

The significance of the COVID-19 pandemic for family caregivers of non-COVID-19 patients in need of specialized palliative care at home: a qualitative study

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ABSTRACT

Purpose: It is well known that being a family caregiver of a palliative patient in general is rewarding as well as burdensome. The COVID-19 pandemic may have exacerbated this situation. We therefore explored the significance of the COVID-19 pandemic for family caregivers of non-COVID-19 patients in need of specialized palliative care at home.

Methods: Open-ended, semi-structured telephone interviews were conducted with 15 family caregivers of patients treated by a specialized palliative outpatient unit in a Danish hospital. Interviews were analysed using inductive thematic analysis.

Results: Four themes concerning the significance of the COVID-19 pandemic were identified: 1) being a family caregiver of a patient whose lifespan is already limited, 2) dealing with the risk of passing on COVID-19 oneself, 3) dealing with the risk of others passing on COVID-19 to the patient at home, and 4) living with modified specialized palliative care.

Conclusion: The COVID-19 pandemic had a radical impact on some family caregivers causing emotional despair. They feared not only infecting the patient with SARS-CoV-2 to cause an untimely death but also being unable to be there for the patient during hospitalization, especially in the patient's final days.

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Introduction

The COVID-19 pandemic is having a great impact on healthcare services worldwide. In Denmark, the government decided to lock down the country on 11 March 2020 and social distancing and hand sanitizers were introduced as the main tools to prevent the disease from spreading. The lockdown, which ended in late April 2020, meant that the Danish health system suspended most non-acute healthcare services and directed its efforts towards managing the COVID-19 pandemic. This suspension of non-acute care also applied to specialized palliative care units. Because of the suspension and a desire to mitigate the risk of infecting a group of patients at great risk from SARS-CoV-2, the health professionals in a specialized palliative care unit of one Danish hospital initially ceased their home visits, maintaining contact with patients and their families only by telephone. It was not possible to offer video consultations due to a lack of technology. The unit cares for patients with life-threatening diseases, experiencing severe and complex symptoms, and for their family caregivers. The unit consists of an outpatient clinic offering care to about 200 patients and their families annually and an inpatient section with six beds. Before the

pandemic, outpatient care primarily took place as home visits by nurses.

While recent palliative care studies involving the COVID-19 outbreak focus on patients (Konradsen et al., 2021; Louvardi et al., 2020; Shinan-Altman et al., 2020) and health professionals (Franchini et al., 2021), this study concentrates on family caregivers. It is well known that being a family caregiver of a palliative patient in general is rewarding (Ateş et al., 2018; Oechsle, 2019) as well as burdensome (Ateş et al., 2018; Hudson & Payne, 2011; Oechsle, 2019) and the COVID-19 pandemic may have exacerbated the situation (Fieselmann et al., 2022; Fusar-Poli et al., 2022; Hart et al., 2020; Kent et al., 2020). The aim of this article is thus to explore the significance of the COVID-19 pandemic for family caregivers of non-COVID-19 patients needing specialized palliative care at home during the first lockdown period in Denmark.

Methods

This qualitative study applied interviews with family caregivers of patients treated by a specialized palliative

outpatient unit of a Danish hospital during the first wave lockdown and the very early stage of the reopening, in April 2020. Due to the risk of infection with SARS-CoV-2 the interviews took place by telephone. The study was conducted in relation to another study investigating being a non-COVID-19 patient in need of specialized palliative care at home during the COVID-19 pandemic (Konradsen et al., 2021).

Recruitment

To capture differences, complexities and nuances, we used purposive sampling (Patton, 2015), aiming to achieve maximum variation in the sample of family caregivers in terms of age, gender, and either living with the patient as a partner or living apart as a parent, child, sibling or grandchild of the patient. Nineteen patients were contacted by healthcare professionals from the unit; the professionals asked them to identify their most significant family caregiver. The healthcare professionals then contacted the identified family caregivers by telephone, informed them about the study, obtained oral informed consent to send the caregiver's name and telephone number to one of the two interviewers (first and second author) and arranged an interview date. The two interviewers then contacted the family caregivers by telephone on the agreed date. Four of the 19 declined due to deterioration in the patient's condition, or because participation was more than they could manage in their current situation. Participants were consecutively selected until we reached the required variation and heterogeneity.

