BMJ Open

The impact of COVID-19 on the quality care at the end of life: interviews with healthcare professionals from different settings (the CO-LIVE study).

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-063267
Article Type:	Original research
Date Submitted by the Author:	06-Apr-2022
Complete List of Authors:	Zee, Masha; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Bagchus, Lotje; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Becqué, Yvonne ; Rotterdam University of Applied Sciences, Research Center Innovations in Care Witkamp, Erica; Rotterdam University of Applied Sciences, Research Center Innovations in Care; Erasmus MC University Medical Center, Department of Public Health van der Heide, Agnes; Erasmus MC University Medical Center, Department of Public Health van Lent, Liza; Erasmus MC Cancer Institute, Medical Oncology Goossensen, Anne; University of Humanistic Studies Korfage, Ida; Erasmus MC, University Medical Center Rotterdam, Public Health Onwuteaka-Philipsen, Bregje; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Pasman, H. Roeline; Amsterdam UMC Locatie VUmc, Public and Occupational Health
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH

The impact of COVID-19 on the quality care at the end of life: interviews with healthcare professionals from different settings (the CO-LIVE study).

Authors

Masha S. Zee[1], Lotje Bagchus[1], Yvonne N Becqué[2], F. Erica Witkamp[2,3], Agnes van der Heide[3] Liza G.G. van Lent[4], Anne Goossensen[5], Ida J. Korfage[3], Bregje D. Onwuteaka-Philipsen[1], H. Roeline W. Pasman[1]

Affiliations

1. Department of public and occupational health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, Amsterdam, the Netherlands
2. Research Center Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands
3. Department of Public Health, Erasmus MC University Medical Center, Rotterdam, the Netherlands
4. Department of Medical Oncology, Erasmus MC Cancer Institute, Rotterdam, the Netherlands
5. University of Humanistic Studies, Utrecht, The Netherlands

Correspondence:

Masha Zee, Department of Public and Occupational Health, Amsterdam UMC, van der Boechorststraat 7,1081 BT Amsterdam, the Netherlands; m.zee@amsterdamumc.nl

Word count: 4058

Number of tables / boxes: 1 table / 4 boxes

Abstract:

Objectives: It is likely that the COVID-19 pandemic endangered end-of-life care in the different domains of the palliative approach. The objective of this study is to better understand how the COVID-19 outbreak impacted the different domains of the palliative care approach to end-of-life care from the perspective of HCPs (healthcare professionals) with different professions, working in different settings during the COVID-19 outbreak in the Netherlands.

Methods: An in-depth qualitative interview study among HCPs of patients who died between March and July 2020 in different healthcare settings in the Netherlands. Data were analysed following the principles of thematic analysis.

Results: Not all HCPs were satisfied with the quality of end-of-life care. Several aspects impacted the quality of (the palliative care approach to) care at the end of life. First, COVID-19 was a new disease and this led to challenges in the physical domain of end-of-life care e.g. a lack of knowledge to manage symptoms and a unreliable clinical view. Second, the high workload HCPs experienced impacted the quality of end-of-life care, especially in the emotional, social and spiritual domains, since they only had time for urgent, physical care. Lastly, COVID-19 is a contagious disease and measures taken to prevent the spread of the virus hampered care for both patients and relatives. For example, because of the visiting restrictions, HCPs were limited in providing emotional support to relatives. However, the COVID-19 outbreak also provided potentially positive effects for the longer term, e.g. more awareness of advance care planning and the importance of end-of-life care including all the domains.

Conclusion: The palliative care approach, key for good end-of-life care, was often negatively influenced by COVID-19, predominantly in the emotional, social and spiritual domains. This was related to a focus on essential physical care and prevention of the spread of COVID-19.

Keywords: COVID-19, Palliative Care, End-of-life Care, Quality of Care, Qualitative Research

Strength's and limitations:

- This study describes a broad range of perspectives, since it includes healthcare professionals from all care settings, with different professions who cared for COVID-19 and non-COVID-19 patients.
- Respondents were eager to share their experiences despite of the fact that the interviews were held via (video) call.
- Because the situation of the COVID-19 pandemic was hectic and unique, five researchers started with interviewing respondents. By continuously discussing of the topic list and findings, uniformity was guaranteed.
- During the last interviews in this study, no new things came up in comparison to the earlier interviews. However, since the situation of COVID-19 was so complex, and kept changing so quickly, we cannot say with certainty that we reached saturation.

Introduction

The COVID-19 pandemic confronted the world with an unknown disease, which had an impact on care in all healthcare settings. To limit transmission and reduce mortality and morbidity from COVID-19, the World Health Organization (WHO) published guidelines to take public health and social measures (PHSM) (1). These measures included, among others, personal protective measures, such as wearing masks, and physical distancing measures, such as maintaining distance in public or workplaces. As other countries, the Netherlands were also confronted with high numbers of patients with COVID-19, excess mortality due to COVID-19, and implementation of most of the abovementioned measures (2, 3).

The situation surrounding COVID-19, affected care at the end of life for both patients and their relatives (4). Measures, such as visiting restrictions and keeping a physical distance changed human contact inherently and influenced the way end-of-life care was provided (5-7). Furthermore, because of the high number of patients with COVID-19 there might be less time for emotional and existential support for patients and their relatives in a time where this support is very much needed (4-6).

Good quality of end-of-life care asks for a palliative care approach that focusses on the quality of life of patients and their families. It aims to provide person-centered care that not only focuses on the medical condition of the patient, but also takes on a more holistic approach, looking at the psychological, social and spiritual domains of care as well (8). It pays special attention to specific needs and preferences in these domains and it not only provides support to patients, but also to their relatives and includes bereavement counselling (8).

It is likely that these domains of the palliative care approach were endangered during the COVID-19 pandemic. The aim of this study is to better understand how the COVID-19 outbreak impacted the different domains of the palliative care approach to end of life care from the perspective of HCPs (healthcare professionals), working in different health care settings during the COVID-19 outbreak in the Netherlands.

Methods

Design, Setting and Participants

An in-depth qualitative interview study was conducted among HCPs of patients who died between March and July 2020 in different healthcare settings in the Netherland as part of the CO-LIVE study. CO-LIVE is a mixed-methods study on the experiences of both bereaved relatives and HCPs during the COVID-19 pandemic. Participants were recruited through an online survey about the last days of life of a patient who died during the first wave of the COVID-19 outbreak (9). Maximum variation sampling was used in the group of participants that was interested to take part in an interview. Variation was sought in setting, profession, and how HCPs qualified the death of the patient about whom they filled in the survey (both positive and negative qualifications) and potential respondents were approached via e-mail. Since nursing assistants working in nursing homes were underrepresented in the survey, two were recruited via our own network. Eventually, sixteen HCPs were interviewed: nine nurses, two nursing assistants, one coordinator in a hospice and four physicians. Four participants worked in a special COVID unit in the hospital, two in an intensive care unit (ICU), five in a nursing home, three in a hospice and two in home/community care (Table 1). Some participants had cared for COVID-patients only, others had also cared for non-COVID-patients. We followed the standards for reporting qualitative research (SRQR).

Table 1. Characteristics participants

	Profession	**Setting**	**Sex**	**Age Range**
1	Nursing assistant	Nursing home	Female	<40
2	Nursing assistant	Nursing home	Female	40-60
3	Nurse	ICU	Female	<40
4	Nurse	Hospice	Female	40-60
5	Nurse	Hospital (COVID-ward)	Female	40-60
6	Nurse	Home	Female	40-60
7	Nurse	Hospice	Female	<40
8	Nurse	Home	Female	40-60
9	Nurse	Hospital (COVID-ward)	Female	<40
10	Nurse	Hospital (COVID-ward)	Female	<40
11	Nurse	ICU	Female	<40
12	General Practitioner	Home/hospice	Male	>60
13	Pulmonologist	Hospital (COVID-ward)	Female	40-60
14	Geriatrician	Nursing home	Female	>60
15	Geriatrician	Nursing home	Male	>60
16	Coordinator	Hospice	Female	40-60

Patient and public involvement

Patients and the public were not involved in the design and conduct of this study.

Data collection

Five researchers (MZ: 2, LB: 8, YB: 4, EW: 1 and RP: 1) conducted the interviews. Because of COVID-measures, all interviews were held via (video)calls. The interviewers used a topic list, that included questions about the responses as given in the survey and questions about new experiences (Additional file 1). The interviews were conducted in Dutch, lasted between 25 and 70 minutes and were audio-recorded.

Data analysis

Data were transcribed verbatim and analysed using qualitative data analysis software MAXQDA, following the principles of thematic analysis based on a phenomenological approach (10, 11). First LB and RP went through the transcripts and made summaries, which were discussed with all interviewers and another member of the research group (BOP). After becoming familiar with the data by reading the transcripts, MZ coded the data. The analyses were discussed with all members of the research group and on multiple occasions with the different interviewers. Thereafter, MZ, LB, BOP and RP sorted the codes into groups developing overarching themes (Additional file 2). Themes and corresponding codes were continuously compared, discussed and categorized. Finally, appropriate quotes were selected by MZ and LB and translated by a professional translator. The research group consists of researchers with different backgrounds (health sciences, medical anthropology, nursing, sociology, psychology and medicine).

Ethical considerations

Before the interview, participants gave verbal informed consent to participate in the interview and to have this interview recorded. All data were anonymized to make sure the participants and their patients were unidentifiable. After transcription, audio recordings were deleted. The Medical Ethics Committee Erasmus MC of Rotterdam, The Netherlands, assessed that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply (MEC-2020-0254).

Results

The COVID-19 outbreak led to an impactful and unique situation for healthcare, and HCPs stated that it affected care at the end of life. This was the case for HCPs of all disciplines and for all care settings, albeit sometimes in different ways. They mentioned that the care was good 'given the circumstances', but not comparable with their usual standard of care. They did what they could do, knowing that they could not do everything they wanted to do (box 1, quote 1). HCPs explained that it was not satisfying to work under these circumstances and wished they could have done more (box 1, quote 2). Some said that the quality of care was poor and described (aspects of) it as "inhumane" (box 1, quote 3 & quote 4). HCPs also felt that there was too much focus on the medical aspects of care of this new disease compared to emotional and spiritual care (box 1, quote 5).

Several themes arose from the interviews after thematic analysis, that were characteristic for this impactful and exceptional situation and, mostly negatively, impacted the quality of end-of-life care: COVID-19 being a new disease, the disease leading to a higher workload for HCPs, and the disease being contagious. Both the positive and negative effects are described in the following paragraphs.

BOX 1: Quotes - Exceptional situation	
1.	“I don’t think we could have done things any differently than we did. Sure, this patient was quite early on [in the coronavirus crisis], as it were, so I think we were all very much trying to figure out what to do and what rules we should have. So yes, at that point I don’t think it could have gone any differently to how it actually went.” **(3: Nurse, ICU)**
2.	“I found it difficult — it’s OK now. I still think of him from time to time. I’ll never forget him, but that’s hardly surprising. I often have that with people. But I went through a bad patch a couple of days afterwards. Mainly because you’re so powerless, the fact that you are there but can’t actually do anything. Plus the fact that you’re in this protective clothing from head to foot so it feels as if you can’t get close to the patient, or to the family. I felt particularly sorry for the family because – unlike the patient – they were of course perfectly capable of communicating, and they were distressed. I really felt I should be sitting next to these people, in physical contact. But that was not allowed. That’s a dilemma. I just thought it was awful for that man that he didn’t pass away peacefully.” **(10: Nurse, hospital COVID ward)**
3.	“So you have that whole routine that’s basically aimed at making sure everything goes smoothly and you just do your best in that final stage to give someone a soft landing, as it were. But now it’s disrupted because you can’t be there, because the protocol says that... or that you need a complete change of clothes. Um, with a face mask on, so you’re unrecognizable — who’s that standing next to my bed? Well, that. And I find that degrading in the sense that you’re turning that person into an object; they’ve become an object. It’s not a person lying there anymore, it’s an object.” **(15: Geriatrician, nursing home)**
4.	“In that respect, I didn’t think there was much privacy, so... of course, there were really strict visiting rules so I felt patients got a bit abandoned. And with the IC cohort, that was completely [...], right, that was basically 18 people lying in a single room, all on their stomachs, all kind of like interchangeable. So when we had our shift, we’d start by turning the first one back over, and then go through the whole lot one by one, as it were. It was almost like a production line. With no curtains in between, they’d all been removed, so I found it incredibly degrading.” **(9: Nurse, hospital COVID ward)**
5	“We were too focused on that COVID-19 rather than thinking about making them comfortable and how we should do this or how we should do that. In fact, we weren’t thinking about that final phase of life at all... Of course that became clearer later on, so you’re thinking about it more then. But in the beginning we were more concerned about tackling the clinical picture and not really thinking to ourselves that there’s nothing more we could do here, so how should we make it as comfortable as possible for them?” **(2: Nursing assistant, nursing home)**

New disease – Lack of knowledge to manage symptoms

In the first wave of the COVID-19 outbreak, little was known about the course of the disease, the prognosis, treatment and symptom relief. This led to difficulties in the physical domain of end-of-life care. HCPs said that their ‘clinical view’ was not reliable anymore because the disease course for COVID-19 patients was unpredictable (box 2, quote 1). In some cases, the patient unexpectedly deteriorated very quickly, making it difficult to anticipate, for instance to timely inform family members. Furthermore, they said it was hard to relieve symptoms for some dying patients because existing treatments for similar symptoms in other diseases had no or little effect for COVID-19 patients. (box 2, quote 2).

High workload – Lack of time and staff for good end-of-life care

The COVID-19 outbreak led to a great influx of patients with COVID-19 on top of the regular patients, resulting in a high workload for HCPs, especially HCPs at the ICU and COVID-wards in hospitals. Besides, HCPs in nursing homes also had a higher workload since they had to isolate residents with COVID-19 from residents without COVID-19. This created more wards than usual, that they had to distribute the same amount of HCPs over (box 2, quote 3). Furthermore, because of a lack of knowledge on how to prevent COVID-19 infections, many HCPs mentioned how (especially in the beginning of the pandemic) measures and rules about visitation or protective equipment were unclear or kept changing. Being updated on the rules took a lot of time, creating a higher workload (box 2, quote 4). These aspects were mentioned by HCPs from all settings, also those who had not cared for COVID-19 patients.

Due to lack of time and staff, the quality of end-of-life care was hampered. Some HCPs mentioned that they only had time for the essential, physical care, but not enough time for care in the emotional, social and spiritual domains (box 2, quote 5). However, HCPs, specifically in the ICU, also mentioned some difficulties in the physical domain. They mentioned that, because of a lack of staff, HCPs from other disciplines or wards helped them. However, not all of these new colleagues had the right skills or experience and this sometimes negatively impacted the quality of physical care (box 2, quote 6). Furthermore, HCPs mentioned that there was a higher chance of mistakes because of the time pressure (box 2, quote 7).

Because of the shortage of (skilled) staff, schedules of HCPs were sometimes unclear or constantly changing. Therefore, HCPs saw a lot of different patients and did not see one particular patient as often as usual. A respondent mentioned that this led to poor continuity of care because individual HCPs were not as involved with and informed about their patients as usual, which made it difficult to be aware of personal needs and preferences (box 2, quote 8).

Due to the staff shortage and higher workload, there was also less time for another important part of the palliative care approach: supporting relatives. HCPs mentioned that they could not spend as much time on supporting the relatives as they were used to and that it was unsatisfying for them (box 2, quote 9). In some cases, HCPs in the ICU were limited in the time they could give relatives to say goodbye to their loved ones. (box 2, quote 10).

