories. To cope with the care-related strains and challenges, a large proportion of family caregivers usually turn to formal care and support services for relief, such as support provided by day care and short-term care facilities (Jeon et al., 2005; Reinhard et al., 2008). During the pandemic, these services were temporarily suspended, increasing the challenges for family caregivers. Rothgang et al. came to similar conclusions based on an online survey of informal caregivers where 57% of respondents stated that their daily care-related burden had increased since the beginning of the pandemic (Rothgang et al., 2020). Comparable findings are reported by studies from other countries (Carpinelli Mazzi et al., 2020; Cohen et al., 2020; Gallagher & Wetherell, 2020). Support services, therefore, must be regarded essential relief measures for family caregivers that should not be canceled without providing appropriate alternatives.
If services cannot be maintained despite the proper implementation of thorough measures of infection control, at least financial compensation should be provided. Likewise, extensive possibilities for caregiving-related leave from work should be offered.

The findings 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 (Teubner et al., 2020). Particularly in the beginning of the pandemic, family caregivers had difficulties to obtain protective equipment, such as disinfectants. Although availability has improved over time, about one sixth of family caregivers reported continuing to lack necessary protective materials in previous studies (Rothgang et al., 2020). 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 (Rothgang et al., 2020).

Nursing and medical staff in the inpatient sector are also experiencing an increase in challenges such as stress and psychological strain as a result of the COVID-19 pandemic (Bohlken et al., 2020; Fiabane et al., 2021). This was also reported by users of social media posts; accordingly, caregivers who work in the health sector are affected by additional stress, both professionally and privately.

Support measures aiming to reduce burdens for family caregivers during the pandemic must address the very shortcomings pointed out by the users. These comprise 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 providing 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 (Kent et al., 2020; Lightfoot & Moone, 2020; Phillips et al., 2020). The analysis found that there is a lack of clarity and confusion about pandemic-related measures. This could be addressed through independent information centers or dedicated contact persons in regional public health departments that provide advice and guidance on questions and regulations related to the pandemic. This is all the more important considering the heterogeneity of existing regulations and recommendations across federal states.

To the best of 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 predominantly users in the age group of 14 to 49 years (Faktenkontor, 2019; Rohleder, 2018). According to routine data, most family caregivers, in contrast, are between 50 to 70 years old (Rothgang et al., 2018). 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 subgroup 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. Nonetheless the findings of this study complement results of previous research by the perspective of social media users who may be underrepresented in data collected through other forms of recruitment. In addition, the coding of the social media posts selected for analysis was performed by only one author (JF), which means that postings were interpreted subjectively and other possible 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. Because it can be assumed that the perception changed in the course of the pandemic, possibly, other relevant dimensions have not been considered because of the time frame of the study. Future research should determine how opinions expressed in social media posts evolved after that time.

5 | CONCLUSIONS AND RELEVANCE FOR CLINICAL PRACTICE

The results 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 heterogeneity of these strains and therefore must include the promotion of mental health, provide protective materials, and consider information needs that arise for family caregivers during that time. Services must be user centered and as accessible as possible with no unnecessary bureaucratic red tape in order to avoid further burden. The results of the present study are relevant beyond the early phase of the pandemic and can contribute to the development of appropriate support services for this population group that take into account their heterogeneity in terms of age, disabilities, religion, and the respective home care setting.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

For this study, data from social media sites were used. Because these are open forums, users’ posts were considered publicly available secondary data, following the procedure of previous studies in the field (Soussan & Kjellgren, 2014). As described in the methods section, several steps were followed to ensure anonymity of the data.
ACKNOWLEDGMENT

Open Access funding enabled and organized by Projekt DEAL.

CONFLICT OF INTEREST

None declared.

AUTHOR CONTRIBUTIONS

Study design: Patrick Brzoska, Yüce Yilmaz-Aslan. Data collection: Jana Fieselmann. Data analysis: Jana Fieselmann, Diana Wahidie, Yüce Yilmaz-Aslan, Patrick Brzoska. Manuscript writing: Jana Fieselmann, Diana Wahidie, Yüce Yilmaz-Aslan, Patrick Brzoska.