Data collection

The telephone interviews were semi-structured, open-ended, and contained non-directive questions that allowed participants to describe topics in their own words and to initiate topics not introduced by the researchers (Roulston, 2011). The questions were: Can you tell me about your experience of being a family caregiver during the COVID-19 crisis? Can you tell me about your everyday life as a family caregiver during the COVID-19 crisis? Can you tell me about your contact, and the patient's contact, with the specialized palliative unit during the COVID-19 crisis? The interviews lasted for 17–52 minutes, and were audio recorded and saved on a secure server. The interviews were not transcribed in full since careful listening to audio recordings has been shown to be a trustworthy method (Greenwood et al., 2017).

Analysis

We used a data-driven inductive approach (Patton, 2015) and Braun and Clarke's stages of thematic analysis (Braun & Clarke, 2006) to identify patterns

and capture participants' lived experience, perspectives and practices within and across data (Clarke & Braun, 2017). Stage one: the two interviewers each listened carefully and repeatedly to the recordings to become familiar with the data. Stage two: the two interviewers summarized the family context and extracted significant citations. They compared and discussed these findings after the first and again after the second listen through and generated initial codes. Stage three: the two interviewers used a visual mind-map to collate codes that fitted together into initial subthemes which was then organized into broader overarching themes. Stage four and five: the two interviewers reviewed the potential themes in relation to the coded data and the entire dataset, discussed the themes with the other authors, before finally defining and naming them ensuring that the themes did not overlap.

Ethics

The study followed the General Data Protection Regulation, allowing participants to consent to certain areas of scientific research. Participants were assured of confidentiality and their rights to withdraw from the study at any time, without giving a reason. Participants were offered the opportunity to contact the interviewer or the specialized palliative outpatient unit after the interview in case the interview had brought up emotions or questions which required further support. None of the participants made use of the offer. Ethical review by a health research ethics committee is not required for qualitative studies in Denmark (National Committee on Health Research Ethics, 2018).

Results

Fifteen family caregivers participated in the study (see, Table I). The patients were suffering from cancer, heart disorders, kidney disorders, lung rejection, or congenital progressive disorders.

Four themes were identified: (1) being a family caregiver during COVID-19 of a patient whose lifespan is limited, (2) dealing with the risk of passing on COVID-19 oneself, (3) dealing with the risk of others passing on COVID-19 to the patient at home and (4) living with modified specialized palliative care.

Theme 1: being a family caregiver during COVID-19 of a patient whose lifespan is limited

The COVID-19 pandemic forced people to put their lives on hold but neither family caregivers nor the patients themselves could postpone their mutual lives. Time spent with the patient was felt to be limited, which meant that life needed to be lived fully right now.

“All the time we have left is precious to us, so all the months we still have him are worth their weight in gold. One of the toughest things is that I can’t be with him, because we don’t know how long we’ll still have him.” (Family caregiver 14, sister of the patient)

One family caregiver found it heartbreaking that his brother who was currently feeling a little better could not leave his house because of COVID-19:

“His immune system cannot stand it if he gets it (COVID-19). It’s really hard. But he has to go out and live his life and he has to do it now! [...] The worst thing, and it’s really unfair – it’s that right now when he’s having a period of feeling a bit better, then he’s confined to his house.” (Family caregiver 12, brother of the patient)

Another family caregiver was also afraid that the COVID-19 crisis would continue for another 1½ years and because of the limited time her husband had left she reflected on how to enjoy life whilst dying and the impossibility of maintaining adherence to the strict COVID-19 restrictions the couple were otherwise following to prevent infection:

“Then we’ll have to ease off a bit here and there to make it work. We really have to and perhaps sometimes even take some risks, you know (travelling in

Denmark and staying at hotels).” (Family caregiver 3, wife of the patient)

Fearing the future also meant fearing the opening up of society post-lockdown. For these family caregivers living with a vulnerable patient in specialized palliative care reopening of the society would not mean a safe return to live life fully in the moment but still involve a risk of infection with SARS-CoV-2 causing an untimely death.