224

BOX 2: Quotes - New disease & high workload	
1	“No, you have this feeling that you’re less in control of the situation. [...] And I think no one had that feeling that they knew what was coming in the case of COVID. [...] In the terminal phase too, I felt it was like hey, suddenly it all changed... and they were dead, or hey, suddenly they were stable, or hey, everything suddenly fell apart. Normally you would be dropping in on them regularly and you’d see things happening, you know, and you adjust accordingly. But for me this wasn’t like that... it was more difficult.” **(4: Nurse, hospice)**
2	“But when you saw him, he really wasn’t comfortable. Laboured breathing, high respiratory rate, increasing heart rate. You could see the panic in his eyes but there came a point when we couldn’t communicate with him anymore. He was kind of asleep, as it were, but you could see that he was still physically really hard at work. If he’d been a non-COVID patient I would have said he’s not comfortable so we need to do something with the medication. And so that’s what we did. Only it didn’t work well enough for this man. And that remained the case up to the end. I found that difficult.”**(10: Nurse, hospital COVID ward)**
3	“You’ve got the extra shifts that have to be covered, because an entire team was put on that COVID unit. And you have to find them in a small institution. But all my colleagues — I don’t know of a single colleague who worked shorter hours. Even the housekeeping. We had to arrange a separate housekeeping team for our COVID unit. So absolutely everyone put in a lot of hours.” **(2: Nursing assistant, nursing home)**
4	“Too busy with the protocols. The protocol kept changing... sometimes you had two new protocols in one day. So RIVM [the National Institute for Public Health and the Environment] was prescribing such-and-such one moment, and something else the next... One minute you had to wear this, the next minute that. Then you had to wear one of those face masks, you know — that kind of thing. Too busy with all that to arrange it all properly.” **(2: Nursing assistant, nursing home)**
5	“We provided the necessary care. In the end, we were never really satisfied with what we did and how we did it. We were never really satisfied, because we simply couldn’t give assistance in social and emotional aspects and I find that very important. So it was just a case of giving people the essential care, trying to keep them stable.” **(9: Nurse, hospital COVID ward)**
6	“What you also realize afterwards is that, because it wasn’t just IC nurses but other people too, they didn’t have all the necessary knowledge. So now I’m increasingly hearing that people have ended up with eye problems because they didn’t get the drops every so often, and the eyes became dehydrated. Then I think to myself: oh, there are some things we made a right mess of.” **(9: Nurse, hospital COVID ward)**
7	“Well medication safety is an issue if you’re working under real pressure, so you connect up the wrong syringe by mistake, or make the wrong changeover... Of course it’s very easy to make a mistake, you know.” **(9: Nurse, hospital COVID ward)**
8	“Well, in the end there was a long list with the shift roster that was put up each week and you had to search for your name, see which ward you were on and that was where you went that day. You could easily be somewhere else the next day. [...] So yes, there was also very little continuity in the care for patients. [...] I did find that difficult. Normally, we’re used to providing as much continuity as possible. So if you switch from a morning shift to an evening shift, you try to have the same patient who you had in your morning shift in the evening shift too. Now I might not be on my own ward, as it were, for three weeks because I’d be working all over the place, then I’d come back and oh, that patient’s been there a long time. Well, you don’t know what that means because you didn’t get any of the news about the patient.” **(3: Nurse, ICU)**
9	“We also had more patients to care for than we would normally, so we had less time available to spend on the family. In the normal situation, if we know a patient is going to die, we always try to make sure there’s one nurse who can focus entirely on that and give the family their full assistance and go through that whole process properly. But that wasn’t possible during the COVID period. That did make it rather unsatisfying for everyone, yes.” **(3: Nurse, ICU)**
10	“Yes, then we would just phone the family at home and that was often for medical reasons. A conversation with the family and, yes, the tricky thing... we would agree with them who else needs to come. How do we want the final goodbye... what’s the procedure? But at the same time we didn’t want it to take days because you needed the beds. So it was really 24 hours max. And then it was indeed a question of stopping, removing the ventilation and then it was often less than quarter of an hour and the patient was dead. So that often happened very quickly. And then the patient would be removed, room cleaned, new patient put in. Yes, that was really weird.” **(9: Nurse, hospital COVID ward)**

Contagiousness – Preventative measures hampered good end-of-life care

In healthcare settings, different measures were taken to prevent the spread of COVID-19, such as visiting restrictions, keeping physical distance and wearing personal protective equipment (PPE). There was little difference between COVID-19 and non-COVID-19 patients regarding the impact of these measures on care, since most measures applied to everyone. HCPs stated that caregiving at the end of life was hampered, due to the priorities that government and overall healthcare had when dealing with COVID-19. They said that preventing the spread of the virus seemed more important than the quality of end-of-life care and that this impacted, in particular, the emotional and spiritual aspects of care (box 3, quote 1).

Limited family visits and goodbyes

All HCPs mentioned that family visits and goodbyes were limited to smaller or greater extent which impacted end-of-life care for both patients and their relatives. There were restrictions in the number of people who were allowed to visit patients, the number of visits per day, and the amount of time relatives were allowed to visit a patient. Visiting restrictions varied between settings; HCPs from hospitals and especially nursing homes mentioned that these restrictions were very strict and that it was difficult to deviate from them. In homecare, patients or HCPs could decide themselves on visitation (restrictions).

According to the HCPs the limited family visits and goodbyes impacted the patients greatly. Some participants mentioned that dying patients could not see everyone they wanted to see and that some patients were completely alone in the last days of their life (box 3, quote 2). One nurse described a case where a patient did not want to die in a hospital setting, because of their visitation restrictions. However, this sudden transfer to her home led to chaotic last days of life (box 3, quote 3). Furthermore, the visiting restrictions impacted to what extent HCPs could get to know their patients and therefore impacted end-of-life care. If unconscious or very ill patients were not able to talk, care became less personal, because no family was around to share the patients' preferences and wishes. (box 3, quote 4 and quote 5). Furthermore, a nurse working in homecare mentioned that the restrictions were used as a good excuse when patients did not want a specific person to visit them and say goodbye (box 3, quote 6). In some cases, there were new digital ways for patients to contact their relatives (e.g. video calls) and HCPs were mostly positive about the usage of these resources, although it did not fully replace the physical family visits (box 3, quote 7).

Because of visitation restrictions, HCPs did not see relatives (as much) making it difficult for HCP's to give emotional support to families (box 3, quote 8). Even if the distance could be bridged using digital communication, HCP's felt they could not support the relatives sufficiently from a distance (box 3, quote 9).

Physical distance between HCPs and patients and their relatives

When providing good end-of-life care in all domains of palliative care, the contact and connection of HCPs with patients and their relatives is really important. Physical distance hampered the care and connection in all settings for patients with and without COVID-19. Some HCPs felt detached from the patient, mostly because they could not touch the patient, apart from when they performed medical procedures. They explained that touching patients is an important part of emotional support (box 3, quote 10). In some cases, spiritual counselors were not allowed to be physically present with patients anymore and this impacted the spiritual domain of the end-of-life care (box 3, quote 11). Furthermore, when a patient had died, HCPs mentioned that they were not allowed to take care of the deceased patient to prepare them for relatives to say goodbye (box 3, quote 12 & quote 13). Finally, the physical distance also limited HCPs in providing emotional support to relatives, because they could not get near to the relatives or touch them to console them (box 3, quote 14).

Feelings of detachment due to personal protective equipment

Another measure that created distance between HCPs and patients and their relatives, was the personal protective equipment HCPs needed to wear under certain circumstances. When wearing PPE, they were unrecognizable for patients, and it was sometimes difficult for patients to hear them (box 3, quote 15). Furthermore, some HCPs mentioned that it was scary for patients with dementia or psychological problems to be cared for by staff wearing PPE (box 3, quote 16). However, HCPs also said that they were happy to be wearing PPE, because it allowed them to touch their patients and to them come closer (box 3, quote 17). Some HCPs had experienced a shortage of PPE, or had to economize PPE to prevent a shortage and this made HCPs more reluctant to come near to patients, because it would cost extra PPE (box 3, quote 18). In specific COVID-wards, it was not necessary to change PPE all the time which was seen as an advantage of working in such wards.

	BOX 3: Quotes - Contagiousness
1	“But suddenly we ended up in a situation in which we were only talking about the risk of infection, about infection rates, well, just the medical side. And everything that makes someone a human being was no longer being discussed. I found that very confusing. I even got really angry about this at one point and said how crazy this was, how we were now going completely against everything we’d learned over the past decades about what’s important for people with dementia who lose their bearings. Apparently that was no longer important. All that mattered was that we didn’t want people to get infected. That was weird. [...] I found that very difficult to cope with in the past little while, and I still do.” **(6: Nurse, home)**

3.1.: Limited family visits and goodbye’s	
2	“In principle two people were allowed to come, and then indeed for just half an hour or maybe three quarters of an hour, but only a very brief period. Often, either the patient died during that visit, or just afterwards or they came too late. [...] I mainly found it very sad, distressing, a failing where you can’t offer what’s best, because you can’t replace the person who isn’t there, or maybe you aren’t in a position to be there because you don’t belong there. But at the same time it feels like a failing with regard to them, and how do you assist them in that? [...] But then when you’re driving home later, you always have that feeling that you should be doing things differently, or you’re not getting a sense of satisfaction. That’s what I call failings.” **(11: Nurse, ICU)**
3	“Um, well that was that lady who only came home to die; she died that same day. That was started because of COVID: sending them home as quickly as possible to die. That wasn’t exactly a peaceful deathbed. Really chaotic. Preparing for the discharge, quickly off home and then dying. It wasn’t ideal but it was what she herself wanted: she wanted to die at home, and she was able to do that. But the way in which it happened — no, it was not a peaceful deathbed.” **(9: Nurse, home).**
4	“But what I certainly also remember is the fact that visitors weren’t allowed. That makes the care for the patient a lot more impersonal. IC patients in general spend a lot of the time asleep, but that was especially so with the COVID patients — they were all so sick and heavily sedated, you didn’t have any contact with them at all. And if you don’t have any contact with the family either to get to know the person behind the patient, well, it becomes a very abstract exercise.” **(3: Nurse, Hospital ICU).**
5	“Yes, I definitely recognize that [not knowing who the patient was]. Especially if patients have reached a stage where you can’t really communicate with them, then you feel you can’t easily do much – aside from basic good nursing care – for the patient themselves: anything that’s more than just cleaning them up and administering medication on time. It’s more about being there for someone as the person they once were, let’s say. Or connecting to that at any rate. And that was tricky with this man. You still had a bit of contact but it was all very minimal. And if they don’t have relatives, you can’t... I guess my basic principle is always to talk to the person even if they can’t always respond any more. Yet you still talk to someone. If you know where that person is from, if they liked to travel or — I don’t know — were crazy about their dog, you can just mention that, say ‘oh, you had a dog, didn’t you’, something like that. I think that’s so important, because we don’t know what people can hear and what they can’t. So that was tricky in the case of this man.” **(5: Nurse, hospital COVID ward)**
6	“The circle around someone simply becomes smaller; she has... And it’s quite natural that only the really intimate circle are still allowed to visit. But well, at a certain point we did rather use this fact [the visiting restrictions], yes. To protect that lady, to help her and keep people away from her. Yes, that was quite funny.” **(6: Nurse, home)**
7	“Fortunately we’d set up video calling and we still have that. That’s something positive, that was a positive effect.” **(1: Nursing assistant, nursing home)**
8	“Patients are mostly on our ward for a while, so you’ve had contact with the family. So when the patient eventually dies, you’re able to assist their family really well with that process because you’ve already had quite a lot of contact. But now it became so that when a patient died, you were then seeing the family for the very first time. So there was no bond.” **(3: Nurse, ICU)**
9	“Yes, basically you try... The tricky thing is, normally you have the family around the bed and you can point things out, explain that this is how you see the situation. You can get a feel for the atmosphere and how people respond to him or what the care is like. But now all you had was a Skype or phone call, so you try to get as much information across as possible, or things you want to say, but I think it’s much more difficult to explain things with just words.” **(11: Nurse, ICU)**

3.2.: Physical distance between healthcare professionals and patients and their relatives	
10	“I notice that I also find it very tricky myself because... well, being the kind of person I am, I believe that closeness, literally touching someone, has real value in healthcare. That was all different. So yes, it definitely affected the healthcare.” **(12: General practitioner)**
11	“Yes. “We have pastoral staff who normally visit our ward a lot, so if there’s a patient who isn’t doing well or has been there a long time, then they basically have a chat with the family, completely without any obligations, just so that they’ve spoken with them. So when it comes to the point where someone dies, they’ve already talked to the family and you already have that contact... and that wasn’t the case now either.” **(3: Nurse, ICU)**
12	“It was really tough, because you weren’t allowed to lay out the client; you had to put them in that body bag. Then they had to be removed from the nursing home within half an hour. You didn’t even have the chance to warn the family or anything like that if you’d have wanted to.” **(2: Nursing assistant, nursing home)**
13	“Right, we’d leave the resuscitation tube in until the last moment. The idea was of course that it was mainly in the lungs, so there was a big risk that aerosols would escape too when you took the tube out. Well, normally when a patient dies, you make sure that you remove all the tubes so that the patient looks a bit more normal for the family, to let them say goodbye. But that wasn’t possible now because that tube at least had to stay in. And because we didn’t want to do it before then, I guess... we took that tube out, pulled the sheet over the body and removed the patient. That was the agreement. Which meant that the patient’s family, well they saw someone lying there with various tubes coming out of them, and that makes it more difficult for them.” **(3: Nurse, ICU)**
14	“What I also reckon from my perspective... I’m someone who always likes to be there for the family in the terminal phase, but then I also like to be able to touch someone — just put a hand on their shoulder, that kind of thing — but none of that was possible. That’s basically still the case. I still find it weird that it’s not allowed, that you can’t have a moment of physical contact when the family is in so much distress.” **(3: Nurse, ICU)**

3.3.: Feelings of detachment due to personal protective equipment	
	“Yes, definitely. They can’t see your facial expressions. And as for talking, even now... well, they often say ‘What did you say?’ And then you have to raise your voice a bit. We still regularly get told that they find it quite annoying that we have that thing covering our face.” **(1: Nursing assistant, nursing home)**
16	R: “And how did she react to, well, all that gear you all wore?” I: “Afraid. She hated it. We did too. We’d stand crying into our safety goggles next to her bed because we... That’s simply... You want to care for her and make her less anxious but you can’t because you’ve got that protective suit on. Which you yourself hate and which she hates.” **(7: Nurse, hospice)**
17	“I personally liked it. I was completely covered in the protective suit so I could take someone’s hand without any worries, I could stroke someone’s cheek without any worries, I could just... that’s nice, you know.” **(5: Nurse, Hospital COVID ward)**
18	“Um, well, yes. Of course, you’re less likely to just pop in on a patient; you need to put on the complete protective suit so there really needs to be something you have to do. Because it uses up personal protective equipment every time.” **(14: Geriatrician, nursing home)**

Positive effects of the exceptional situation for the long term

Respondents mentioned that the situation also (potentially) had positive effects on future end-of-life care. Due to the danger of shortage of beds, there was more awareness for the importance of talking about potentially futile treatments for patients and advance care planning (box 4, quote 1 and quote 2). Furthermore, there was more awareness about everlasting shortage of healthcare staff, and discussions were started about better staff policy for the future, which is important because a palliative approach to good end-of-life care takes time and attention from staff (box 4, quote 3). Lastly, HCPs said that they had realized (again) what the importance is of adequate care at the end of life, and that this care entails much more than physical care only (box 4, quote 4 and quote 5).

BOX 4: Quotes - Long-term positive effects	
1	“I think an awful lot of people don’t think about their own death or the terminal phase until it gets to that stage. They have a romantic idea of it. But now it has been in the news so much and is a real hot topic, people are talking about it more. So I guess it’s easier for me to talk to people about it. [...] All you have to do is to turn on the television or open a newspaper and they’re going on about COVID, about dying, ending up in intensive care, not wanting further treatment. So it’s almost a no-brainer to start that conversation and ask them what they personally would want. How do they see it? Have they discussed it at all with each other? In that regard, this period has made the difficult conversations easier.” **(8: Nurse, home)**
2	“Yes, I think we should anyway... this [the COVID-19 pandemic] has emphasized that it’s something we all need to consider a bit more. Not just what people want in terms of treatment, but also what they have a right to. I think we do that pretty well here in the Netherlands. I mean, we need to consider whether it’s realistic to send such-and-such person to the hospital, and certainly to an ICU — how will that affect them? What about afterwards? And is it realistic to spend so much money, energy and time on it, resources that were now scarce? So it was more things I was already thinking about, where I thought: okay, this makes it all a bit more urgent, it means we all need to give a bit more consideration to the issue.” **(16: Coordinator, Hospice)**
3	“Of course what you now see is that we’re getting this discussion and I think it’s important – given the ageing population and from a policy point of view – that we start looking at how we can get a really solid intake of new staff. And keep them too.” **(9: Nurse, hospital COVID ward)**
4	“I’ve become much more aware of the fact that you have to tailor the care. So even though there are guidelines for palliative care, you really need to see what’s right for each individual patient.” **(10: Nurse, hospital COVID ward)**

5	“I’ve become even more aware of how important it is for people to be able to touch one another. Without wanting to get all mystical, I increasingly realize that there are certain things you can’t get across using words alone. Because some people are in such a panic that they don’t hear the words at all. You can tell them the same thing ten times, but if their mother is in that bed dying... It really doesn’t matter what someone else is saying at that point. But it does matter what they do. And you remember that.” **(6: Nurse, hospice)**

Discussion

The aim of this study was to better understand how the COVID-19 outbreak impacted care in the different domains of palliative care at the end-of-life from the perspective of HCPs working in different settings. This interview study shows that care at the end of life was seriously hampered by the exceptional situation and led to a combination of challenges: uncertainty about how to best treat patients with this unknown disease, a high workload for HCPs, and strict preventative measures to prevent the spread of this contagious disease. The situation hampered professionals to provide care as they used to or wanted to provide in all domains of palliative care, but predominantly in the psychological, social and spiritual domain. The situation impacted the care to a varying degree, from annoying (e.g. wearing masks hindered patients to hear staff very well), to falling short in care (e.g. there was no time to support family, or not getting to know patient) to degrading or inhumane care (e.g. patients dying without relatives being present). Furthermore, the situation impacted the quality of end-of-life care in all settings and for both COVID-19 and non-COVID-19 patients. However, the situation also brought some long term positive effects on care, such as awareness of the importance of talking about advance care planning and potentially futile treatments, and of the importance of good care at the end of life within all the domains.

Strength and limitations

A strength of this study is the inclusion of HCPs from all care settings, with different professions who cared for COVID-19 and non-COVID-19 patients. Hereby we can show that the situation affected all and provide a broad range of perspectives. Because of the COVID-19 measures, we held all interviews via (video) call. This could have hampered building rapport with respondents and thereby the depth of the interviews. However, we experienced that respondents were eager to tell their experiences and we do not feel that these interviews were of less depth than face-to-face interviews we used to do.

