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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)

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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, for example, 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. Finally, the COVID-19 outbreak also had a potentially positive impact in the longer term, for example, 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.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study describes a broad range of perspectives since it includes healthcare professionals from all care settings and different professions who cared for patients with COVID-19 and patients with non-COVID-19.
⇒ 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 WHO published guidelines on what public health and social measures should be taken.[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 focuses 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 HCP organisations, palliative care networks and organisations, volunteer organisations 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 under-represented in the survey, two were recruited via our own network. Eventually, 16 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 patients with COVID only, while others had also cared for patients with non-COVID. We followed the standards for reporting qualitative research.

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 (MSZ: 2, LB: 8, YNB: 4, EW: 1 and H.RP: 1). Because of COVID measures,

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

ICU, intensive care unit.

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 (online supplemental file 1). The interviews were conducted in Dutch, lasted between 25 min and 70 min and were audio-recorded.

Data analysis

The interviews were transcribed verbatim and analysed using the qualitative data analysis software MAXQDA (2020). We followed the principles of thematic analysis based on a phenomenological approach, focusing on the lived experiences of the respondents.[10 11] First LB and H.RP went through the transcripts and made summaries, which were discussed with all interviewers and another member of the research group (BO-P). After becoming familiar with the data by reading the transcripts, MSZ coded the data. The analyses were discussed with all members of the research group and on multiple occasions with the different interviewers. Thereafter, MSZ, LB, BO-P and H.RP sorted the codes into groups to develop overarching themes (online supplemental file 2). During the process of sorting the codes into themes, MSZ, LB, BO-P and H.RP continuously compared and discussed their decisions. Finally, appropriate quotes were selected by MSZ and LB, 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).

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, although 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 (table 2, 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 patients with COVID-19 (table 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 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 patients with COVID-19.

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 (table 2, 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 (table 2, 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 (table 2, 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 (table 2, 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 (table 2, 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 (table 2, quote 8).

Table 2 Quotes—new disease and 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 patients with COVID-19 and patients with non-COVID-19 regarding the impact of these measures on care, since most measures applied to everyone. HCPs stated that care giving 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 (table 3, 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 homecare, 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

Table 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 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**).
3.2.: 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**).
3.3.: 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**).

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 (table 3, 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 homeled 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 (table 3, quote 3). However, a nurse working in homecare said that the restrictions were used as a good excuse when patients did not want a specific person to visit them and say goodbye (table 3, quote 4). In some cases, there were new digital ways for patients to contact their relatives (eg, 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 are really important. Because of visiting restrictions, HCPs did not see relatives as much, making it difficult for HCPs to provide emotional support to families (table 3, quote 5). Even if the distance could be bridged using digital communication, HCPs felt that they could not support the relatives sufficiently from a distance (table 3, 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 (table 3, 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 (table 3, 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 (table 3, 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 (table 3, quote 10).

Feelings of detachment due to PPE

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 unrecognisable due to wearing PPE (table 3, 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 (table 3, 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 economise 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 (table 3, quote 13). On wards for only patients with COVID, it was not necessary to change the PPE all the time, which was seen as an advantage of working in such wards.

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

Table 4 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, ho**me).

patients and of advance care planning (ACP) (table 4, 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. Finally, HCPs said that the pandemic had reminded them of how important appropriate and individualised care is at the end of life, and that this care entails much more than physical care only (table 4, quote 3 and quote 4).

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 patients with COVID-19 and patients with non-COVID-19. 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 rapport 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 with 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 patients with COVID-19 and non-COVID-19, the impact varied in degree from an annoyance (eg, wearing masks meant patients could not hear staff very well) to care that fell short (eg, there was no time to support the family or to get to know the patient) to care that was degrading or inhumane (eg, 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 prioritised. 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 personalised 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 emphasised 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 learnt 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 ACP and focussing on patients' individual needs and preferences. In the Netherlands, this resulted in the development of national guidance for ACP that was supported by the relevant Dutch professional and scientific organisations.[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]

Finally, 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, for example, 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.

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