“When the children draw those drawings with rainbows and write that everything will be all right again. Well - it won’t! Because the moment society opens up, we’re in deep trouble.” (Family caregiver 1, wife of the patient)

Theme 2: Dealing with the risk of passing on COVID-19 oneself

The fear of infecting the patient with SARS-CoV-2 had a huge impact on family caregivers who lived apart from the patient. Some stayed completely away because they would never forgive themselves if they passed on SARS-CoV-2, causing an untimely death.

“The fact that I can’t physically go to his home is unpleasant. It feels like you’re a huge bacterial bomb walking around, even though you might not be. I would never ever forgive myself if I happened to infect him with Corona. Never ever.” (Family caregiver 14, sister of the patient)

Some, like one grandson (Family caregiver 15), stated that he limited how often he visited the patient and made sure to keep a safe distance when visiting. Others avoided seeing other people to enable them to continue visiting the patient.

“I’ve decided not to see my best friend because if there’s any possibility of seeing my mum then I can’t have met anyone. I need to keep as safe from infection as possible because of this (COVID-19).” (Family caregiver 11, daughter of the patient)

This daughter had recently returned to Denmark from a holiday abroad and seeing her mother was risky, as it was not easy at that time of the lockdown to be tested for SARS-CoV-2.

“Should we risk it [meeting each other], should we go against the doctors or should we wait until I can get tested [for SARS-CoV-2]? Or what are we actually supposed to do? Because we must see each other. Month after month after month can’t pass before we see each other. What if my mother falls ill or dies or something and we hadn’t seen each other?” (Family caregiver 11, daughter of the patient)

The daughter is facing an unbearable decision; she either risks infecting her mother or not seeing her mother before she dies.

Table 1. Characteristics of the 15 family caregivers included in the study.

Variable	N
Gender	
Female	10
Male	5
Relationship to the patient	
Spouse/partner	8
Adult child	1
Adult grandchild	1
Mother	2
Adult sibling	3
Living arrangement	
Together	8
Apart	7
Age of family caregiver	
20–29	1
30–39	1
40–49	1
50–59	4
60–69	2
70–79	6
Age of patient	
10–19	1
40–49	1
50–59	4
60–69	4
70–79	3
80–89	2
Contact with palliative unit before lock-down	
Weekly home visits	5
Biweekly home visits	7
Home visits every 6–8 weeks	3
Contact with palliative unit during lock-down	
Home visits (outdoor)	2
Phone	13
Admitted to the palliative unit for	
<1 year	8
1–2 years	6
3 years	1

For family caregivers living with the patient, the fear of bringing SARS-CoV-2 home and causing the patient's untimely death was overwhelming.

"I'm so afraid of bringing the illness home. If she gets it then I don't know ... er ... whether she'll survive."
(Family caregiver 8, husband of the patient)

Because of this fear, some family caregivers chose to isolate themselves at home, restricting their contact with other family members and society as a whole.

"It (COVID-19) keeps me from visiting our children and grandchildren – because if I bring it home to him the writing will be on the wall!" (Family caregiver 2, wife of the patient)

Some family caregivers also stated that they missed respite in the form of leisure activities, such as gymnastics, singing in a choir, and bingo. Restricted social contact with others created loneliness.

"They said it's (the COVID-19 pandemic) going to last the rest of the year and I thought: Oh God – that's a really long time. That's awful because I find it so lonely." (Family caregiver 2, wife of the patient)

The restricted social contact also created emotional despair and forced family caregivers to balance emotional needs with reason. One still went for a daily walk but only in the morning when fewer people were out. Another one reasoned that she could not hug and comfort her very upset grown-up daughter because she might become infected herself and then risk infecting her ill husband.

"I'm sitting here getting upset again [because she could not comfort her daughter]. It's something I miss, of course it is, but your common sense tells you it's necessary, doesn't it? He's definitely in the high-risk group. He mustn't catch anything. So reason must prevail." (Family caregiver 5, wife of the patient)

For others, the restricted social contact and limited respite led to more quarrels with the patient.

"It (COVID-19) has covered us with a big blanket. At least me [...] I feel like my wings have been clipped. My energy is at zero. [...] We snarl and snap at each other a bit more than we used to. [...] You don't get out of the house and do things like you did before and you kept going on and had something new to see or talk about and so on, you know. Everything's just the same, and the same, and the same." (Family caregiver 3, wife of the patient)

For one family caregiver who was already confined to the home due to the care needs of the patient, the COVID-19 pandemic did not make a huge difference.