Because the situation of the COVID-19 pandemic was hectic and unique, five researchers started with interviewing respondents. Each interviewer did one interview and thereafter they discussed the used topic list with, to see if it was sufficient and if adjustments were needed. By continuously discussing of the topic list and findings, uniformity was guaranteed.

During the last interviews in this study, no new things came up in comparison to the earlier interviews. However, since the situation of COVID-19 was so complex, unique in every healthcare setting and kept changing so quickly, we cannot say with certainty that we reached saturation.

Psychosocial and spiritual care for patients and relatives was most at stake and affected all care settings

Care at the end of life was hampered in all domains of palliative care, but especially impacted the psychosocial and spiritual domain. This already arose from our quantitative study among HCPs (9), but the in-depth interviews have provided a better understanding of this finding. HCPs mentioned they were limited in their possibilities to provide end-of-life care in these domains because they could not get to know the patient well, but predominantly because they were limited in their care due to the measures and lack of time. Furthermore, the situation affected the care for the relatives. Because they were not always allowed to visit, HCPs were not able to take care of them too and support them in this difficult time.

The results of the current study echo the findings of studies from different countries, in which several aspects of end-of-life care in times of COVID-19 were studied (12-17), Similar to our findings, they too found staff believed that they fell short in care at the end of life due to the lack of physical contact, wearing of PPE and visiting restrictions. In Hanna et al. and Mitchinson et al., HCPs also mentioned that there was more of a focus on essential physical care, and less focus on the other domains of end-of-life care, mostly because of the increased workload (12, 15). As in our study, Mitchinson et al, found that emotional care was hampered because of absence of human connections and distance between HCPs in hospitals and patients (12). Mitchell et al. found that community nurses and GPs indicated they provided less support to family carers than usual during the pandemic (16). Both Kentish-Barnes and Sinding found that HCPs were unable to provide good emotional support to families, due to limited family visits in combination with digital communication not being satisfactory (14, 18). Similar to our study, Mayland et al., found in a study among bereaved relatives of patients that died during the COVID-19 pandemic, that the quality of end-of-life care could be maintained when healthcare services still prioritize (among other things) the holistic aspects of end-of-life care and acknowledge the significance of individual deaths (19).

When comparing our results with the findings of other studies, it shows that there are a lot of similarities within the different situations (and measures) in different countries. Because our study included different settings and focused on the quality of care, we also could expose similarities and differences between different healthcare setting regarding care.

The need for individual assessment and adapting rules and measures

From our interviews, it appeared that nursing home and hospital staff felt more limited by the measures that had to be taken than HCPs working in home care or hospice care. This might be related to the fact that staff in hospices and at home more often were able to take individual decisions with regard to the measures in order to tailor care to the individual patient. They possibly had or felt more room to deviate from the measures, for instance to allow more visitors or not always keep their distance.

The need for leeway to adapt rules and measures is also acknowledged by the WHO in their updated guidance to implement PHSM in November 2020. One of their key points states: "The decision to introduce, adapt or lift PHSM should be based primarily on a situational assessment of the intensity of transmission and the capacity of the health system to respond, but must also be considered in light of the effects these measures may have on the general welfare of society and individuals." (1). In the

Netherlands we already saw some adaptation of the measures during the second wave of COVID-19 (September 2020 – February 2021), aimed at providing better care at the end of life. For instance, in most settings visitors were allowed also outside the terminal phase, but the number of visitors and time of the visits generally remained restricted.

COVID-19 provided chances to improve care at the end of life

Apart from many negative effects of the COVID-19 outbreak, we also found some potential positive effects of the crisis to improve care at the end of life in the future. First, the shortage of (mainly nursing) staff was already present and discussed before the COVID-19 outbreak, but staff in our study mentioned that this shortage was now more visible and discussed more extensively in the media. The outbreak showed that good qualified nursing staff is essential for good end-of-life care. This appreciation may lead to awareness for better working circumstances for nurses, and consequently more nursing staff in the future.

Second, another potentially positive effect is the increased attention for weighing the pros and cons of medical treatment for frail patients and the increased awareness of the importance of advance care planning and focusing on individual needs and preferences of patients. In the Netherlands, this resulted in the development of a national guidance for advance care planning that was supported by relevant Dutch professional and scientific organizations (20).

Last, HCPs mentioned that the importance is psychosocial care and the value of participation of relatives in at the end of life has been emphasized. This may provide fertile ground for efforts to improve palliative care, by e.g. promoting consulting palliative care teams or following palliative care vocational training.

Conclusion

The palliative care approach, key for good care at the end of life, was often negatively influenced by the COVID-19 outbreak, and seriously harmed patients and relatives. This predominantly concerned the emotional, social and spiritual domains of care, and was related to a focus on essential physical care and prevention of the spread of COVID-19. Negative effects could be limited when professionals feel room to adapt to rules and measures in individual cases. However, the experiences also show what aspects are most important for good care at the end of life. These lessons learned can potentially improve care at the end of life in the future.

List of abbreviations

HCP: Healthcare professional
WHO: World Health Organization
PHSM: Public health and social measures
ICU: Intensive care unit
PPE: Personal protective equipment

Declarations

Ethics approval and consent to participate

The Medical Ethics Committee Erasmus MC of Rotterdam, The Netherlands, assessed that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply (MEC-2020-0254). Verbal informed consent was obtained from all participants.

Consent for publication

Not applicable since this manuscript does not contain any details about individuals.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Conflicts of interest

The authors declare that they have no conflicts of interests.

Funding

This work was supported by ZonMw (project number: 844001803).

Authors' contributions

All authors contributed to the design of the study. Interviews were conducted by MZ, LB, YB, EW and RP. Analysis was done by MZ, LB, RP and BOP and discussed with all member of the research group. Quotes were selected by MZ and LB. MZ drafted the manuscript. All authors provided critical comments on drafts of the manuscripts and approved the final manuscript.

Acknowledgements

We would like to thank all the participants for their time and their stories. We also thank the organizations that helped with the recruitment of participants for the questionnaire.

References

1. WHO. Considerations for implementing and adjusting public health and social measures in the context of COVID-19. 2020.
2. RIVM. Ontwikkeling COVID-19 in grafieken 2021 [Available from: https://www.rivm.nl/coronavirus-covid-19/grafieken.
3. CBS. Bijna 169 duizend mensen overleden in 2020, 10 procent meer dan verwacht. 2021 [Available from: https://www.cbs.nl/nl-nl/nieuws/2021/04/bijna-169-duizend-mensen-overleden-in-2020-10-procent-meer-dan-verwacht.
4. Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. The Lancet. 2020;395(10235):1467-9.
5. Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: beyond ventilators and saving lives. Canadian Medical Association journal. 2020;192(15):400-4.
6. Yardley S, Rolph M. Death and dying during the pandemic. BMJ. 2020;369:1472.
7. Wakam GK, Montgomery JR, Biesterveld BE, Brown CS. Not Dying Alone - Modern Compassionate Care in the Covid-19 Pandemic. The New England journal of medicine. 2020;382(24):e88.
8. WHO. Palliative Care 2020 [Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care.
9. Onwuteaka-Philipsen BD, Pasman HRW, Korfage IJ, Witkamp E, Zee M, van Lent LG, et al. Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study). Palliative Medicine. 2021;35(5):830-42.
10. Boyatzsis RE. Transforming qualitative information: Thematic analysis and code development. Sage, editor. California: Thousand Oaks; 1998.
11. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. Handbook of research methods in health social sciences. 2018:1-18.
12. Mitchinson L, Dowrick A, Buck C, Hoernke K, Martin S, Vanderslott S, et al. Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic. Palliative Medicine. 2021;35(5):852 - 61.
13. Cook DJ, Takaoka A, Hoad N, Swinton M, Clarke FJ, Rudkowski JC, et al. Clinician Perspectives on Caring for Dying Patients During the Pandemic : A Mixed-Methods Study. Annals of internal medicine. 2021;174(4):493-500.
14. Kentish-Barnes N, Morin L, Cohen-Solal Z, Cariou A, Demoule A, Azoulay E. The Lived Experience of ICU Clinicians During the Coronavirus Disease 2019 Outbreak: A Qualitative Study. Critical Care Medicine. 2021;49(6):585-97.
15. Hanna JR, Rapa E, Dalton LJ, Hughes R, Quarmby LM, McGlinchey T, et al. Health and social care professionals' experiences of providing end of life care during the COVID-19 pandemic: A qualitative study. Palliative Medicine. 2021;35(7):1249-57.
16. Mitchell S, Oliver P, Gardiner C, Chapman H, Khan D, Boyd K, et al. Community end-of-life care during the COVID-19 pandemic: findings of a UK primary care survey. BJGP open. 2021;5(4).
17. Dohmen MDW, van den Eijnde C, Thielman CLE, Lindenberg J, Huijg JM, Abma TA. Good Care during COVID-19: A Narrative Approach to Care Home Staff's Experiences of the

Pandemic. International Journal of Environmental Research and Public Health. 2022;19(4):2106.

18. Sinding C, Cape S, Charles L, Gosselin C, Kettings M, Taniguchi A, et al. When 'Being There'Is Disallowed: Disruptions to Knowing and Caring During COVID-19 Visitor Restrictions. Journal of Social Work in End-of-Life & Palliative Care. 2022:1-17.

19. Mayland CR, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. Palliative Medicine. 2021;35(8):1480-91.

20. Boddaert M, Caffarel J, Dermois M, Kodde A, Reyners AKL. Leidraad voor het proces en uniform vastleggen van proactieve zorgplanning naar aanleiding van de COVID-19-pandemie. 2020.

525

Additional file 1: Interviewguide

1. Start the interview: introduce yourself, ask if it is a convenient moment for the interview. Ask if the interviewee gives permission to record the interview: if yes, start recording. Explain that anonymity is guaranteed, that personal data is not stored and that everything discussed is handled with confidence. Ask if the interviewee has any questions and agrees.

2. Ask about the interviewee recent experience of end-of-life care.

   Probes:

   - How many patients have you cared for during the last days of their lives?
   - What protective measures are taken in your care setting?
   - What is your experience of those measures?

3. Ask if the interviewee can remember the patient from the questionnaire.

   a. If not, go to 4.

   b. If yes, ask about this patient's story.

      Refer if necessary to answers in the questionnaire, as in: You indicated in the questionnaire that …: can you tell me more about that? What do you mean by that? What did you miss? What would you rather have seen? Etc.

      Pay attention to:

   - Symptoms and symptom management
   - Treatment restrictions
   - Influence of the Corona measures, including visits
   - Place of death
   - How death was characterized in the questionnaire
   - Experiences after the moment of dying

Probes:

- What did this patient's disease trajectory look like?
- What care dilemmas did you experience?
- What did you like in this case and what not?

- What exactly made the care as provided in this case right or wrong?
- What do you know about experiences of other members of the care team?
- How was the situation different from normal as a result of the corona crisis?

Where item 3 has been discussed extensively and concerned a positive experience, 4 can be skipped.

Where item 3 has been discussed extensively and concerned a negative experience, 5 can be skipped.

4. Can you give me an example of a patient for whom you thought end-of-life care went really well.
   Discuss experience of:
   - Symptoms and symptom management
   - Any treatment restrictions
   - Influence of the Corona measures, including visits
   - Place of death
   - How death was characterized in the questionnaire
   - Experiences after the moment of dying

   Probes:
   - Can you tell me about that situation?
   - Who was this patient (age, gender, setting, condition, covid-infection)?
   - How would you describe the care this patient received in the last phase of life?
   - What exactly makes this case a good case?
   - And how was this for the team? For you?

5. Can you give me an example of a patient for whom you thought end-of-life care really could have been better.

   Discuss experience of:
   - Symptoms and symptom management
   - Any treatment restrictions
   - Influence of the Corona measures, including visits
   - Place of death
   - How death was characterized in the questionnaire

- Experiences after the moment of dying

Probes:

- Can you tell me about that situation?
- Who was this patient (age, gender, setting, condition, covid infection)?
- How would you describe the care this patient received in the last phase of life?
- What exactly makes this case a poor case?
- And how was this for the team? For you?

6. Have these and other recent experiences with end-of-life care affected your views on good end-of-life care?

   Probes:

   - Can you tell me something about that?
   - What about your health, quality of life and emotions as reported in the questionnaire?
   - Safety and protection issues?

7. Have these and other recent experiences with end-of-life care affected your own health and wellbeing?

   Probes:

   - Can you tell me something about that?
   - What about your health, quality of life and emotions as reported in the questionnaire?
   - Safety and protection issues?

8. Conclusion: ask if the interviewee wants to add anything that has not yet been discussed. Thank the interviewee and wish them strength. Indicate that if the interviewee wants to add something, they can always send an e-mail. In case the interview evoked emotions, recommend that the interviewee talks to someone or contacts a colleague or their GP.

Table 2. Themes, subthemes and codes

Theme	**Subtheme**	**Code**
New disease		Clinical view not reliable (-)
		Unexpected deterioration (-)
		Symptom relief was hard (-)
High workload		Not enough time for care (-)
		Lack of HCP's with the right skills (-)
		Higher chance of mistakes (-)
		Poor continuity of care (-)
		No time to support relatives (-)
		Limited in time they could relatives to say goodbye (-)
Contagiousness		Too much focus on prevention of infections (-)
	Limited family visits and goodbye's	Patients were not able to say goodbye to everyone (-)
		HCPs could not get to know the patient (-)
		Good excuse to refuse someone to say goodbye to the patient (+)
		New digital methods for contact (+)
		Limited in giving emotional support to relatives (-)
	Physical distance between HCP's and patients and their relatives	Feeling detached from the patient (-)
		Spiritual counselors were not allowed (-)
		Limited in taking care of deceased patient (-)
		Limited in giving emotional support to relatives (-)
	Feelings of detachment due to personal protective equipment (PPE)	HCP's were unrecognizable, not understandable and scary for patients (-)
		Allowed HCP's to touch patients (+)
		Being more reluctant to visit patients because they had to change in PPE (-)
Positive effects for the long term		More awareness for advance care planning (+)
		More awareness for better staff policy (+)
		Realization the importance of adequate end-of-life care (+)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p. 1/ l. 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p. 2-3 / l. 27-57

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p. 3-5 / l. 57 - 105
Purpose or research question - Purpose of the study and specific objectives or questions	p.5 / l. 101 - 105

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	p. 5 / l. 108 p. 7 / l. 137 - 139
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p. 7 / l. 147 - 149
Context - Setting/site and salient contextual factors; rationale**	p. 5 / l. 120 - 122
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	p.5 / l. 113 - 119
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p. 7 / l. 152 - 157
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	p. 6 / l. 131 - 135

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p. 6 / l. 131 - 135
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	P. 5-6 / l. 119 - 126
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	p. 7 / l. 137 - 149 p. 7 / l.152 - 157
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	p. 7 / l. 137 - 149
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	p. 7 / l. 137 - 149 p.20 / l. 342 - 346

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p. 8- 18 / l. 158 – 310
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p. 9 / l. 175 p. 12 / l. 224 p. 16 / l. 296 p. 18 / l. 311

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p.19-23/ l. 313 - 435
Limitations - Trustworthiness and limitations of findings	p.19-20 / l. 332 - 351

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p.24/ l. 454
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p. 25/l. 456

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

BMJ Open

The impact of COVID-19 during the first months of the pandemic on care at the end of life from the perspective of healthcare professionals from different settings; a qualitative interview study (the CO-LIVE study).

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-063267.R1
Article Type:	Original research
Date Submitted by the Author:	16-Dec-2022
Complete List of Authors:	Zee, Masha; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Bagchus, Lotje; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Becqué, Yvonne ; Rotterdam University of Applied Sciences, Research Center Innovations in Care Witkamp, Erica; Rotterdam University of Applied Sciences, Research Center Innovations in Care; Erasmus MC University Medical Center, Department of Public Health van der Heide, Agnes; Erasmus MC University Medical Center, Department of Public Health van Lent, Liza; Erasmus MC Cancer Institute, Medical Oncology Goossensen, Anne; University of Humanistic Studies Korfage, Ida; Erasmus MC, University Medical Center Rotterdam, Public Health Onwuteaka-Philipsen, Bregje; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Pasman, H. Roeline; Amsterdam UMC Locatie VUmc, Public and Occupational Health
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Public health, Qualitative research
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH, PUBLIC HEALTH

The impact of COVID-19 during the first months of the pandemic on care at the end of life from the perspective of healthcare professionals from different settings; a qualitative interview study (the CO-LIVE study).

Authors

Masha S. Zee[1], Lotje Bagchus[1], Yvonne N Becqué[2], F. Erica Witkamp[2,3], Agnes van der Heide[3] Liza G.G. van Lent[4], Anne Goossensen[5], Ida J. Korfage[3], Bregje D. Onwuteaka-Philipsen[1], H. Roeline W. Pasman[1]

Affiliations

1. Department of public and occupational health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, Amsterdam, the Netherlands
2. Research Center Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands
3. Department of Public Health, Erasmus MC University Medical Center, Rotterdam, the Netherlands
4. Department of Medical Oncology, Erasmus MC Cancer Institute, Rotterdam, the Netherlands
5. University of Humanistic Studies, Utrecht, The Netherlands

Correspondence:

Masha Zee, Department of Public and Occupational Health, Amsterdam UMC, van der Boechorststraat 7,1081 BT Amsterdam, the Netherlands; m.zee@amsterdamumc.nl

Word count: 3855

Number of tables / boxes: 1 table / 3 boxes

Abstract:

Objectives: The objective of this study is to better understand how the COVID-19 outbreak impacted the different domains of the palliative care approach to end-of-life care from the perspective of healthcare professionals (HCPs) with different professions, working in different settings during the first months of the COVID-19 outbreak in the Netherlands.