DATA AVAILABILITY STATEMENT

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

ORCID

Patrick Brzoska https://orcid.org/0000-0001-6489-5198

REFERENCES

Beisch, N., & Schäfer, C. (2020). Ergebnisse der ARD/ZDF-Onlinestudie 2020: Internutzung mit großer Dynamik: Medien, Kommunikation, Social Media. Media Perspektiven, 9, 462–481. https://www.ard-werbung.de/fileadmin/user_upload/media-perspektiven/pdf/2020/0920_Beisch_Schafer_2020-11-1.pdf

Böhken, J., Schömg, F., Lemke, M. R., Pumberger, M., & Riedel-Heller, S. G. (2020). COVID-19-Pandemie: Belastungen des medizinischen personals [COVID-19 pandemic: Stress experience of healthcare workers - a short current review]. Psychiatrische Praxis, 47(4), 190–197.

Bömher, M. M., Buchholz, U., Corman, V. M., Hoch, M., Katz, K., Marosevic, D. V., Böhm, S., Woudenberg, T., Ackermann, N., Konrad, R., Eberle, U., Treis, B., Dangel, A., Bengs, K., Fingerle, V., Berger, A., Hörmansdorfer, S., Ippisch, S., Wicklein, B., … Zapf, A. (2020). Investigation of a COVID-19 outbreak in Germany resulting from a single travel-associated primary case: A case series. The Lancet Infectious Diseases, 20(8), 920–928.

Budnick, A., Hering, C., Eggert, S., Teubner, C., Suhr, R., Kuhlmeier, A., & Gellert, P. (2021). Informal caregivers during the COVID-19 pandemic perceive additional burden: Findings from an ad-hoc survey in Germany. BMC Health Services Research, 21(1), 353.

Bundesministerium für Gesundheit. (2020). Coronavirus SARS-CoV-2: Chronik der bisherigen Maßnahmen. https://www.bundesgesundheitsministerium.de/coronavirus/chronik-coronavirus.html

Büthe, T., Messerschmidt, L., & Cheng, C. (2020). Policy responses to the coronavirus in Germany. In G. L. Gardini (Ed.), The world before and after Covid-19 (pp. 97–102). Stockholm: European Institute of International Studies Press.

Carpinelli Mazzi, M., Iavarone, A., Musella, C., Luca, M. d., de Vita, D., Branciforte, S., Coppola, A., Scarpa, R., Raimondo, S., Sorrentino, S., Lualdi, F., & Postiglione, A. (2020). Time of isolation, education and gender influence the psychological outcome during COVID-19 lockdown in caregivers of patients with dementia. European Geriatric Medicine, 11(6), 1095–1098.

the recommendations for secondary data analysis (Stevens et al., 2015) as well as national guidelines (Swart et al. 2015), no further ethical review was required for this analysis.

Centers for Disease Control and Prevention. (2020). Caregiving for family and friends—A public health issue. Centers for Disease Control and Prevention. https://www.cdc.gov/aging/agingdata/docs/caregiver-brief-508.pdf

Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. F. (2020). Living with dementia: Increased level of caregiver stress in times of COVID-19. International Psychogeriatrics, 32(11), 1377–1381.

Fagerström, C., Elmsl, S., & Wrander, L. S. (2020). Analyzing the situation of older family caregivers with a focus on health-related quality of life and pain: A cross-sectional cohort study. Health and Quality of Life Outcomes, 18, 1–10.

Faktenkontor. (2019). Wie die Deutschen im Web 2.0 surfen. Faktenkontor. https://www.faktenkontor.de/pressemeldungen/wie-die-deutschen-im-web-2-0-surfen/

Fiabane, E., Gabanelli, P., La Rovere, M. T., Tremoli, E., Pistorini, C., & Gorini, A. (2021). Psychological and work-related factors associated with emotional exhaustion among healthcare professionals during the COVID-19 outbreak in Italian hospitals. Nursing & Health Sciences, 23(3), 670–675.

Gallagher, S., & Wetherell, M. A. (2020). Risk of depression in family caregivers: Unintended consequence of COVID-19. BJPsych Open, 6(6), e119.