"There's hardly any difference for me as a caregiver between the corona crisis and before. Because her situation has worsened so I'm more or less confined to the house much of the time." (Family caregiver 7, husband of the patient)

Theme 3: dealing with the risk of others passing on COVID-19 to the patient at home

The family caregivers did not only worry about passing on COVID-19 themselves, but also about other people infecting the patient in their home. In the beginning of the pandemic some caregivers living with the patient kept family and friends completely away from home; they later allowed it but the visitors had to keep a safe distance. At the prospect of society reopening, some planned to keep family and friends with young children away again.

"We don't see anyone, you know. And when we do it's always outside in the garden." (Family caregiver 4, wife of the patient)

The fear of others passing on COVID-19 to the patient also included visits from home care.

"They [home care] arrive straight from another patient, from another home and how strict are they [following COVID-19 guidelines]? I'm not happy about so many different [home care workers] coming into our home. And I can't force them to do anything [use COVID-19 protective equipment]. [...] He needs the help they provide. It's a dilemma, because what they do is important." (Family caregiver 5, wife of the patient)

Theme 4: living with modified specialized palliative care

Some of the family caregivers felt emotional despair at realizing that specialized palliative care, especially hospitalization, was now regulated differently. One patient's sister recalled how her brother phoned her in the middle of the night to bid her his last farewell.

"He called me in the middle of night and actually said goodbye to me and that the ambulance was now coming to fetch him. And it's frustrating that I can't even go to the hospital and be there. It's all those frustrations, that you can't be there in person – it's absolutely awful." (Family caregiver 14, sister of the patient)

Being unable to be there for the patient in the hospital created a sense of deserting the patient.

"It was deeply frustrating not being able to be there [in hospital] for my sister. Because I've been there every single time since she fell ill in 2016. I've been there for all the treatments and meetings. And suddenly I couldn't and I felt I let her down. It's been really difficult, and it upsets me [starts crying]. [...] Now I'm more used to not being there [outpatient clinic], now it's more like: what if she has to be admitted and I can't be there? What if she's going to die and I'm not allowed to be there?" (Family caregiver 13, sister of the patient)

During the COVID-19 pandemic, hospital visiting regulations were altered several times, which was frustrating for some family caregivers.

“There was a misunderstanding. [Name of husband] suddenly had difficulty breathing and he was admitted. And I was told I couldn’t visit him. But the last day somebody told me that I could have visited him. And I got kind of – urgh! [...] Because I’m used to being with him, all the time.” (Family caregiver 5, wife of the patient)

At the very beginning of the lockdown, the unit cancelled nearly all home visits, which made some family caregivers feel completely abandoned by the unit.

“The worst thing was in fact the feeling of being left all alone [without any contact with the unit].” (Family caregiver 1, wife of the patient)

During the lockdown most of the patients (see, Table I) only had telephone contact with the unit, which meant that for some caregivers it was more difficult to keep track of developments. Other caregivers were quite satisfied with the change in care from home visits to telephone calls during the lockdown period.

“When the nurse calls, I can hear half the conversation – what [name of his wife] is saying. Nothing is hidden. I don’t miss anything. I get a full summary afterwards.” (Family caregiver 8, husband of the patient)

For one family caregiver home visits continued unaltered because the patient could not speak (family caregiver 6), while for another they were resumed after a month due to the patient’s burdensome symptoms, which was a great relief to the family caregiver.

“He’s much more himself when they visit. He panics less often when they’ve visited. I can feel that it’s easier to be around him.” (Family caregiver 1, wife of the patient)

Discussion

This study shows the significance of the COVID-19 pandemic during the first wave lockdown of society for family caregivers of patients needing specialized palliative care at home. For some family caregivers, the pandemic had a radical impact on their lives, while for others it was less significant.

The COVID-19 pandemic made less difference to those family caregivers who were already living confined lives at home, because of the care needs of the patient and because they were satisfied with the contact with the palliative unit. Other family caregivers felt left out because of the modified contact with the palliative unit from home visits to phone calls. It is thus vital that healthcare professionals in specialized palliative units can triage those family caregivers and patients for whom home visits are essential, while only making phone calls to others.