Methods: An in-depth qualitative interview study among 16 HCPs of patients who died between March and July 2020 in different healthcare settings in the Netherlands. The HCPs participated in an online survey about end-of-life care. Maximum variation sampling was used. Data were analysed following the principles of thematic analysis.

Results: Not all HCPs were satisfied with the quality of end-of-life care. Several aspects impacted the quality of (the palliative care approach to) care at the end of life. First, COVID-19 was a new disease and this led to challenges in the physical domain of end-of-life care e.g. a lack of knowledge to manage symptoms and a unreliable clinical view. Second, the high workload HCPs experienced impacted the quality of end-of-life care, especially in the emotional, social and spiritual domains, since they only had time for urgent, physical care. Third, COVID-19 is a contagious disease and measures taken to prevent the spread of the virus hampered care for both patients and relatives. For example, because of the visiting restrictions, HCPs were limited in providing emotional support to relatives. Lastly, the COVID-19 outbreak also provided potentially positive impact for the longer term, e.g. more awareness of advance care planning and the importance of end-of-life care including all the domains.

Conclusion: The palliative care approach, key for good end-of-life care, was often negatively influenced by COVID-19, predominantly in the emotional, social and spiritual domains. This was related to a focus on essential physical care and prevention of the spread of COVID-19.

Keywords: COVID-19, Palliative Care, End-of-life Care, Quality of Care, Qualitative Research

Strengths and limitations:

- This study describes a broad range of perspectives, since it includes healthcare professionals from all care settings, with different professions who cared for COVID-19 and non-COVID-19 patients.
- Respondents were eager to share their experiences despite of the fact that the interviews were held via (video) call.
- Despite the fact that five researchers interviewed respondents, uniformity was guaranteed by continuously discussing the topic list and findings.
- We cannot say with certainty that data saturation was reached, since the situation of COVID-19 was so complex and kept changing so quickly.

Introduction

The COVID-19 pandemic confronted the world with an unknown disease, which had an impact on care in all healthcare settings. To limit transmission and reduce mortality and morbidity from COVID-19, the World Health Organization (WHO) published guidelines to take public health and social measures (PHSM) (1). These measures included, among others, personal protective measures, such as wearing masks, and physical distancing measures, such as maintaining distance in public or workplaces. As other countries, the Netherlands were also confronted with high numbers of patients with COVID-19, excess mortality due to COVID-19, and implementation of most of the abovementioned measures (2, 3).

The situation surrounding COVID-19, affected care at the end of life for both patients and their relatives during the first months of the pandemic (4). Measures, such as visiting restrictions and keeping a physical distance changed human contact inherently and influenced the way end-of-life care was provided (5-7). Furthermore, because of the high number of patients with COVID-19 there might be less time for emotional and existential support for patients and their relatives in a time where this support is very much needed (4-6).

Good quality of end-of-life care asks for a palliative care approach that focusses on the quality of life of patients and their families. It aims to provide person-centered care that not only focuses on the medical condition of the patient, but also takes on a more holistic approach, looking at the psychological, social and spiritual domains of care as well (8). It pays special attention to specific needs and preferences in these domains and it not only provides support to patients, but also to their relatives and includes bereavement counselling (8).

It is likely that these domains of the palliative care approach were endangered during the COVID-19 pandemic. The aim of this study is to better understand how the COVID-19 outbreak impacted the different domains of the palliative care approach to end of life care from the perspective of HCPs (healthcare professionals), working in different health care settings during the first months of the COVID-19 outbreak in the Netherlands.

Methods

Design, Setting and Participants

An in-depth qualitative interview study was conducted among HCPs of patients who died between March and July 2020 in different healthcare settings in the Netherland as part of the CO-LIVE study. CO-LIVE is a mixed-methods study on the experiences of both bereaved relatives and HCPs during the COVID-19 pandemic. Participants were recruited through an online survey about the last days of life of a patient who died during the first wave of the COVID-19 outbreak. This survey was distributed through relevant healthcare professional organizations, palliative care networks and organizations, volunteer organizations and personal contacts throughout the Netherlands. (9)Maximum variation sampling was used in the group of participants that was interested to take part in an interview. Variation was sought in setting, profession, and how HCPs qualified the death of the patient about whom they filled in the survey (both positive and negative qualifications) and potential respondents were approached via e-mail. Since nursing assistants working in nursing homes were underrepresented in the survey, two were recruited via our own network. Eventually, sixteen HCPs were interviewed: nine nurses, two nursing assistants, one coordinator in a hospice and four physicians. Four participants worked in a special COVID unit in the hospital, two in an intensive care unit (ICU), five in a nursing home, three in a hospice and two in home/community care (Table 1). Some participants had cared for COVID-patients only, others had also cared for non-COVID-patients. We followed the standards for reporting qualitative research (SRQR).

Table 1. Characteristics participants

	Profession	Setting	Sex	Age Range
1	Nursing assistant	Nursing home	Female	<40
2	Nursing assistant	Nursing home	Female	40-60
3	Nurse	ICU	Female	<40
4	Nurse	Hospice	Female	40-60
5	Nurse	Hospital (COVID-ward)	Female	40-60
6	Nurse	Home	Female	40-60
7	Nurse	Hospice	Female	<40
8	Nurse	Home	Female	40-60
9	Nurse	Hospital (COVID-ward)	Female	<40
10	Nurse	Hospital (COVID-ward)	Female	<40
11	Nurse	ICU	Female	<40
12	General Practitioner	Home/hospice	Male	>60
13	Pulmonologist	Hospital (COVID-ward)	Female	40-60
14	Geriatrician	Nursing home	Female	>60
15	Geriatrician	Nursing home	Male	>60
16	Coordinator	Hospice	Female	40-60

Patient and public involvement

Patients and the public were not involved in the design and conduct of this study.

Data collection

Five researchers (MZ: 2, LB: 8, YB: 4, EW: 1 and RP: 1) conducted the interviews. Because of COVID-measures, all interviews were held via (video)calls. The interviewers used a topic list, that included questions about the responses as given in the survey and questions about new experiences (Additional file 1). The interviews were conducted in Dutch, lasted between 25 and 70 minutes and were audio-recorded.

Data analysis

Data were transcribed verbatim and analysed using qualitative data analysis software MAXQDA. We followed the principles of thematic analysis based on a phenomenological approach; focusing on the lived experiences from the respondents (10, 11). First LB and RP went through the transcripts and made summaries, which were discussed with all interviewers and another member of the research group (BOP). After becoming familiar with the data by reading the transcripts, MZ coded the data. The analyses were discussed with all members of the research group and on multiple occasions with the different interviewers. Thereafter, MZ, LB, BOP and RP sorted the codes into groups developing overarching themes (Additional file 2). During the process of sorting the codes into themes, MZ, LB, BOP and RP continuously compared and discussed their decisions. Finally, appropriate quotes were selected by MZ and LB and translated by a professional translator. The research group consists of researchers with different backgrounds (health sciences, medical anthropology, nursing, sociology, psychology and medicine).

Ethical considerations

Before the interview, participants gave verbal informed consent to participate in the interview and to have this interview recorded. After transcription, audio recordings were deleted and all data were anonymized to make sure the participants and their patients were unidentifiable. Personal information and transcripts were saved in separate folders that both could only be accessed by the researchers. The Medical Ethics Committee Erasmus MC of Rotterdam, The Netherlands, assessed that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply (MEC-2020-0254).

Results

The COVID-19 outbreak led to an impactful and unique situation for healthcare, and HCPs stated that it affected care at the end of life. This was the case for HCPs of all disciplines and for all care settings, albeit sometimes in different ways.

Several themes arose from the interviews after thematic analysis, that were characteristic for this impactful and exceptional situation and, mostly negatively, impacted the quality of end-of-life care during the first months of the COVID-19 pandemic: COVID-19 being a new disease, the disease leading to a higher workload for HCPs, the disease being contagious and the long-term positive impact of the COVID-19 pandemic on end-of-life care.

New disease – Lack of knowledge to manage symptoms

In the first months of the COVID-19 outbreak, little was known about the course of the disease, the prognosis, treatment and symptom relief. This led to difficulties in the physical domain of end-of-life care. HCPs said that their ‘clinical view’ was not reliable anymore because the disease course for COVID-19 patients was unpredictable (box 1, quote 1). In some cases, the patient unexpectedly deteriorated very quickly, making it difficult to anticipate, for instance to timely inform family members. Furthermore, they said it was hard to relieve symptoms for some dying patients because existing treatments for similar symptoms in other diseases had no or little effect for COVID-19 patients. (box 1, quote 2).

High workload – Lack of time and staff for good end-of-life care

The COVID-19 outbreak led to a great influx of patients with COVID-19 on top of the regular patients, resulting in a high workload for HCPs, especially at the ICU and COVID-wards in hospitals. Besides, HCPs in nursing homes also had a higher workload since they had to isolate residents with COVID-19 from residents without COVID-19. This created more wards than usual, that they had to distribute the same amount of HCPs over. Furthermore, because of a lack of knowledge on how to prevent COVID-19 infections, many HCPs mentioned how (especially in the first months of the pandemic) measures and rules about visitation or protective equipment were unclear or kept changing. Being updated on the rules took a lot of time, creating a higher workload. These aspects were mentioned by HCPs from all settings, also those who had not cared for COVID-19 patients.

Due to the great influx of patients, the quality of end-of-life care was hampered. HCPs mentioned degrading situations for patients where there were crowded wards with little privacy and work that felt like a production line (box 1, quote 3). Some HCPs mentioned that they only had time for the essential, physical care, but not enough time for care in the emotional, social and spiritual domains (box 1, quote 4). However, HCPs, specifically in the ICU, also mentioned some difficulties in the physical domain. They mentioned that, because of a lack of staff, HCPs from other disciplines or wards helped them. However, not all of these new colleagues had the right skills or experience and this sometimes negatively impacted the quality of physical care (box 1, quote 5). Furthermore, HCPs mentioned that medication safety was an issue because of the time pressure.

Because of the shortage of (skilled) staff, schedules of HCPs were sometimes unclear or constantly changing. Therefore, HCPs saw a lot of different patients and did not see one particular patient as often as usual. A respondent mentioned that this led to poor continuity of care because individual HCPs were not as involved with and informed about their patients as usual, which made it difficult to be aware of personal needs and preferences (box 1, quote 6).

Due to the staff shortage and higher workload, there was also less time for another important part of the palliative care approach: supporting relatives. HCPs mentioned that they could not spend as much time on supporting the relatives as they were used to and that it was unsatisfying for them (box 1, quote 7). In some cases, HCPs in the ICU were limited in the time they could give relatives to say goodbye to their loved ones. (box 1, quote 8).

BOX 1: Quotes - New disease & high workload

1	“No, you have this feeling that you’re less in control of the situation. [...] And I think no one had that feeling that they knew what was coming in the case of COVID. [...] In the terminal phase too, I felt it was like hey, suddenly it all changed... and they were dead, or hey, suddenly they were stable, or hey, everything suddenly fell apart. Normally you would be dropping in on them regularly and you’d see things happening, you know, and you adjust accordingly. But for me this wasn’t like that... it was more difficult.” **(4: Nurse, hospice)**
2	“But when you saw him, he really wasn’t comfortable. Laboured breathing, high respiratory rate, increasing heart rate. You could see the panic in his eyes but there came a point when we couldn’t communicate with him anymore. He was kind of asleep, as it were, but you could see that he was still physically really hard at work. If he’d been a non-COVID patient I would have said he’s not comfortable so we need to do something with the medication. And so that’s what we did. Only it didn’t work well enough for this man. And that remained the case up to the end. I found that difficult.”**(10: Nurse, hospital COVID ward)**
3	“In that respect, I didn’t think there was much privacy, so... of course, there were really strict visiting rules so I felt patients got a bit abandoned. And with the IC cohort, that was completely [...], right, that was basically 18 people lying in a single room, all on their stomachs, all kind of like interchangeable. So when we had our shift, we’d start by turning the first one back over, and then go through the whole lot one by one, as it were. It was almost like a production line. With no curtains in between, they’d all been removed, so I found it incredibly degrading.” **(9: Nurse, hospital COVID ward)**
4	“We provided the necessary care. In the end, we were never really satisfied with what we did and how we did it. We were never really satisfied, because we simply couldn’t give assistance in social and emotional aspects and I find that very important. So it was just a case of giving people the essential care, trying to keep them stable.” **(9: Nurse, hospital COVID ward)**
5	“What you also realize afterwards is that, because it wasn’t just IC nurses but other people too, they didn’t have all the necessary knowledge. So now I’m increasingly hearing that people have ended up with eye problems because they didn’t get the drops every so often, and the eyes became dehydrated. Then I think to myself: oh, there are some things we made a right mess of.” **(9: Nurse, hospital COVID ward)**
6	“Normally, we’re used to providing as much continuity as possible. So if you switch from a morning shift to an evening shift, you try to have the same patient who you had in your morning shift in the evening shift too. Now I might not be on my own ward, as it were, for three weeks because I’d be working all over the place, then I’d come back and oh, that patient’s been there a long time. Well, you don’t know what that means because you didn’t get any of the news about the patient.” **(3: Nurse, ICU)**
7	“We also had more patients to care for than we would normally, so we had less time available to spend on the family. In the normal situation, if we know a patient is going to die, we always try to make sure there’s one nurse who can focus entirely on that and give the family their full assistance and go through that whole process properly. But that wasn’t possible during the COVID period. That did make it rather unsatisfying for everyone, yes.” **(3: Nurse, ICU)**
8	“Yes, then we would just phone the family at home and that was often for medical reasons. A conversation with the family and, yes, the tricky thing... we would agree with them who else needs to come. How do we want the final goodbye... what’s the procedure? But at the same time we didn’t want it to take days because you needed the beds. So it was really 24 hours max. And then it was indeed a question of stopping, removing the ventilation and then it was often less than quarter of an hour and the patient was dead. So that often happened very quickly. And then the patient would be removed, room cleaned, new patient put in. Yes, that was really weird.” **(9: Nurse, hospital COVID ward)**

Contagiousness – Preventative measures hampered good end-of-life care

In healthcare settings, different measures were taken to prevent the spread of COVID-19, such as visiting restrictions, keeping physical distance and wearing personal protective equipment (PPE). There was little difference between COVID-19 and non-COVID-19 patients regarding the impact of these measures on care, since most measures applied to everyone. HCPs stated that caregiving at the end of life was hampered, due to the priorities that government and overall healthcare had when dealing with COVID-19. They said that preventing the spread of the virus seemed more important than the quality of end-of-life care and that this impacted, in particular, the emotional and spiritual aspects of care (box 2, quote 1).

Limited family visits and goodbyes

All HCPs mentioned that family visits and goodbyes were limited to smaller or greater extent which impacted end-of-life care for both patients and their relatives. There were restrictions in the number of people who were allowed to visit patients, the number of visits per day, and the amount of time relatives were allowed to visit a patient. Visiting restrictions varied between settings; HCPs from hospitals and especially nursing homes mentioned that these restrictions were very strict and that it was difficult to deviate from them. In homecare, patients or HCPs could decide themselves on visitation (restrictions).

According to the HCPs the limited family visits and goodbyes impacted the patients greatly, mostly in the psychological and social domains. Some participants mentioned that dying patients could not see everyone they wanted to see and that some patients were completely alone in the last days of their life (box 2, quote 2). One nurse described a case where a patient did not want to die in a hospital setting, because of their visiting restrictions. However, this sudden transfer to her home led to chaotic last days of life. Furthermore, the visiting restrictions impacted to what extent HCPs could get to know their patients and therefore impacted end-of-life care. If unconscious or very ill patients were not able to talk, care became less personal, because no family was around to share the patients' preferences and wishes. (box 2, quote 3). Furthermore, a nurse working in homecare mentioned that the restrictions were used as a good excuse when patients did not want a specific person to visit them and say goodbye (box 2, quote 4). In some cases, there were new digital ways for patients to contact their relatives (e.g. video calls) and HCPs were mostly positive about the usage of these resources, although it did not fully replace the physical family visits.

When providing good end-of-life care in all domains of palliative care, the contact and connection of HCPs with patients and their relatives is really important. Because of visitation restrictions, HCPs did not see relatives (as much) making it difficult for HCP's to provide emotional support to families (box 2, quote 5). Even if the distance could be bridged using digital communication, HCP's felt they could not support the relatives sufficiently from a distance (box 2, quote 6).

Physical distance between HCPs and patients and their relatives

Physical distance hampered the care and connection in all settings for patients with and without COVID-19. Some HCPs felt detached from the patient, mostly because they could not touch the patient, apart from when they performed medical procedures. They explained that touching patients is an important part of emotional support and thus within the psychological domain of care (box 2, quote 7). In some cases, spiritual counselors were not allowed to be physically present with patients anymore and this impacted the spiritual domain of the end-of-life care (box 2, quote 8). Furthermore, when a patient had died, HCPs mentioned that they were not allowed to take care of the deceased patient to prepare them for relatives to say goodbye (box 2, quote 9). Finally, the physical distance also limited HCPs in providing emotional support to relatives, because they could not get near to the relatives or touch them to console them (box 2, quote 10).