German Federal Government. (2020). Zweites Gesetz zum Schutz der Bevölkerung bei einer epidemischen Lage von nationaler Tragweite. https://www.bundesgesundheitsministerium.de/covid-19-bevölkerungsschutz-2.html

Hookway, N. (2008). ‘entering the blogosphere’: Some strategies for using blogs in social research. Qualitative Research, 8(1), 91–113.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. Qualitative Health Research, 15(9), 1277–1288.

Jeon, Y.-H., Brodaty, H., & Chesterson, J. (2005). Respite care for caregivers and people with severe mental illness: Literature review. Journal of Advanced Nursing, 49(3), 297–306.

Johansen, S., Cvanarova, M., & Ruland, C. (2018). The effect of cancer Patients’ and their family Caregivers’ physical and emotional symptoms on caregiver burden. Cancer Nursing, 41(2), 91–99.

Kent, E. E., Ornstein, K. A., & Dionne-Odom, J. N. (2020). The family caregiving crisis meets an actual pandemic. Journal of Pain and Symptom Management, 60(1), e66–e69.

Killen, A., Olsen, K., McKeith, I. G., Thomas, A. J., O’Brien, J. T., Donaghy, P., & Taylor, J.-P. (2020). The challenges of COVID-19 for people with dementia with Lewy bodies and family caregivers. International Journal of Geriatric Psychiatry, 25(12), 1431–1436.

Lightfoot, E., & Moore, R. P. (2020). Caregiving in times of uncertainty: Helping adult children of aging parents find support during the COVID-19 outbreak. Journal of Gerontological Social Work, 63(6–7), 542–552.

Parohan, M., Yaghoubi, S., Seraji, A., Javanbakht, M. H., Sarraf, P., & Djali, M. (2020). Risk factors for mortality in patients with coronavirus disease 2019 (COVID-19) infection: A systematic review and meta-analysis of observational studies. The Aging Male, 23(5), 1416–1424.

Phillips, D., Paul, G., Fahy, M., Dowling-Hetherington, L., Kroll, T., Moloney, B., Duffy, C., Fealy, G., & Lafferty, A. (2020). The invisible workforce during the COVID-19 pandemic: Family carers at the frontline. HRB Open Research, 3, 24.

Press- und Informationsamt der Bundesregierung, (2020). Maßnahmen der Bundesregierung zur Eindämmung der COVID-19-Pandemie und zur Bewältigung ihrer Folgen. https://www.bundesregierung.de/resource/blob/975226/1747726/0bbb9147be95465e9e845e9418634b93/2020-04-27-zwlbilanz-corona-data.pdf

Reinhard, S. C., Given, B., Pettic, N. H., & Bemis, A. (2008). Supporting Family Caregivers in Providing Care. In R. G. Hughes (Ed.), Patient safety and quality: An evidence-based handbook for nurses: Supporting family caregivers.Rockville: Agency for Healthcare Research and Quality.

Ribé, J. M., Salamero, M., Pérez-Testor, C., Mercadal, J., Aguilera, C., & Cleris, M. (2018). Quality of life in family caregivers of schizophrenia patients in Spain: Caregiving characteristics, caregiving burden, family...
functioning, and social and professional support. *International Journal of Psychiatry in Clinical Practice*, 22(1), 25–33.

Robert Koch-Institut. (2019). Coronavirus Disease 2019 (COVID-19) Weekly Situation Report from the Robert Koch Institute: Calendar Week 16/2021-Current status for Germany. https://www.rki.de/DE/Content/InfAZ/N/Neuartiges_Coronavirus/Situationsberichte/Apr_2021/2021-04-22-en.pdf?__blob=publicationFile

Rohleder, B. (2018). Social-Media-Trends 2018. Bundesverband Informationswirtschaft, Telekommunikation und neue Medien. https://www.bitkom.org/sites/default/files/pdf/Presse/Anhaenge-an-Pis/2018/180227-Bitkom-PK-Charts-Social-Media-Trends-2.pdf

Rothgang, H., Müller, R., Runte, R., & Unger, R. (2018). Pflegereport 2018: Schriftreihe zur Gesundheitsanalyse. Berlin: Barmer. https://www.barmer.de/blob/170372/9186b971babcb3f80267fc329d63f8e6e/data/dl-pflegereport-komplett.pdf