One of the greatest fears of some family caregivers was to infect the patients with COVID-19. This fear led to different strategies to avoid infecting the patient depending on whether they lived with or apart from the patient. As shown, those living with the patient restricted their social contact with others, creating a caregiver burden of loneliness and emotional despair. A lack of support from other family members and friends has been found to decrease family caregivers’ protection against perceptions of powerlessness and helplessness (Milberg & Strang, 2011). Furthermore, although family caregivers of end-of-life patients have varying support needs and “one size does not fit all” (Bijnsdorp et al., 2020), this study shows that those living with the patient under restricted social contact were longing for respite opportunities. Some suppressed their needs for respite while others sought to find a balance between reason and emotion, safety and needs by maintaining daily respite activities. This study shows that family caregivers found this balancing burdensome. It is therefore important that health professionals provide support in this challenging balance by reminding family caregivers of the extraordinary circumstances brought on by the pandemic. Here, Kent et al. (2020) suggest reassuring caregivers that they are doing everything they can, and encouraging them to leverage their social networks in whatever way is helpful and safe.

Being-there and being-with the patient is the very essence of being a family caregiver and pivotal to them, especially at the end of life. Being-with is not a physical presence but a feeling of closeness to the patient. Being-there is the need to be physically present, in the company of the patient (Peacock et al., 2014). As this study shows, a major concern for some family caregivers was the impossibility of being-there. Those who lived apart from the patient had been there for the patient throughout the illness, sometimes for many years. Not being there created a sense of deserting the patient, which can cause complicated grief (Kokou-Kpolou et al., 2020; Li et al., 2019) as it is known that family caregivers can feel guilty if they cannot be there during the patient’s final days. Irrespective of whether the family caregivers in this study lived with or apart from the patient, they were fearful of the patient being admitted or dying without being able to be there. Being there is according to Henriksson et al. (2015) also one of the greatest rewards of being a family caregiver, but one from which some caregivers in this study were excluded. It is therefore vital that health professionals are clearly aware of the possibilities for family caregivers to be there. The European Respiratory Society also recommends that family caregivers be allowed to visit dying patients despite the infection risk (Janssen et al., 2020) and recent studies of bereaved relatives highlight this issue (Becqué

et al., 2021; Guité-Verret et al., 2021; Hanna et al., 2021). Furthermore, visiting regulations must be communicated clearly and be easy to understand (Hart et al., 2020). As this study shows, this applies during actual hospitalization but is also essential in general to mitigate the fear of not being there in case of death or hospitalization.

COVID-19 forced some family caregivers and patients to put their lives on hold in a situation where the patients' lifespan was already limited. The remaining time had to be lived fully and was felt by the caregivers to be of utmost importance. As described by Peacock et al. (2014), time is already melting away quickly for family caregivers of patients in end-of-life care. The family caregivers in this study therefore did not have time to wait for the pandemic to end to spend whatever little time they had left with their loved ones; they also worried that COVID-19 would lead to the patients' untimely death. Furthermore, some family caregivers struggled between sticking to the rigid pandemic rules and restrictions to sustain life of the patient as long as possible and the need to live fully in the moment and to enjoy life together whilst waiting for the patient to die. It is thus important to encourage family caregivers and patients to engage in difficult but necessary talk about their wishes (Kent et al., 2020) and that health professionals are aware of how to support family caregivers in this delicate matter.

Strengths and limitations

This qualitative study has generated valuable in-depth knowledge of the lived experiences of family caregivers; such knowledge may be useful during future waves of the COVID-19 pandemic and if new pandemics occur. However, the study was conducted at the onset of the COVID-19 pandemic. The results are thus influenced by the novelty and associated uncertainty of the entire COVID-19 situation. In this situation, health authorities worldwide constantly had to invent and adapt novel crisis standards and protocols. Danish society also had to become used to new procedures, including those applicable to family caregivers of patients in need of specialized palliative care. Further, it was not known when a vaccine would be available and whether it would arrive in time to vaccinate these patients and their family caregivers. Further studies evaluating the period after the implementation of the different vaccines and the development of new variants of SARS-CoV-2 are needed.