Feelings of detachment due to personal protective equipment

Another measure that created distance between HCPs and patients and their relatives, was the PPE HCPs needed to wear under certain circumstances. A HCP described how they felt it was degrading for patients to provide care when being unrecognizable due to wearing PPE (box 2, quote 11). Furthermore, some HCPs mentioned that it was scary for patients with dementia or psychological problems to be cared for by staff wearing PPE and therefore hindered care in the psychological domain (box 2, quote 12). However, HCPs also said that they were happy to be wearing PPE, because it allowed them to touch their patients and to them come closer. Some HCPs had experienced a shortage of PPE, or had to economize PPE to prevent a shortage and this made HCPs more reluctant to come near to patients, because it would cost extra PPE, hindering care in all domains (box 2, quote 13). In specific COVID-wards, it was not necessary to change PPE all the time which was seen as an advantage of working in such wards.

	BOX 2: Quotes - Contagiousness
1	“But suddenly we ended up in a situation in which we were only talking about the risk of infection, about infection rates, well, just the medical side. And everything that makes someone a human being was no longer being discussed. I found that very confusing. I even got really angry about this at one point and said how crazy this was, how we were now going completely against everything we’d learned over the past decades about what’s important for people with dementia who lose their bearings. Apparently that was no longer important. All that mattered was that we didn’t want people to get infected. That was weird. [...] I found that very difficult to cope with in the past little while, and I still do.” **(6: Nurse, home)**

2.1.: Limited family visits and goodbye’s	
2	“In principle two people were allowed to come, and then indeed for just half an hour or maybe three quarters of an hour, but only a very brief period. Often, either the patient died during that visit, or just afterwards or they came too late. [...] I mainly found it very sad, distressing, a failing where you can’t offer what’s best, because you can’t replace the person who isn’t there, or maybe you aren’t in a position to be there because you don’t belong there. But at the same time it feels like a failing with regard to them, and how do you assist them in that? [...] But then when you’re driving home later, you always have that feeling that you should be doing things differently, or you’re not getting a sense of satisfaction. That’s what I call failings.” **(11: Nurse, ICU)**
3	“But what I certainly also remember is the fact that visitors weren’t allowed. That makes the care for the patient a lot more impersonal. IC patients in general spend a lot of the time asleep, but that was especially so with the COVID patients — they were all so sick and heavily sedated, you didn’t have any contact with them at all. And if you don’t have any contact with the family either to get to know the person behind the patient, well, it becomes a very abstract exercise.” **(3: Nurse, Hospital ICU).**
4	“The circle around someone simply becomes smaller; she has... And it’s quite natural that only the really intimate circle are still allowed to visit. But well, at a certain point we did rather use this fact [the visiting restrictions], yes. To protect that lady, to help her and keep people away from her. Yes, that was quite funny.” **(6: Nurse, home)**
5	“Patients are mostly on our ward for a while, so you’ve had contact with the family. So when the patient eventually dies, you’re able to assist their family really well with that process because you’ve already had quite a lot of contact. But now it became so that when a patient died, you were then seeing the family for the very first time. So there was no bond.” **(3: Nurse, ICU)**
6	“Yes, basically you try... The tricky thing is, normally you have the family around the bed and you can point things out, explain that this is how you see the situation. You can get a feel for the atmosphere and how people respond to him or what the care is like. But now all you had was a Skype or phone call, so you try to get as much information across as possible, or things you want to say, but I think it’s much more difficult to explain things with just words.” **(11: Nurse, ICU)**

2.2.: Physical distance between healthcare professionals and patients and their relatives	
7	“I notice that I also find it very tricky myself because... well, being the kind of person I am, I believe that closeness, literally touching someone, has real value in healthcare. That was all different. So yes, it definitely affected the healthcare.” **(12: General practitioner)**
8	“Yes. “We have pastoral staff who normally visit our ward a lot, so if there’s a patient who isn’t doing well or has been there a long time, then they basically have a chat with the family, completely without any obligations, just so that they’ve spoken with them. So when it comes to the point where someone dies, they’ve already talked to the family and you already have that contact... and that wasn’t the case now either.” **(3: Nurse, ICU)**
9	“It was really tough, because you weren’t allowed to lay out the client; you had to put them in that body bag. Then they had to be removed from the nursing home within half an hour. You didn’t even have the chance to warn the family or anything like that if you’d have wanted to.” **(2: Nursing assistant, nursing home)**
10	“I felt particularly sorry for the family because – unlike the patient – they were of course perfectly capable of communicating, and they were distressed. I really felt I should be sitting next to these people, in physical contact. But that was not allowed. That’s a dilemma.” **(10: Nurse, hospital COVID ward)**

2.3.: Feelings of detachment due to personal protective equipment	
11	“with a face mask on, so you’re unrecognizable — who’s that standing next to my bed? Well, that. And I find that degrading in the sense that you’re turning that person into an object; they’ve become an object. It’s not a person lying there anymore, it’s an object.” **(15: Geriatrician, nursing home)**
12	R: “And how did she react to, well, all that gear you all wore?” I: “Afraid. She hated it. We did too. We’d stand crying into our safety goggles next to her bed because we... That’s simply... You want to care for her and make her less anxious but you can’t because you’ve got that protective suit on. Which you yourself hate and which she hates.” **(7: Nurse, hospice)**
13	“Um, well, yes. Of course, you’re less likely to just pop in on a patient; you need to put on the complete protective suit so there really needs to be something you have to do. Because it uses up personal protective equipment every time.” **(14: Geriatrician, nursing home)**

Positive impact of the exceptional situation for the long term

Besides direct, mostly negative impact, respondents also mentioned that the situation (potentially) had a positive impact on future end-of-life care. Due to the danger of shortage of beds, there was more awareness for the importance of talking about potentially futile treatments for patients and advance care planning (box 3, quote 1 and quote 2). Furthermore, there was more awareness about everlasting shortage of healthcare staff, and discussions were started about better staff policy for the future, which is important because a palliative approach to good end-of-life care in all domains takes time and attention from staff. Lastly, HCPs said that they had realized (again) what the importance is of adequate and individualized care at the end of life, and that this care entails much more than physical care only (box 3, quote 3 and quote 4).

BOX 3: Quotes – Long-term positive impact	
1	“~~So~~ I guess it’s easier for me to talk to people about it (their own death and whishes). […] All you have to do is to turn on the television or open a newspaper and they’re going on about COVID, about dying, ending up in intensive care, not wanting further treatment. So it’s almost a no-brainer to start that conversation and ask them what they personally would want. How do they see it? Have they discussed it at all with each other? In that regard, this period has made the difficult conversations easier.” **(8: Nurse, home)**
2	“Yes, I think we should anyway... this [the COVID-19 pandemic] has emphasized that it’s something we all need to consider a bit more. Not just what people want in terms of treatment, but also what they have a right to. I think we do that pretty well here in the Netherlands. I mean, we need to consider whether it’s realistic to send such-and-such person to the hospital, and certainly to an ICU — how will that affect them? What about afterwards? And is it realistic to spend so much money, energy and time on it, resources that were now scarce? So it was more things I was already thinking about, where I thought: okay, this makes it all a bit more urgent, it means we all need to give a bit more consideration to the issue.” **(16: Coordinator, Hospice)**
3	“I’ve become much more aware of the fact that you have to tailor the care. So even though there are guidelines for palliative care, you really need to see what’s right for each individual patient.” **(10: Nurse, hospital COVID ward)**
4	“I’ve become even more aware of how important it is for people to be able to touch one another. Without wanting to get all mystical, I increasingly realize that there are certain things you can’t get across using words alone. Because some people are in such a panic that they don’t hear the words at all. You can tell them the same thing ten times, but if their mother is in that bed dying... It really doesn’t matter what someone else is saying at that point. But it does matter what they do. And you remember that.” **(6: Nurse, hospice)**

Discussion

This interview study, held in the first months of the COVID-19 pandemic, shows that care at the end of life was seriously hampered by the exceptional situation and led to a combination of challenges in all domains of end-of-life care: uncertainty about how to best treat patients with this unknown disease, a high workload for HCPs, and strict preventive measures to prevent the spread of this contagious disease. However, the situation also brought some potential long-term positive impact on care, such as awareness of the importance of talking about advance care planning and potentially futile treatments, and of the importance of good care at the end of life within all the domains.

Strength and limitations

A strength of this study is the inclusion of HCPs from all care settings, with different professions who cared for COVID-19 and non-COVID-19 patients. Hereby we can show that the situation affected all and provide a broad range of perspectives. Because of the COVID-19 measures, we held all interviews via (video) call. This could have hampered building rapport with respondents and thereby the depth of the interviews. However, we experienced that respondents were eager to tell their experiences and we do not feel that these interviews were of less depth than face-to-face interviews we used to do.

Because the situation of the COVID-19 pandemic was hectic and unique, five researchers started with interviewing respondents. Each interviewer did one interview and thereafter they discussed the used topic list with, to see if it was sufficient and if adjustments were needed. By continuously discussing of the topic list and findings, uniformity was guaranteed.

During the last interviews in this study, no new topics came up in comparison to the earlier interviews. However, since the situation of COVID-19 was so complex, unique in every healthcare setting and kept changing so quickly, we cannot say with certainty that we reached saturation.

Psychosocial and spiritual care for patients and relatives was most at stake and affected all care settings

The situation impacted the care in all domains. This already arose from our quantitative study among HCPs (9), however the in-depth interviews have provided a better understanding of this finding. The impact varied in degree, in all settings and for both COVID-19 and non-COVID-19 patients, from annoying (e.g. wearing masks hindered patients to hear staff very well), to falling short in care (e.g. there was no time to support family, or not getting to know the patient) to degrading or inhumane care (e.g. patients dying without relatives being present).

The fact that COVID-19 was a new unknown disease seems to mostly impacted care in the physical domain. However, the other themes related predominately to the psychosocial and spiritual domain of care. The high workload hindered physical care, but mostly care in the psychosocial and spiritual domain (for both patients and relatives), since there was not enough staff or time and physical care was prioritized. The preventative measures taken, impact all the domains of care in different ways It is notable that a social intervention as visit restrictions, did not only impact the social domain of end-of-life care, but also personalized care in the psychological domain and that the physical distance measure, had an impact on all domains, including spiritual care.

The results of the current study echo the findings of studies from different countries, in which several aspects of end-of-life care during the first months of the COVID-19 pandemic were studied (12-17), Similar to our findings, they too found staff believed that they fell short in different domains of palliative care at the end of life due to the lack of physical contact, wearing of PPE and visiting restrictions. Other studies also showed that HCPs in different settings found it difficult to provide good emotional support to families due to limited family visits and not being able to touch them, in combination with digital communication not being satisfactory (14, 16, 18, 19) .

As in our study, HCPs and bereaved relatives in other studies emphasized the importance of holistic care (in all domains of the palliative approach) and mentioned that there often was a focus on physical care compared to the psychosocial and spiritual domain (12, 20, 21). Bradshaw et al., described how the measures to prevent the spread of the virus hindered HCPs in providing person-centered and holistic care, in accordance to their professional values (22).

COVID-19 provided chances to improve care at the end of life

Our study presents findings about the first months of the COVID-19 pandemic. Since then, there were a lot of changes that could have improved or changed the care in all domains at the end of life during the pandemic. For example, we learned that the lockdown of nursing homes was very harmful for the residents and measures became less restrictive. However, studies about experiences of HCPs after the first year of the pandemic are at date still scarce. We do not know if the problems highlighted in our study or previously mentioned studies persisted after the first months of the pandemic, even with more knowledge on the disease (and the prevention of the disease), less restrictive measures and enough PPE. We have a do know that new problems arose, such as more aggression of visitors, but most importantly, the shortage of healthcare staff (due to for example long-covid and burn-out) which is still very evident. Research about the later phases of the pandemic probably will shed more light on this.

In our study, we found that HCPs thought that the pandemic could have a long-term positive impact on end-of-life care. Despite the challenges mentioned earlier, we believe that the pandemic provides chances to improve care at the end of life. The outbreak showed that good qualified nursing staff is essential for good end-of-life care. This appreciation may lead to awareness for good education in palliative and end-of-life care in all care settings, better working circumstances for nurses, and consequently more nursing staff in the future.

Second, another mentioned potentially positive effect is the increased attention for weighing the pros and cons of medical treatment for frail patients and the increased awareness of the importance of advance care planning and focusing on individual needs and preferences of patients. In the Netherlands, this resulted in the development of a national guidance for advance care planning that was supported by relevant Dutch professional and scientific organizations (23). Bradshaw et al., discussed how HCPs are now more often involved in ACP and more involved in advising and educating about ACP in response to the pandemic (24).

Last, HCPs mentioned that the importance is psychosocial care and the value of participation of relatives in at the end of life has been emphasized. This may provide fertile ground for efforts to improve palliative care, by e.g. promoting consulting palliative care teams or following palliative care vocational training.

Conclusion

The palliative care approach, key for good care at the end of life, was often negatively influenced in the first months of the COVID-19 outbreak, and seriously harmed patients and relatives. This predominantly concerned the emotional, social and spiritual domains of care, and was related to an emphasis on essential physical care and prevention of the spread of COVID-19. Negative effects could be limited when professionals feel room to adapt to rules and measures in individual cases. However, the pandemic and the restrictive measures shed light on the importance of multidimensional care at the end-of-life. These lessons learned can potentially improve care at the end of life in the future.

List of abbreviations

HCP: Healthcare professional

WHO: World Health Organization

PHSM: Public health and social measures

ICU: Intensive care unit

PPE: Personal protective equipment

Declarations

Ethics approval and consent to participate

The Medical Ethics Committee Erasmus MC of Rotterdam, The Netherlands, assessed that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply (MEC-2020-0254). Verbal informed consent was obtained from all participants.

Consent for publication

Not applicable since this manuscript does not contain any details about individuals.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Conflicts of interest

The authors declare that they have no conflicts of interests.

Funding

This work was supported by ZonMw (project number: 844001803).

Authors' contributions

MZ, LB, YB, EW, AH, LL, AG, IK, BOP and RP contributed to the design of the study. Interviews were conducted by MZ, LB, YB, EW and RP. Analysis was done by MZ, LB, RP and BOP and discussed with YB, EW, AH, LL, AG and IK. Quotes were selected by MZ and LB. MZ drafted the manuscript. MZ, LB, YB, EW, AH, LL, AG, IK, BOP and RP provided critical comments on drafts of the manuscripts and approved the final manuscript.

Acknowledgements

We would like to thank all the participants for their time and their stories. We also thank the organizations that helped with the recruitment of participants for the questionnaire.

References

1. WHO. Considerations for implementing and adjusting public health and social measures in the context of COVID-19. 2020.
2. RIVM. Ontwikkeling COVID-19 in grafieken 2021 [Available from: https://www.rivm.nl/coronavirus-covid-19/grafieken.
3. CBS. Bijna 169 duizend mensen overleden in 2020, 10 procent meer dan verwacht. 2021 [Available from: https://www.cbs.nl/nl-nl/nieuws/2021/04/bijna-169-duizend-mensen-overleden-in-2020-10-procent-meer-dan-verwacht.
4. Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. The Lancet. 2020;395(10235):1467-9.
5. Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: beyond ventilators and saving lives. Canadian Medical Association journal. 2020;192(15):400-4.
6. Yardley S, Rolph M. Death and dying during the pandemic. BMJ. 2020;369:1472.
7. Wakam GK, Montgomery JR, Biesterveld BE, Brown CS. Not Dying Alone - Modern Compassionate Care in the Covid-19 Pandemic. The New England journal of medicine. 2020;382(24):e88.
8. WHO. Palliative Care 2020 [Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care.
9. Onwuteaka-Philipsen BD, Pasman HRW, Korfage IJ, Witkamp E, Zee M, van Lent LG, et al. Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study). Palliative Medicine. 2021;35(5):830-42.
10. Boyatzsis RE. Transforming qualitative information: Thematic analysis and code development. Sage, editor. California: Thousand Oaks; 1998.
11. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. Handbook of research methods in health social sciences. 2018:1-18.

12. Mitchinson L, Dowrick A, Buck C, Hoernke K, Martin S, Vanderslott S, et al. Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic. Palliative Medicine. 2021;35(5):852 - 61.

13. Cook DJ, Takaoka A, Hoad N, Swinton M, Clarke FJ, Rudkowski JC, et al. Clinician Perspectives on Caring for Dying Patients During the Pandemic : A Mixed-Methods Study. Annals of internal medicine. 2021;174(4):493-500.

14. Kentish-Barnes N, Morin L, Cohen-Solal Z, Cariou A, Demoule A, Azoulay E. The Lived Experience of ICU Clinicians During the Coronavirus Disease 2019 Outbreak: A Qualitative Study. Critical Care Medicine. 2021;49(6):585-97.

15. Hanna JR, Rapa E, Dalton LJ, Hughes R, Quarmby LM, McGlinchey T, et al. Health and social care professionals' experiences of providing end of life care during the COVID-19 pandemic: A qualitative study. Palliative Medicine. 2021;35(7):1249-57.

16. Mitchell S, Oliver P, Gardiner C, Chapman H, Khan D, Boyd K, et al. Community end-of-life care during the COVID-19 pandemic: findings of a UK primary care survey. BJGP open. 2021;5(4).