Rothgang, H., Wölfl-Ostermann, K., Domhoff, D., Heinze, F., Heß, M., Kalwitzki, T., Ratz, K., Schmidt, A., Seibert, K., Stolle, C., & Wiegelmann, H. (2020). Zur Situation der häuslichen Pflege in Deutschland während der Corona-Pandemie: Ergebnisse einer Online-Befragung von informellen Pflegepersonen im erwerbsfähigen Alter. Bremen: Universität Bremen. https://www.soziun.uni-bremen.de/lib/download.php?file=147f603c99.pdf&filename=Schnellbericht_Befragung_pflegenderAngeh%C3%B6riger.pdf

Russell, B. S., Hutchison, M., Tambling, R., Tomkunas, A. J., & Horton, A. L. (2020). Initial challenges of caregiving during COVID-19: Caregiver burden, mental health, and the parent-child relationship. *Child Psychiatry and Human Development*, 51(5), 671–682.

Schieron, M., & Zegelein, A. (2021). Pflegende Angehörige. *Pflege* - Psychotherapie Im Dialog, 22(01), 56–60.

Souza, H., Frontini, R., Ribeiro, O., Paul, C., Costa, E., Amado, L., Miranda, V., Ribeiro, F., & Figueiredo, D. (2021). Caring for patients with end-stage renal disease during COVID-19 lockdown: What (additional) challenges to family caregivers? *Scandinavian Journal of Caring Sciences*, 215–224. https://doi.org/10.1111/scs.12980

Soussan, C., & Kjellgren, A. (2014). Harm reduction and knowledge exchange—a qualitative analysis of drug-related internet discussion forums. *Harm Reduction Journal*, 11, 25.

Statistisches Bundesamt (2019). Drei Viertel der Pflegebedürftigen zu Hause versorgt. https://www.destatis.de/DE/Presse/Pressemittelungen/Zahl-der-Woche/2019/PD19_36_p002.html

Stevens, G., O’Donnell, V. L., & Williams, L. (2015). Public domain or private data? Developing an ethical approach to social media research in an inter-disciplinary project. *Educational Research and Evaluation*, 21(2), 154–167.

Swart, E., Gothe H., Geyer, S., Jaunzeme, J., Maier, B., Grobe, T., & Ihle, P. (2015). Gute Praxis Sekundärdatenanalyse (GPS): Leitlinien und Empfehlungen. *Das Gesundheitswesen*, 77(02), 120–126. https://doi.org/10.1055/s-0034-1396815

Teubner, C, Budnick, A, Gellert, P, Eggert, S., & Kluitz, H. (2020). Pflegende Angehörige in der COVID-19-Krise Ergebnisse einer bundesweiten Befragung. Berlin: Zentrum für Qualität in der Pflege. https://www.zqp.de/wp-content/uploads/ZQP-Analyse-Angeh%C3%B6rigerCOVID19.pdf

United Nations. (2019). The challenging roles of informal carers. United Nations. UNECE Policy Brief on Ageing. https://unece.org/DAM/pau/Policy_briefs/ECE_WG1_31.pdf

Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjer, E., & Erikmo, T. A. (2017). Informal care in Europe: Findings from the European social survey (2014) special module on the social determinants of health. *European Journal of Public Health*, 27(suppl_1), 90–95.

Wetzstein, M., Rommel, A., & Lange, C. (2015). Pflegende Angehörige - Deutschlands größter Pflegedienst. GBE kompakt, 6, 1–11.

Woodrell, C. D., Mitra, A., Hamilton, A., & Hansen, L. (2021). Burden, quality of life, and palliative Care for Family Caregivers of individuals with advanced liver disease: A systematic literature review. *Current Hepatology Reports*, 20, 198–212.

Zarit, S. H., & Zarit, J. M. (2015). Family caregiving. In *Psychology and geriatrics* (pp. 21–43). Elsevier.

**How to cite this article:** Fieselmann, J., Wahidie, D., Yilmaz-Aslan, Y., & Brzoska, P. (2022). Additional burdens of family caregivers during the COVID-19 pandemic: A qualitative analysis of social media in Germany. *Nursing & Health Sciences*, 24(2), 414–422. https://doi.org/10.1111/nhs.12937