Conclusion

This study shows the significance of the COVID-19 pandemic during the first wave lockdown for family

caregivers of non-COVID-19 patients in need of specialized palliative care at home. The COVID-19 pandemic had a radical impact on some family caregivers, causing emotional despair. They feared infecting the patient with SARS-CoV-2, thus causing an untimely death. This fear led to different strategies depending on whether the family caregiver lived with or apart from the patient, either isolating her/himself with the patient or keeping away from the patient. Furthermore, the family caregivers feared being unable to be there for the patient during hospitalization, especially in the patient's final days. The study has generated valuable knowledge of the lived experiences of family caregivers, which can be useful during future waves of the COVID-19 pandemic and possible new pandemics.

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Data availability statement

The data consists of audio files in Danish. In the audio files the family caregivers reveal highly personal health information including their own names and the names of the patients, which means that sharing the data would compromise their and their relatives' anonymity. The data are therefore not publicly available due to privacy and ethical restrictions.

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References

- Ateş, G., Ebenau, A. F., Busa, C., Csikos, Á., Hasselaar, J., Jaspers, B., Menten, J., Payne, S., Van Beek, K., Varey, S., Groot, M., & Radbruch, L. (2018). "Never at ease" - family carers within integrated palliative care: A multinational, mixed method study. *BMC Palliative Care*, 17(1), 39. <https://doi.org/10.1186/s12904-018-0291-7>
- Becqué, Y. N., van der Geugten, W., van der Heide, A., Korfage, I. J., Pasman, H. R. W., Onwuteaka-Philipsen, B. D and Goossensen, A. (2021). Dignity reflections based on experiences of end-of-life care during the first wave of the COVID-19 pandemic: A qualitative inquiry among bereaved relatives in the Netherlands (the CO-LIVE study) [published online ahead of print, 2021 Oct 9]. *Scandinavian Journal of Caring Sciences*, 00,1-13. 10.1111/scs.13038. <https://doi.org/10.1111/scs.13038>
- Bijnsdorp, F. M., Pasman, H. R. W., Boot, C. R. L., van Hooft, S. M., van Staa, A., & Francke, A. L. (2020). Profiles of family caregivers of patients at the end of life at home: A Q-methodological study into family caregiver' support needs. *BMC Palliative Care*, 19(1), 51. <https://doi.org/10.1186/s12904-020-00560-x>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, 12(3), 297–298. <https://doi.org/10.1080/17439760.2016.1262613>
- Fieslmann, 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>
- Franchini, L., Varani, S., Ostan, R., Bocchi, I, Pannuti, R, Biasco, G, & Bruera, E.(2021). Home palliative care professionals' perception of challenges during the Covid-19 outbreak: A qualitative study. *Palliative Medicine*, 35(5), 862–874. <https://doi.org/10.1177/02692163211008732>
- Fusar-Poli, L., Surace, T., Meo, V., Patania, F, Avanzato, C, Pulvirenti, A, & Signorelli, M. S. (2022). Psychological well-being and family distress of Italian caregivers during the COVID-19 outbreak. *Journal of Community Psychology*, 50(5), 2243–2259. <https://doi.org/10.1002/jcop.22772>
- Greenwood, M., Kendrick, T., Davies, H., & Gill, F. J. (2017). Hearing voices: Comparing two methods for analysis of focus group data. *Applied Nursing Research*, 35, 90–93. <https://reader.elsevier.com/reader/sd/pii/S0897189716301239?token=15F9EFE46CF4E994C0305F1A13364BDBD8857FD8537A092C2120B538C75C98FE0CC10E93147FCC3768A5CCB7A51B04E5&originRegion=eu-west-1&originCreation=20220815071640>
- Guité-Verret, A., Vachon, M., Ummel, D., Lessard, E., & Francoeur-Carron, C. (2021). Expressing grief through metaphors: Family caregivers' experience of care and grief during the Covid-19 pandemic. *International Journal of Qualitative Studies on Health and Well-being*, 16(1), 1996872. <https://doi.org/10.1080/17482631.2021.1996872>
- Hanna, J. R., Rapa, E., Dalton, L. J., Hughes, R., McGlinchey, T., Bennett, K. M., Donnellan, W. J., Mason, S. R., & Mayland, C. R. (2021). A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. *Palliative Medicine*, 35(5), 843–851. <https://doi.org/10.1177/02692163211004210>
- Hart, J. L., Turnbull, A. E., Oppenheim, I. M., & Courtright, K. R. (2020). Family-centered care during the COVID-19 era. *Journal of Pain and Symptom Management*, 60(2), e93–e97. <https://doi.org/10.1016/j.jpainsymman.2020.04.017>
- Henriksson, A., Carlander, I., & Årestedt, K. (2015). Feelings of rewards among family caregivers during ongoing palliative care. *Palliative and Supportive Care*, 13(6), 1509–1517. <https://doi.org/10.1017/S1478951513000540>
- Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: Current status and agenda for the future. *Journal of Palliative Medicine*, 14(7), 864–869. <https://doi.org/10.1089/jpm.2010.0413>
- Janssen, D. A., Ekström, M., Currow, D. C., Johnson, M. J., Maddocks, M., Simonds, A. K., Tonia, T., & Marsaa, K. (2020). COVID-19: Guidance on palliative care from a European respiratory society international task force. *European Respiratory Journal*, 56(3), 2002583. <https://doi.org/10.1183/13993003.02583-2020>
- Kent, E. E., Ornstein, K., & Dionne-Odom, J. N. (2020). The family caregiving crisis meets an actual pandemic. *Journal of Pain and Symptom Management*, 60(1), e66–e69. <https://doi.org/10.1016/j.jpainsymman.2020.04.006>
- Kokou-Kpolou, C. K., Fernández-Alcántara, M., & Cénat, J. M. (2020). Prolonged grief related to COVID-19 deaths: Do we have to fear a steep rise in traumatic and disenfranchised griefs? *Psychological Trauma*, 12(S1), S94–S95. <https://doi.org/10.1037/tra0000798>
- Konradsen, H., True, T. S., Vedsegaard, H. W., Wind, G., & Marsaa, K. (2021). Maintaining control: A qualitative study of being a patient in need of specialized palliative care during the COVID-19 pandemic. *Progress in Palliative Care*, 29(4), 186–190. <https://doi.org/10.1080/09699260.2021.1872139>
- Li, J., Tendeiro, J. N., & Stroebe, M. (2019). Guilt in bereavement: Its relationship with complicated grief and depression. *International Journal of Psychology*, 54(5), 454–461. <https://doi.org/10.1002/ijop.12483>
- Louvardi, M., Pelekasis, P., Chrousos, G. P., & Darviri, C. (2020). Mental health in chronic disease patients during the COVID-19 quarantine in Greece. *Palliative and*