17. Dohmen MDW, van den Eijnde C, Thielman CLE, Lindenberg J, Huijg JM, Abma TA. Good Care during COVID-19: A Narrative Approach to Care Home Staff's Experiences of the Pandemic. International Journal of Environmental Research and Public Health. 2022;19(4):2106.

18. Sinding C, Cape S, Charles L, Gosselin C, Kettings M, Taniguchi A, et al. When 'Being There'Is Disallowed: Disruptions to Knowing and Caring During COVID-19 Visitor Restrictions. Journal of Social Work in End-of-Life & Palliative Care. 2022:1-17.

19. Frey R, Balmer D. COVID-19 and hospice community palliative care in New Zealand: A qualitative study. Health & social care in the community. 2022.

20. Hanna JR, Rapa E, Dalton LJ, Hughes R, McGlinchey T, Bennett KM, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. Palliative Medicine. 2021;35(5):843-51.

21. Mayland CR, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. Palliative Medicine. 2021;35(8):1480-91.

22. Bradshaw A, Dunleavy L, Garner I, Preston N, Bajwah S, Cripps R, et al. Experiences of staff providing specialist palliative care during COVID-19: a multiple qualitative case study. Journal of the Royal Society of Medicine. 2022:01410768221077366.

23. Boddaert M, Caffarel J, Dermois M, Kodde A, Reyners AKL. Leidraad voor het proces en uniform vastleggen van proactieve zorgplanning naar aanleiding van de COVID-19-pandemie. 2020.

24. Bradshaw A, Dunleavy L, Walshe C, Preston N, Cripps RL, Hocaoglu M, et al. Understanding and addressing challenges for advance care planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services. Palliat Med. 2021;35(7):1225-37.

532

Additional file 1: Interviewguide

1. Start the interview: introduce yourself, ask if it is a convenient moment for the interview. Ask if the interviewee gives permission to record the interview: if yes, start recording. Explain that anonymity is guaranteed, that personal data is not stored and that everything discussed is handled with confidence. Ask if the interviewee has any questions and agrees.

2. Ask about the interviewee recent experience of end-of-life care.

   Probes:

   - How many patients have you cared for during the last days of their lives?
   - What protective measures are taken in your care setting?
   - What is your experience of those measures?

3. Ask if the interviewee can remember the patient from the questionnaire.

   a. If not, go to 4.

   b. If yes, ask about this patient's story.

      Refer if necessary to answers in the questionnaire, as in: You indicated in the questionnaire that …: can you tell me more about that? What do you mean by that? What did you miss? What would you rather have seen? Etc.

      Pay attention to:

      - Symptoms and symptom management
      - Treatment restrictions
      - Influence of the Corona measures, including visits
      - Place of death
      - How death was characterized in the questionnaire
      - Experiences after the moment of dying

Probes:

- What did this patient's disease trajectory look like?
- What care dilemmas did you experience?
- What did you like in this case and what not?

- What exactly made the care as provided in this case right or wrong?
- What do you know about experiences of other members of the care team?
- How was the situation different from normal as a result of the corona crisis?

Where item 3 has been discussed extensively and concerned a positive experience, 4 can be skipped.

Where item 3 has been discussed extensively and concerned a negative experience, 5 can be skipped.

4. Can you give me an example of a patient for whom you thought end-of-life care went really well. Discuss experience of:
    - Symptoms and symptom management
    - Any treatment restrictions
    - Influence of the Corona measures, including visits
    - Place of death
    - How death was characterized in the questionnaire
    - Experiences after the moment of dying

    Probes:
    - Can you tell me about that situation?
    - Who was this patient (age, gender, setting, condition, covid-infection)?
    - How would you describe the care this patient received in the last phase of life?
    - What exactly makes this case a good case?
    - And how was this for the team? For you?

5. Can you give me an example of a patient for whom you thought end-of-life care really could have been better.

    Discuss experience of:
    - Symptoms and symptom management
    - Any treatment restrictions
    - Influence of the Corona measures, including visits
    - Place of death
    - How death was characterized in the questionnaire

- Experiences after the moment of dying

Probes:

- Can you tell me about that situation?
- Who was this patient (age, gender, setting, condition, covid infection)?
- How would you describe the care this patient received in the last phase of life?
- What exactly makes this case a poor case?
- And how was this for the team? For you?

6. Have these and other recent experiences with end-of-life care affected your views on good end-of-life care?

   Probes:

   - Can you tell me something about that?
   - What about your health, quality of life and emotions as reported in the questionnaire?
   - Safety and protection issues?

7. Have these and other recent experiences with end-of-life care affected your own health and wellbeing?

   Probes:

   - Can you tell me something about that?
   - What about your health, quality of life and emotions as reported in the questionnaire?
   - Safety and protection issues?

8. Conclusion: ask if the interviewee wants to add anything that has not yet been discussed. Thank the interviewee and wish them strength. Indicate that if the interviewee wants to add something, they can always send an e-mail. In case the interview evoked emotions, recommend that the interviewee talks to someone or contacts a colleague or their GP.

Table 2. Themes, subthemes and codes

Theme	**Subtheme**	**Code**
New disease		Clinical view not reliable (-)
		Unexpected deterioration (-)
		Symptom relief was hard (-)
High workload		Not enough time for care (-)
		Lack of HCP's with the right skills (-)
		Higher chance of mistakes (-)
		Poor continuity of care (-)
		No time to support relatives (-)
		Limited in time they could relatives to say goodbye (-)
Contagiousness		Too much focus on prevention of infections (-)
	Limited family visits and goodbye's	Patients were not able to say goodbye to everyone (-)
		HCPs could not get to know the patient (-)
		Good excuse to refuse someone to say goodbye to the patient (+)
		New digital methods for contact (+)
		Limited in giving emotional support to relatives (-)
	Physical distance between HCP's and patients and their relatives	Feeling detached from the patient (-)
		Spiritual counselors were not allowed (-)
		Limited in taking care of deceased patient (-)
		Limited in giving emotional support to relatives (-)
	Feelings of detachment due to personal protective equipment (PPE)	HCP's were unrecognizable, not understandable and scary for patients (-)
		Allowed HCP's to touch patients (+)
		Being more reluctant to visit patients because they had to change in PPE (-)
Positive effects for the long term		More awareness for advance care planning (+)
		More awareness for better staff policy (+)
		Realization the importance of adequate end-of-life care (+)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p. 1/ l. 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p. 2-3 / l. 27-57

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p. 3-5 / l. 57 - 105
Purpose or research question - Purpose of the study and specific objectives or questions	p.5 / l. 101 - 105

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	p. 5 / l. 108 p. 7 / l. 137 - 139
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p. 7 / l. 147 - 149
Context - Setting/site and salient contextual factors; rationale**	p. 5 / l. 120 - 122
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	p.5 / l. 113 - 119
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p. 7 / l. 152 - 157
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	p. 6 / l. 131 - 135

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p. 6 / l. 131 - 135
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	P. 5-6 / l. 119 - 126
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	p. 7 / l. 137 - 149 p. 7 / l.152 - 157
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	p. 7 / l. 137 - 149
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	p. 7 / l. 137 - 149 p.20 / l. 342 - 346

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p. 8- 18 / l. 158 – 310
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p. 9 / l. 175 p. 12 / l. 224 p. 16 / l. 296 p. 18 / l. 311

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p.19-23/ l. 313 - 435
Limitations - Trustworthiness and limitations of findings	p.19-20 / l. 332 - 351

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p.24/ l. 454
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p. 25/l. 456

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

The impact of COVID-19 on care at the end of life during the first months of the pandemic from the perspective of healthcare professionals from different settings; a qualitative interview study (the CO-LIVE study)

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-063267.R2
Article Type:	Original research
Date Submitted by the Author:	14-Feb-2023
Complete List of Authors:	Zee, Masha; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Bagchus, Lotje; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Becqué, Yvonne ; Rotterdam University of Applied Sciences, Research Center Innovations in Care Witkamp, Erica; Rotterdam University of Applied Sciences, Research Center Innovations in Care; Erasmus MC University Medical Center, Department of Public Health van der Heide, Agnes; Erasmus MC University Medical Center, Department of Public Health van Lent, Liza; Erasmus MC Cancer Institute, Medical Oncology Goossensen, Anne; University of Humanistic Studies Korfage, Ida; Erasmus MC, University Medical Center Rotterdam, Public Health Onwuteaka-Philipsen, Bregje; Amsterdam UMC Locatie VUmc, Department of Public and Occupational Health Pasman, H. Roeline; Amsterdam UMC Locatie VUmc, Public and Occupational Health
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Public health, Qualitative research
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH, PUBLIC HEALTH

The impact of COVID-19 on care at the end of life during the first months of the pandemic from the perspective of healthcare professionals from different settings; a qualitative interview study (the CO-LIVE study).

Authors

Masha S. Zee[1], Lotje Bagchus[1], Yvonne N Becqué[2], F. Erica Witkamp[2,3], Agnes van der Heide[3] Liza G.G. van Lent[4], Anne Goossensen[5], Ida J. Korfage[3], Bregje D. Onwuteaka-Philipsen[1], H. Roeline W. Pasman[1]

Affiliations

1. Department of public and occupational health, Expertise Center for Palliative Care, Amsterdam UMC, VU University, Amsterdam, the Netherlands
2. Research Center Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, the Netherlands
3. Department of Public Health, Erasmus MC University Medical Center, Rotterdam, the Netherlands
4. Department of Medical Oncology, Erasmus MC Cancer Institute, Rotterdam, the Netherlands
5. University of Humanistic Studies, Utrecht, The Netherlands

Correspondence:

Masha Zee, Department of Public and Occupational Health, Amsterdam UMC, van der Boechorststraat 7,1081 BT Amsterdam, the Netherlands; m.zee@amsterdamumc.nl

Word count: 3855

Number of tables / boxes: 1 table / 3 boxes

Abstract:

Objectives: The objective of this study is to better understand how the COVID-19 outbreak impacted the different domains of the palliative care approach to end-of-life care from the perspective of healthcare professionals (HCPs) from different professions, working in different settings during the first months of the COVID-19 outbreak in the Netherlands.

Methods: An in-depth qualitative interview study among 16 HCPs of patients who died between March and July 2020 in different healthcare settings in the Netherlands. The HCPs were recruited through an online survey about end-of-life care. Maximum variation sampling was used. Data were analysed following the principles of thematic analysis.

Results: Several aspects impacted the quality of the palliative care approach to care at the end of life. First, COVID-19 was a new disease and this led to challenges in the physical domain of end-of-life care e.g. a lack of knowledge on how to manage symptoms and an unreliable clinical view. Second, the high workload HCPs experienced impacted the quality of end-of-life care, especially in the emotional, social and spiritual domains, since they only had time for urgent, physical care. Third, COVID-19 is a contagious disease and measures taken to prevent the spread of the virus hampered care for both patients and relatives. For example, because of the visiting restrictions, HCPs were not able to provide emotional support to relatives. Lastly, the COVID-19 outbreak also had a potentially positive impact in the longer term, e.g. more awareness of advance care planning and the importance of end-of-life care that includes all the domains.

Conclusion: The palliative care approach, which is key to good end-of-life care, was often negatively influenced by the COVID-19 pandemic, predominantly in the emotional, social and spiritual domains. This was related to a focus on essential physical care and prevention of the spread of COVID-19.

Keywords: COVID-19, Palliative Care, End-of-life Care, Quality of Care, Qualitative Research

Strengths and limitations:

- This study describes a broad range of perspectives since it includes healthcare professionals from all care settings and different professions who cared for COVID-19 patients and non-COVID-19 patients.
- Respondents were eager to share their experiences despite the fact that the interviews were held via (video) calls.
- Despite the fact that five researchers interviewed respondents, uniformity was guaranteed by continuously discussing the topic list and findings.
- We cannot say with certainty that data saturation was reached, since the COVID-19 situation was so complex and kept changing so quickly.

Introduction

The COVID-19 pandemic confronted the world with an unknown disease, which had an impact on care in all healthcare settings. To limit transmission and reduce mortality and morbidity from COVID-19, the World Health Organization (WHO) published guidelines on what public health and social measures should be taken (PHSM) (1). These measures included personal protective measures, such as wearing masks, and physical distancing measures, such as maintaining distance in public spaces or workplaces. As other countries, the Netherlands was also confronted with high numbers of patients with COVID-19 and excess mortality due to COVID-19, and most of the above-mentioned measures were implemented (2, 3).

The situation surrounding COVID-19 affected care at the end of life for both patients and their relatives during the first months of the pandemic (4). Measures such as visiting restrictions and keeping a physical distance changed human contact inherently and influenced the way end-of-life care was provided (5-7). Furthermore, because of the high number of patients with COVID-19, there may have been less time for emotional and spiritual support for patients and their relatives during a period where this support was very much needed (4-6).

Good-quality end-of-life care requires a palliative care approach that focusses on the quality of life of patients and their families. It aims to provide person-centred care that not only considers the patient’s medical condition, but also takes a more holistic approach, looking at the psychological, social and spiritual domains of care as well (8). Special attention is paid to specific needs and preferences in these domains and support is provided not only to patients, but also to their relatives; this includes bereavement counselling (8).

It is likely that these domains of the palliative care approach were endangered during the COVID-19 pandemic. The aim of this study is to better understand how the COVID-19 outbreak impacted the different domains of the palliative care approach to end-of-life care from the perspective of healthcare professionals (HCPs) working in different healthcare settings during the first months of the COVID-19 outbreak in the Netherlands.

Methods

Design, Setting and Participants

An in-depth qualitative interview study was conducted among HCPs caring for patients who died between March and July 2020 in different healthcare settings in the Netherland as part of the CO-LIVE study. CO-LIVE is a mixed-methods study of the experiences of both bereaved relatives and HCPs during the COVID-19 pandemic. Participants were recruited through an online survey on the last days of life of patients who died during the first wave of the COVID-19 outbreak. This survey was distributed via relevant healthcare professional organizations, palliative care networks and organizations, volunteer organizations and personal contacts throughout the Netherlands (9). Maximum variation sampling was used in the group of participants who were interested in taking part in an interview. Variation was sought in setting, profession and how HCPs qualified the death of the patient about whom they filled in the survey (both positive and negative qualifications). Potential respondents were approached via e-mail. Since nursing assistants working in nursing homes were underrepresented in the survey, two were recruited via our own network. Eventually, sixteen HCPs were interviewed: nine nurses, two nursing assistants, one coordinator in a hospice and four physicians. Four participants worked in a special COVID unit in a hospital, two in an intensive care unit (ICU), five in a nursing home, three in a hospice and two in home/community care (Table 1). Some participants had cared for COVID patients only, while others had also cared for non-COVID-patients. We followed the standards for reporting qualitative research (SRQR).

Table 1. Characteristics of the participants

	Profession	**Setting**	**Sex**	**Age Range**
1	Nursing assistant	Nursing home	Female	<40
2	Nursing assistant	Nursing home	Female	40-60
3	Nurse	ICU	Female	<40
4	Nurse	Hospice	Female	40-60
5	Nurse	Hospital (COVID ward)	Female	40-60
6	Nurse	Home	Female	40-60
7	Nurse	Hospice	Female	<40
8	Nurse	Home	Female	40-60
9	Nurse	Hospital (COVID ward)	Female	<40
10	Nurse	Hospital (COVID ward)	Female	<40
11	Nurse	ICU	Female	<40
12	General Practitioner	Home/hospice	Male	>60
13	Pulmonologist	Hospital (COVID ward)	Female	40-60
14	Geriatrician	Nursing home	Female	>60
15	Geriatrician	Nursing home	Male	>60
16	Coordinator	Hospice	Female	40-60

Patient and Public Involvement

Patients and the public were not involved in the design and execution of this study.

Data Collection

Five researchers conducted the interviews (MZ: 2, LB: 8, YB: 4, EW: 1 and RP: 1). Because of COVID measures, all interviews were held using (video)calls. The interviewers used a topic list that included questions about the responses as given in the survey and questions about new experiences (Additional File 1). The interviews were conducted in Dutch, lasted between 25 and 70 minutes and were audio-recorded.

Data Analysis

The interviews were transcribed verbatim and analysed using the qualitative data analysis software MAXQDA. We followed the principles of thematic analysis based on a phenomenological approach, focussing on the lived experiences of the respondents (10, 11). First LB and RP went through the transcripts and made summaries, which were discussed with all interviewers and another member of the research group (BOP). After becoming familiar with the data by reading the transcripts, MZ coded the data. The analyses were discussed with all members of the research group and on multiple occasions with the different interviewers. Thereafter, MZ, LB, BOP and RP sorted the codes into groups to develop overarching themes (Additional File 2). During the process of sorting the codes into themes, MZ, LB, BOP and RP continuously compared and discussed their decisions. Finally, appropriate quotes were selected by MZ and LB and translated by a professional translator and checked by a second professional translator. The research group consisted of researchers with different backgrounds (health sciences, medical anthropology, nursing, sociology, psychology and medicine).

Ethical Considerations

Before the interview, participants gave verbal informed consent to participate in the interview and to have this interview recorded. After transcription, audio recordings were deleted and all data were anonymized to make sure the participants and their patients were unidentifiable. Personal information and transcripts were saved in separate folders that could only be accessed by the researchers. The Erasmus MC Medical Ethics Committee of Rotterdam, the Netherlands, assessed that the rules laid down in the Medical Research Involving Human Subjects Act did not apply (MEC-2020-0254).

Results

The COVID-19 outbreak led to an impactful and unique situation for healthcare, and HCPs stated that it affected care at the end of life. This was the case for HCPs of all disciplines and for all care settings, albeit sometimes in different ways.

Several themes were identified in the interviews that were characteristic for this impactful and exceptional situation and affected the quality of end-of-life care, mostly negatively, during the first months of the COVID-19 pandemic. These themes were: COVID-19 as a new disease, the disease leading to a higher workload for HCPs, the disease being contagious and the long-term positive impact of the COVID-19 pandemic on end-of-life care.

New Disease – Lack of Knowledge about How to Manage Symptoms

In the first months of the COVID-19 outbreak, little was known about the course of the disease, the prognosis, treatment and symptom relief. This led to difficulties in the physical domain of end-of-life care. HCPs said that their ‘clinical view’ was not reliable anymore because the disease course for COVID-19 patients was unpredictable (box 1, quote 1). In some cases, the patient unexpectedly deteriorated very quickly, making it difficult to take anticipatory action, for instance to inform family members in good time*.* Furthermore, HCPs said it was hard to relieve symptoms for some dying patients because existing treatments for similar symptoms in other diseases had little or no effect for COVID-19 patients (box 1, quote 2).

High Workload – Lack of Time and Staff for Good End-of-life Care

The COVID-19 outbreak led to a great influx of patients with COVID-19 on top of the regular patients, resulting in a high workload for HCPs, especially on the ICU and COVID wards in hospitals. Besides, HCPs in nursing homes also had a higher workload since they had to isolate residents with COVID-19 from residents without COVID-19. This created more wards than usual, which then had to be staffed using the same number of HCPs. Furthermore, because of a lack of knowledge on how to prevent COVID-19 infections, many HCPs mentioned how (especially in the first months of the pandemic) measures and rules about visits or protective equipment were unclear or kept changing. Being updated on the rules took a lot of time, creating a higher workload. These aspects were mentioned by HCPs in all settings, including HCPs who had not cared for COVID-19 patients.

The great influx of patients adversely affected the quality of end-of-life care. HCPs mentioned degrading situations for patients on crowded wards with little privacy, and work that felt like a production line (box 1, quote 3). Some HCPs mentioned that they only had time for the essential, physical care, but not enough time for care in the emotional, social and spiritual domains (box 1, quote 4). However, HCPs (especially in ICUs) also mentioned some difficulties in the physical domain. They said that, because of a lack of staff, HCPs from other disciplines or wards helped them. However, not all of these new colleagues had the right skills or experience and this sometimes negatively impacted the quality of physical care (box 1, quote 5). Furthermore, HCPs mentioned that medication safety was an issue because of the time pressure.

Because of the shortage of skilled staff, HCPs' schedules were sometimes unclear or were constantly changing. Therefore, HCPs saw a lot of different patients and did not see particular individual patients as frequently as usual. A respondent mentioned that this led to poor continuity of care because individual HCPs were not as involved with their patients and as well-informed about them as usual, which made it difficult to be aware of personal needs and preferences (box 1, quote 6).

Due to the staff shortage and higher workload, there was also less time for another important part of the palliative care approach: supporting relatives. HCPs said that they could not spend as much time on supporting the relatives as they were used to and that this was unsatisfying for them (box 1, quote 7). In some cases, HCPs in the ICU were limited in the time they could give relatives to say goodbye to their loved ones (box 1, quote 8).

223

BOX 1: Quotes - New disease & high workload

1	“No, you have this feeling that you’re less in control of the situation. [...] And I think no one had that feeling that they knew what was coming in the case of COVID. [...] In the terminal phase too, I felt it was like hey, suddenly it all changed... and they were dead, or hey, suddenly they were stable, or hey, everything suddenly fell apart. Normally you would be dropping in on them regularly and you’d see things happening, you know, and you adjust accordingly. But for me this wasn’t like that... it was more difficult.” **(4: Nurse, hospice)**
2	“But when you saw him, he really wasn’t comfortable. Laboured breathing, high respiratory rate, increasing heart rate. You could see the panic in his eyes but there came a point when we couldn’t communicate with him anymore. He was kind of asleep, as it were, but you could see that he was still physically really hard at work. If he’d been a non-COVID patient I would have said he’s not comfortable so we need to do something with the medication. And so that’s what we did. Only it didn’t work well enough for this man. And that remained the case up to the end. I found that difficult.”**(10: Nurse, hospital COVID ward)**
3	“In that respect, I didn’t think there was much privacy, so... of course, there were really strict visiting rules so I felt patients got a bit abandoned. And with the IC cohort, that was completely [...], right, that was basically 18 people lying in a single room, all on their stomachs, all kind of like interchangeable. So when we had our shift, we’d start by turning the first one back over, and then go through the whole lot one by one, as it were. It was almost like a production line. With no curtains in between, they’d all been removed, so I found it incredibly degrading.” **(9: Nurse, hospital COVID ward)**
4	“We provided the necessary care. In the end, we were never really satisfied with what we did and how we did it. We were never really satisfied, because we simply couldn’t give assistance in social and emotional aspects and I find that very important. So it was just a case of giving people the essential care, trying to keep them stable.” **(9: Nurse, hospital COVID ward)**
5	“What you also realize afterwards is that, because it wasn’t just IC nurses but other people too, they didn’t have all the necessary knowledge. So now I’m increasingly hearing that people have ended up with eye problems because they didn’t get the drops every so often, and the eyes became dehydrated. Then I think to myself: oh, there are some things we made a right mess of.” **(9: Nurse, hospital COVID ward)**
6	“Normally, we’re used to providing as much continuity as possible. So if you switch from a morning shift to an evening shift, you try to have the same patient who you had in your morning shift in the evening shift too. Now I might not be on my own ward, as it were, for three weeks because I’d be working all over the place, then I’d come back and oh, that patient’s been there a long time. Well, you don’t know what that means because you didn’t get any of the news about the patient.” **(3: Nurse, ICU)**
7	“We also had more patients to care for than we would normally, so we had less time available to spend on the family. In the normal situation, if we know a patient is going to die, we always try to make sure there’s one nurse who can focus entirely on that and give the family their full assistance and go through that whole process properly. But that wasn’t possible during the COVID period. That did make it rather unsatisfying for everyone, yes.” **(3: Nurse, ICU)**
8	“Yes, then we would just phone the family at home and that was often for medical reasons. A conversation with the family and, yes, the tricky thing... we would agree with them who else needs to come. How do we want the final goodbye... what’s the procedure? But at the same time we didn’t want it to take days because you needed the beds. So it was really 24 hours max. And then it was indeed a question of stopping, removing the ventilation and then it was often less than quarter of an hour and the patient was dead. So that often happened very quickly. And then the patient would be removed, room cleaned, new patient put in. Yes, that was really weird.” **(9: Nurse, hospital COVID ward)**

Contagiousness – Preventative Measures Hampered Good End-of-life Care

In healthcare settings, various measures were taken to prevent the spread of COVID-19, such as visiting restrictions, keeping physical distance and wearing personal protective equipment (PPE). There was little difference between COVID-19 and non-COVID-19 patients regarding the impact of these measures on care, since most measures applied to everyone. HCPs stated that caregiving at the end of life was hampered due to the priorities that government and the healthcare service had when dealing with COVID-19. They said that preventing the spread of the virus seemed more important than the quality of end-of-life care and that this impacted, in particular, on the emotional and spiritual aspects of care (box 2, quote 1).

Limited family visits and goodbyes

All HCPs said that restrictions were placed on family visits and goodbyes to a greater or lesser extent, which impacted end-of-life care for both patients and their relatives. There were restrictions on the number of people who were allowed to visit patients, the number of visits per day, and the amount of time relatives were allowed for visiting a patient. Visiting restrictions varied between settings; HCPs in hospitals and, especially, nursing homes mentioned that these restrictions were very strict and that it was difficult to deviate from them. In home care, patients or HCPs could decide themselves on what to do about visits (restrictions).

According to the HCPs, the restrictions on family visits and goodbyes impacted the patients greatly, mostly in the psychological and social domains. Some participants mentioned that dying patients could not see everyone they wanted to see and that some patients were completely alone in the last days of their life (box 2, quote 2). One nurse described a case where a patient did not want to die in a hospital setting because of the visiting restrictions. However, the sudden transfer to her home led to a chaotic last few days of life. Furthermore, the visiting restrictions affected the extent to which HCPs could get to know their patients and therefore impacted end-of-life care. If unconscious or very ill patients were not able to talk, care became less personal because no family was around to share the patients' preferences and wishes (box 2, quote 3). However, a nurse working in home care said that the restrictions were used as a good excuse when patients did not want a specific person to visit them and say goodbye (box 2, quote 4). In some cases, there were new digital ways for patients to contact their relatives (e.g. video calls) and HCPs were mostly positive about the usage of these resources, although they were not a perfect substitute for the physical family visits.

When providing good end-of-life care in all domains of palliative care, the contact and connection between HCPs and patients and their relatives is really important. Because of visiting restrictions, HCPs did not see relatives as much, making it difficult for HCPs to provide emotional support to families (box 2, quote 5). Even if the distance could be bridged using digital communication, HCPs felt they could not support the relatives sufficiently from a distance (box 2, quote 6).

Physical distance between HCPs and patients and their relatives

Physical distance hampered the care and connection in all settings for patients with and without COVID-19. Some HCPs felt detached from the patient, mostly because they could not touch the patient apart from when they performed medical procedures. They explained that touching patients is an important aspect of emotional support, which is part of the psychological domain of care (box 2, quote 7). In some cases, spiritual counsellors were not allowed to be physically present with patients anymore and this impacted the spiritual domain of end-of-life care (box 2, quote 8). Furthermore, when a patient had died, HCPs mentioned that they were not allowed to take care of the deceased patient to prepare them for when relatives came to say goodbye (box 2, quote 9). Finally, the physical distance also made it more difficult for HCPs to provide emotional support to relatives, because they could not get near to the relatives or touch them to console them (box 2, quote 10).

Feelings of detachment due to personal protective equipment

Another measure that created distance between HCPs and patients and their relatives was the PPE HCPs needed to wear under certain circumstances. An HCP described how they felt it was degrading for patients to have care provided by someone who was unrecognizable due to wearing PPE (box 2, quote 11). Furthermore, some HCPs said that it was scary for patients with dementia or psychological problems to be cared for by staff wearing PPE and this therefore hindered care in the psychological domain (box 2, quote 12). However, HCPs also said that they were happy to be wearing PPE because it allowed them to touch their patients and to come closer. Some HCPs had experienced a shortage of PPE or had to economize on PPE to prevent a shortage and this made HCPs more reluctant to come close to patients, because that would cost extra PPE, which hindered care in all domains (box 2, quote 13). On wards for only COVID patients, it was not necessary to change the PPE all the time, which was seen as an advantage of working in such wards.

	BOX 2: Quotes - Contagiousness
1	“But suddenly we ended up in a situation in which we were only talking about the risk of infection, about infection rates, well, just the medical side. And everything that makes someone a human being was no longer being discussed. I found that very confusing. I even got really angry about this at one point and said how crazy this was, how we were now going completely against everything we’d learned over the past decades about what’s important for people with dementia who lose their bearings. Apparently that was no longer important. All that mattered was that we didn’t want people to get infected. That was weird. [...] I found that very difficult to cope with in the past little while, and I still do.” **(6: Nurse, home)**

2.1.: Limited family visits and goodbyes	
2	“In principle two people were allowed to come, and then indeed for just half an hour or maybe three quarters of an hour, but only a very brief period. Often, either the patient died during that visit, or just afterwards or they came too late. [...] I mainly found it very sad, distressing, a failing where you can’t offer what’s best, because you can’t replace the person who isn’t there, or maybe you aren’t in a position to be there because you don’t belong there. But at the same time it feels like a failing with regard to them, and how do you assist them in that? [...] But then when you’re driving home later, you always have that feeling that you should be doing things differently, or you’re not getting a sense of satisfaction. That’s what I call failings.” **(11: Nurse, ICU)**
3	“But what I certainly also remember is the fact that visitors weren’t allowed. That makes the care for the patient a lot more impersonal. IC patients in general spend a lot of the time asleep, but that was especially so with the COVID patients — they were all so sick and heavily sedated, you didn’t have any contact with them at all. And if you don’t have any contact with the family either to get to know the person behind the patient, well, it becomes a very abstract exercise.” **(3: Nurse, Hospital ICU).**
4	“The circle around someone simply becomes smaller; she has... And it’s quite natural that only the really intimate circle are still allowed to visit. But well, at a certain point we did rather use this fact [the visiting restrictions], yes. To protect that lady, to help her and keep people away from her. Yes, that was quite funny.” **(6: Nurse, home)**
5	“Patients are mostly on our ward for a while, so you’ve had contact with the family. So when the patient eventually dies, you’re able to assist their family really well with that process because you’ve already had quite a lot of contact. But now it became so that when a patient died, you were then seeing the family for the very first time. So there was no bond.” **(3: Nurse, ICU)**
6	“Yes, basically you try... The tricky thing is, normally you have the family around the bed and you can point things out, explain that this is how you see the situation. You can get a feel for the atmosphere and how people respond to him or what the care is like. But now all you had was a Skype or phone call, so you try to get as much information across as possible, or things you want to say, but I think it’s much more difficult to explain things with just words.” **(11: Nurse, ICU)**

2.2.: Physical distance between healthcare professionals and patients and their relatives	
7	“I notice that I also find it very tricky myself because... well, being the kind of person I am, I believe that closeness, literally touching someone, has real value in healthcare. That was all different. So yes, it definitely affected the healthcare.” **(12: General practitioner)**
8	“Yes. “We have pastoral staff who normally visit our ward a lot, so if there’s a patient who isn’t doing well or has been there a long time, then they basically have a chat with the family, completely without any obligations, just so that they’ve spoken with them. So when it comes to the point where someone dies, they’ve already talked to the family and you already have that contact... and that wasn’t the case now either.” **(3: Nurse, ICU)**
9	“It was really tough, because you weren’t allowed to lay out the client; you had to put them in that body bag. Then they had to be removed from the nursing home within half an hour. You didn’t even have the chance to warn the family or anything like that if you’d have wanted to.” **(2: Nursing assistant, nursing home)**
10	“I felt particularly sorry for the family because – unlike the patient – they were of course perfectly capable of communicating, and they were distressed. I really felt I should be sitting next to these people, in physical contact. But that was not allowed. That’s a dilemma.” **(10: Nurse, hospital COVID ward)**

2.3.: Feelings of detachment due to personal protective equipment	
11	"with a face mask on, so you're unrecognizable — who's that standing next to my bed? Well, that. And I find that degrading in the sense that you're turning that person into an object; they've become an object. It's not a person lying there anymore, it's an object." **(15: Geriatrician, nursing home)**
12	R: "And how did she react to, well, all that gear you all wore?" I: "Afraid. She hated it. We did too. We'd stand crying into our safety goggles next to her bed because we... That's simply... You want to care for her and make her less anxious but you can't because you've got that protective suit on. Which you yourself hate and which she hates." **(7: Nurse, hospice)**
13	"Um, well, yes. Of course, you're less likely to just pop in on a patient; you need to put on the complete protective suit so there really needs to be something you have to do. Because it uses up personal protective equipment every time." **(14: Geriatrician, nursing home)**

Positive Impact of the Exceptional Situation in the Long Term

Besides direct, mostly negative impacts, respondents also mentioned that the situation potentially had a positive impact on future end-of-life care. Due to the danger of a shortage of beds, there was more awareness of the importance of talking about potentially futile treatments with patients and of advance care planning (ACP) (box 3, quote 1 and quote 2). Furthermore, there was more awareness of the persistent shortage of healthcare staff, and discussions were started about a better staffing policy for the future. This is important because a palliative approach to good end-of-life care in all domains requires staff to devote the necessary time and attention. Lastly, HCPs said that the pandemic had reminded them of how important appropriate and individualized care is at the end of life, and that this care entails much more than physical care only (box 3, quote 3 and quote 4).

	BOX 3: Quotes – Long-term positive impact
1	"I guess it's easier for me to talk to people about it [their own death and wishes]. […] All you have to do is to turn on the television or open a newspaper and they're going on about COVID, about dying, ending up in intensive care, not wanting further treatment. So it's almost a no-brainer to start that conversation and ask them what they personally would want. How do they see it? Have they discussed it at all with each other? In that regard, this period has made the difficult conversations easier." **(8: Nurse, home)**
2	"Yes, I think we should anyway... this [the COVID-19 pandemic] has emphasized that it's something we all need to consider a bit more. Not just what people want in terms of treatment, but also what they have a right to. I think we do that pretty well here in the Netherlands. I mean, we need to consider whether it's realistic to send such-and-such person to the hospital, and certainly to an ICU — how will that affect them? What about afterwards? And is it realistic to spend so much money, energy and time on it, resources that were now scarce? So it was more things I was already thinking about, where I thought: okay, this makes it all a bit more urgent, it means we all need to give a bit more consideration to the issue." **(16: Coordinator, Hospice)**
3	"I've become much more aware of the fact that you have to tailor the care. So even though there are guidelines for palliative care, you really need to see what's right for each individual patient." **(10: Nurse, hospital COVID ward)**

4	“I’ve become even more aware of how important it is for people to be able to touch one another. Without wanting to get all mystical, I increasingly realize that there are certain things you can’t get across using words alone. Because some people are in such a panic that they don’t hear the words at all. You can tell them the same thing ten times, but if their mother is in that bed dying... It really doesn’t matter what someone else is saying at that point. But it does matter what they do. And you remember that.” **(6: Nurse, hospice)**

Discussion

This interview study, held in the first months of the COVID-19 pandemic, shows that care at the end of life was seriously hampered by the exceptional situation, which led to a combination of challenges in all domains of end-of-life care: uncertainty about how to best treat patients with this unknown disease, a high workload for HCPs, and strict preventive measures to prevent the spread of this contagious disease. However, the situation also potentially had a positive long-term impact on care, as it raised awareness of the importance of talking about ACP and potentially futile treatments, and of the importance of good care at the end of life within all the domains.