- Supportive Care*, 18(4), 394–399. <https://doi.org/10.1017/S1478951520000528>
- Milberg, A., & Strang, P. (2011). Protection against perceptions of powerlessness and helplessness during palliative care: The family members' perspective. *Palliative and Supportive Care*, 9(3), 251–262. <https://doi.org/10.1017/S1478951511000204>
- National Committee on Health Research Ethics. Act on Research Ethics Review of Health Research Projects. <https://en.nvk.dk/rules-and-guidelines/act-on-research-ethics-review-of-health-research-projects> (2018, accessed February 15, 2022)
- Oechsle, K. (2019). Current advances in palliative & hospice care: Problems and needs of relatives and family caregivers during palliative and hospice care—an overview of current literature. *Medical Science*, 7(3), 43. doi:10.3390/medsci7030043.
- Patton, M. Q. (2015). *Qualitative research & evaluation methods. Integrating theory and practice* (4th ed.). SAGE Publications Inc.
- Peacock, S., Duggleby, W., & Koop, P. (2014). The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia. *Palliative and Supportive Care*, 12(2), 117–126. <https://doi.org/10.1017/S1478951512001034>
- Roulston, K. (2011). *Reflective interviewing. A guide to theory and practice*. SAGE Publications Inc.
- Shinan-Altman, S., Levkovich, I., & Tavori, G. (2020). Healthcare utilization among breast cancer patients during the COVID-19 outbreak. *Palliative and Supportive Care*, 18(4), 385–391. <https://doi.org/10.1017/S1478951520000516>