Strength and limitations

A strength of this study is the inclusion of HCPs from all care settings, with different professions who cared for COVID-19 patients and non-COVID-19 patients. This means we can show that the situation affected all HCPs and we can provide a broad range of perspectives. Because of the COVID-19 measures, we held all interviews via video calls. This could have made it more difficult to build apport with respondents and thereby have led to less in-depth information from the interviews. However, we found that respondents were eager to talk about their experiences and we do not feel that these interviews were less in-depth than the face-to-face interviews we were used to conducting.

Because the situation with the COVID-19 pandemic was hectic and unique, we started with five researchers interviewing respondents. Each interviewer did one interview, after which they discussed the topic list together to see if it was sufficient and if adjustments were needed. By continuously discussing the topic list and findings, they were able to guarantee uniformity.

No new topics came up during the last interviews in this study when compared to the earlier interviews. However, since the COVID-19 situation was so complex and unique in every healthcare setting and kept changing so quickly, we cannot say with certainty that we reached saturation.

Psychosocial and spiritual care for patients and relatives were the domains most severely affected in all care settings

The situation impacted the care in all domains. This was already shown by our quantitative study among HCPs (9); however, the in-depth interviews have provided a better understanding of this finding. In all settings and for both COVID-19 and non-COVID-19 patients, the impact varied in degree from an annoyance (e.g. wearing masks meant patients could not hear staff very well) to care that fell short (e.g. there was no time to support the family or to get to know the patient) to care that was degrading or inhumane (e.g. patients dying without relatives being present).

The fact that COVID-19 was a new, unknown disease seems to have mostly impacted care in the physical domain. However, the other themes related predominately to the psychosocial and spiritual domains of care. The high workload hindered physical care, but had an even greater effect on care in the psychosocial and spiritual domains (for both patients and relatives), since there was not enough staff or time and physical care was prioritized. The preventative measures taken impacted all the domains of care in different ways. It is notable that a social intervention such as visiting restrictions not only affected the social domain of end-of-life care, but also personalized care in the psychological domain. Similarly, the physical distancing measure had an impact on all domains, including spiritual care.

The results of the current study echo the findings of studies from different countries, in which several aspects of end-of-life care during the first months of the COVID-19 pandemic were studied (12-17), Similar to our findings, they too found staff believed that they fell short in different domains of palliative care at the end of life due to the lack of physical contact, having to wear PPE and visiting restrictions. Other studies also showed that HCPs in different settings found it difficult to provide good emotional support to families due to limited family visits and not being able to touch them, in combination with digital communication not being satisfactory (14, 16, 18, 19) .

As in our study, HCPs and bereaved relatives in other studies emphasized the importance of holistic care (in all domains of the palliative approach) and mentioned that there was often a focus on physical care rather than the psychosocial and spiritual domains (12, 20, 21). Bradshaw et al., described how the measures to prevent the spread of the virus hindered HCPs in providing person-centred and holistic care in accordance with their professional values (22).

COVID-19 provided chances to improve care at the end of life

Our study presents findings about the first months of the COVID-19 pandemic. Since then, there were a lot of changes that could have improved or changed the care in all domains at the end of life during the pandemic. For example, we learned that the lockdown of nursing homes was very harmful for the residents, and as a consequence measures became less restrictive. However, studies of the experiences of HCPs after the first year of the pandemic are still scarce at present. We do not know if the problems highlighted in our study or the studies mentioned above persisted after the first months of the pandemic, despite the greater knowledge about the disease (and the prevention of the disease), the less restrictive measures and the end to PPE shortages. We do know that new problems arose, such as more aggression among visitors, but most importantly, a shortage of healthcare staff (due for example to long COVID and burn-out), which is still very much a problem. Research on the later phases of the pandemic will probably shed more light on this.

In our study, we found that HCPs thought that the pandemic could have a long-term positive impact on end-of-life care. Despite the challenges mentioned earlier, we believe that the pandemic provides chances to improve care at the end of life. The outbreak showed that well-qualified nursing staff are essential for good end-of-life care. This appreciation may lead to an awareness of the need for good education in palliative and end-of-life care in all care settings, better working conditions for nurses, and consequently more nursing staff in the future.

Another potentially positive effect that was mentioned is the increased attention paid to weighing the pros and cons of medical treatment for frail patients and the increased awareness of the importance of advance care planning and focussing on patients' individual needs and preferences. In the Netherlands, this resulted in the development of national guidance for advance care planning that was supported by the relevant Dutch professional and scientific organizations (23). Bradshaw et al. discussed how HCPs are now involved more often in ACP and are more involved in advising others about ACP in response to the pandemic (24).

Lastly, HCPs stressed the importance of psychosocial care and the value of involving relatives at the end of life. This may provide fertile ground for efforts to improve palliative care, by e.g. promoting consulting palliative care teams or giving HCPs palliative care vocational training.

Conclusion

The palliative care approach, which is key for good care at the end of life, was often negatively affected in the first months of the COVID-19 outbreak, and this had a serious adverse impact on patients and relatives. The emotional, social and spiritual domains of care were predominantly affected, which was related to an emphasis on essential physical care and prevention of the spread of COVID-19. Negative effects could be limited when professionals felt they had room to adapt the rules and measures in individual cases. On the positive side, the pandemic and the restrictive measures shed light on the importance of good end-of-life care in all domains of the palliative care approach. of multidimensional care at the end-of-life. These lessons can potentially improve care at the end of life in the future.

List of abbreviations

HCP: Healthcare professional

WHO: World Health Organization

PHSM: Public health and social measures

ICU: Intensive care unit

PPE: Personal protective equipment

Declarations

Ethics approval and consent to participate

The Medical Ethics Committee Erasmus MC of Rotterdam, the Netherlands, assessed that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply (MEC-2020-0254). Verbal informed consent was obtained from all participants.

Consent for publication

Not applicable since this manuscript does not contain any details about individuals.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Conflicts of interest

The authors declare that they have no conflicts of interests.

Funding

This work was supported by ZonMw (project number: 844001803).

Authors' contributions

MZ, LB, YB, EW, AH, LL, AG, IK, BOP and RP contributed to the design of the study. Interviews were conducted by MZ, LB, YB, EW and RP. Analysis was done by MZ, LB, RP and BOP and discussed with YB, EW, AH, LL, AG and IK. Quotes were selected by MZ and LB. MZ drafted the manuscript. MZ, LB, YB, EW, AH, LL, AG, IK, BOP and RP provided critical comments on drafts of the manuscripts and approved the final manuscript.

Acknowledgements

We would like to thank all the participants for their time and their stories. We also thank the organizations that helped with the recruitment of participants for the questionnaire.

References

1. WHO. Considerations for implementing and adjusting public health and social measures in the context of COVID-19. 2020.
2. RIVM. Ontwikkeling COVID-19 in grafieken 2021 [Available from: https://www.rivm.nl/coronavirus-covid-19/grafieken.
3. CBS. Bijna 169 duizend mensen overleden in 2020, 10 procent meer dan verwacht. 2021 [Available from: https://www.cbs.nl/nl-nl/nieuws/2021/04/bijna-169-duizend-mensen-overleden-in-2020-10-procent-meer-dan-verwacht.
4. Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. The Lancet. 2020;395(10235):1467-9.
5. Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: beyond ventilators and saving lives. Canadian Medical Association journal. 2020;192(15):400-4.
6. Yardley S, Rolph M. Death and dying during the pandemic. BMJ. 2020;369:1472.

7. Wakam GK, Montgomery JR, Biesterveld BE, Brown CS. Not Dying Alone - Modern Compassionate Care in the Covid-19 Pandemic. The New England journal of medicine. 2020;382(24):e88.

8. WHO. Palliative Care 2020 [Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care.

9. Onwuteaka-Philipsen BD, Pasman HRW, Korfage IJ, Witkamp E, Zee M, van Lent LG, et al. Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study). Palliative Medicine. 2021;35(5):830-42.

10. Boyatzsis RE. Transforming qualitative information: Thematic analysis and code development. Sage, editor. California: Thousand Oaks; 1998.

11. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. Handbook of research methods in health social sciences. 2018:1-18.

12. Mitchinson L, Dowrick A, Buck C, Hoernke K, Martin S, Vanderslott S, et al. Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic. Palliative Medicine. 2021;35(5):852 - 61.

13. Cook DJ, Takaoka A, Hoad N, Swinton M, Clarke FJ, Rudkowski JC, et al. Clinician Perspectives on Caring for Dying Patients During the Pandemic : A Mixed-Methods Study. Annals of internal medicine. 2021;174(4):493-500.

14. Kentish-Barnes N, Morin L, Cohen-Solal Z, Cariou A, Demoule A, Azoulay E. The Lived Experience of ICU Clinicians During the Coronavirus Disease 2019 Outbreak: A Qualitative Study. Critical Care Medicine. 2021;49(6):585-97.

15. Hanna JR, Rapa E, Dalton LJ, Hughes R, Quarmby LM, McGlinchey T, et al. Health and social care professionals' experiences of providing end of life care during the COVID-19 pandemic: A qualitative study. Palliative Medicine. 2021;35(7):1249-57.

16. Mitchell S, Oliver P, Gardiner C, Chapman H, Khan D, Boyd K, et al. Community end-of-life care during the COVID-19 pandemic: findings of a UK primary care survey. BJGP open. 2021;5(4).

17. Dohmen MDW, van den Eijnde C, Thielman CLE, Lindenberg J, Huijg JM, Abma TA. Good Care during COVID-19: A Narrative Approach to Care Home Staff's Experiences of the Pandemic. International Journal of Environmental Research and Public Health. 2022;19(4):2106.

18. Sinding C, Cape S, Charles L, Gosselin C, Kettings M, Taniguchi A, et al. When 'Being There'Is Disallowed: Disruptions to Knowing and Caring During COVID-19 Visitor Restrictions. Journal of Social Work in End-of-Life & Palliative Care. 2022:1-17.

19. Frey R, Balmer D. COVID-19 and hospice community palliative care in New Zealand: A qualitative study. Health & social care in the community. 2022.

20. Hanna JR, Rapa E, Dalton LJ, Hughes R, McGlinchey T, Bennett KM, et al. A qualitative study of bereaved relatives' end of life experiences during the COVID-19 pandemic. Palliative Medicine. 2021;35(5):843-51.

21. Mayland CR, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, et al. Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic. Palliative Medicine. 2021;35(8):1480-91.

22. Bradshaw A, Dunleavy L, Garner I, Preston N, Bajwah S, Cripps R, et al. Experiences of staff providing specialist palliative care during COVID-19: a multiple qualitative case study. Journal of the Royal Society of Medicine. 2022:01410768221077366.

23. Boddaert M, Caffarel J, Dermois M, Kodde A, Reyners AKL. Leidraad voor het proces en uniform vastleggen van proactieve zorgplanning naar aanleiding van de COVID-19-pandemie. 2020.

24. Bradshaw A, Dunleavy L, Walshe C, Preston N, Cripps RL, Hocaoglu M, et al. Understanding and addressing challenges for advance care planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services. Palliat Med. 2021;35(7):1225-37.

537

Additional file 1: Interviewguide

1. Start the interview: introduce yourself, ask if it is a convenient moment for the interview. Ask if the interviewee gives permission to record the interview: if yes, start recording. Explain that anonymity is guaranteed, that personal data is not stored and that everything discussed is handled with confidence. Ask if the interviewee has any questions and agrees.

2. Ask about the interviewee recent experience of end-of-life care.

   Probes:

   - How many patients have you cared for during the last days of their lives?
   - What protective measures are taken in your care setting?
   - What is your experience of those measures?

3. Ask if the interviewee can remember the patient from the questionnaire.

   a. If not, go to 4.

   b. If yes, ask about this patient's story.

   Refer if necessary to answers in the questionnaire, as in: You indicated in the questionnaire that ...: can you tell me more about that? What do you mean by that? What did you miss? What would you rather have seen? Etc.

   Pay attention to:

   - Symptoms and symptom management
   - Treatment restrictions
   - Influence of the Corona measures, including visits
   - Place of death
   - How death was characterized in the questionnaire
   - Experiences after the moment of dying

Probes:

- What did this patient's disease trajectory look like?
- What care dilemmas did you experience?
- What did you like in this case and what not?

- What exactly made the care as provided in this case right or wrong?
- What do you know about experiences of other members of the care team?
- How was the situation different from normal as a result of the corona crisis?

Where item 3 has been discussed extensively and concerned a positive experience, 4 can be skipped.

Where item 3 has been discussed extensively and concerned a negative experience, 5 can be skipped.

4. Can you give me an example of a patient for whom you thought end-of-life care went really well. Discuss experience of:
    - Symptoms and symptom management
    - Any treatment restrictions
    - Influence of the Corona measures, including visits
    - Place of death
    - How death was characterized in the questionnaire
    - Experiences after the moment of dying

    Probes:
    - Can you tell me about that situation?
    - Who was this patient (age, gender, setting, condition, covid-infection)?
    - How would you describe the care this patient received in the last phase of life?
    - What exactly makes this case a good case?
    - And how was this for the team? For you?

5. Can you give me an example of a patient for whom you thought end-of-life care really could have been better.

    Discuss experience of:
    - Symptoms and symptom management
    - Any treatment restrictions
    - Influence of the Corona measures, including visits
    - Place of death
    - How death was characterized in the questionnaire

- Experiences after the moment of dying

Probes:

- Can you tell me about that situation?
- Who was this patient (age, gender, setting, condition, covid infection)?
- How would you describe the care this patient received in the last phase of life?
- What exactly makes this case a poor case?
- And how was this for the team? For you?

6. Have these and other recent experiences with end-of-life care affected your views on good end-of-life care?

   Probes:

   - Can you tell me something about that?
   - What about your health, quality of life and emotions as reported in the questionnaire?
   - Safety and protection issues?

7. Have these and other recent experiences with end-of-life care affected your own health and wellbeing?

   Probes:

   - Can you tell me something about that?
   - What about your health, quality of life and emotions as reported in the questionnaire?
   - Safety and protection issues?

8. Conclusion: ask if the interviewee wants to add anything that has not yet been discussed. Thank the interviewee and wish them strength. Indicate that if the interviewee wants to add something, they can always send an e-mail. In case the interview evoked emotions, recommend that the interviewee talks to someone or contacts a colleague or their GP.

Additional File 2. Themes, subthemes and codes

Theme	**Subtheme**	**Code**
New disease		Clinical view not reliable (-)
		Unexpected deterioration (-)
		Symptom relief was hard (-)
High workload		Not enough time for care (-)
		Lack of HCP's with the right skills (-)
		Higher chance of mistakes (-)
		Poor continuity of care (-)
		No time to support relatives (-)
		Limited in time they could relatives to say goodbye (-)
Contagiousness		Too much focus on prevention of infections (-)
	Limited family visits and goodbye's	Patients were not able to say goodbye to everyone (-)
		HCPs could not get to know the patient (-)
		Good excuse to refuse someone to say goodbye to the patient (+)
		New digital methods for contact (+)
		Limited in giving emotional support to relatives (-)
	Physical distance between HCP's and patients and their relatives	Feeling detached from the patient (-)
		Spiritual counselors were not allowed (-)
		Limited in taking care of deceased patient (-)
		Limited in giving emotional support to relatives (-)
	Feelings of detachment due to personal protective equipment (PPE)	HCP's were unrecognizable, not understandable and scary for patients (-)
		Allowed HCP's to touch patients (+)
		Being more reluctant to visit patients because they had to change in PPE (-)
Positive effects for the long term		More awareness for advance care planning (+)
		More awareness for better staff policy (+)
		Realization the importance of adequate end-of-life care (+)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p. 1/ l. 1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p. 2-3 / l. 27-57

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p. 3-5 / l. 57 - 105
Purpose or research question - Purpose of the study and specific objectives or questions	p.5 / l. 101 - 105

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	p. 5 / l. 108 p. 7 / l. 137 - 139
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p. 7 / l. 147 - 149
Context - Setting/site and salient contextual factors; rationale**	p. 5 / l. 120 - 122
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	p.5 / l. 113 - 119
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p. 7 / l. 152 - 157
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	p. 6 / l. 131 - 135

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p. 6 / l. 131 - 135
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	P. 5-6 / l. 119 - 126
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	p. 7 / l. 137 - 149 p. 7 / l.152 - 157
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	p. 7 / l. 137 - 149
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	p. 7 / l. 137 - 149 p.20 / l. 342 - 346

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p. 8- 18 / l. 158 – 310
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p. 9 / l. 175 p. 12 / l. 224 p. 16 / l. 296 p. 18 / l. 311

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p.19-23/ l. 313 - 435
Limitations - Trustworthiness and limitations of findings	p.19-20 / l. 332 - 351

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p.24/ l. 454
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p. 25/l. 456

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388