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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).

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3 1 **The impact of COVID-19 on the quality care at the end of life: interviews with**
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5 2 **healthcare professionals from different settings (the CO-LIVE study).**
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9
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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.

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

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

58

59 Strength's and limitations:

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

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Introduction

75
76 The COVID-19 pandemic confronted the world with an unknown disease, which had
77 an impact on care in all healthcare settings. To limit transmission and reduce mortality
78 and morbidity from COVID-19, the World Health Organization (WHO) published
79 guidelines to take public health and social measures (PHSM) (1). These measures
80 included, among others, personal protective measures, such as wearing masks, and
81 physical distancing measures, such as maintaining distance in public or workplaces.
82 As other countries, the Netherlands were also confronted with high numbers of patients
83 with COVID-19, excess mortality due to COVID-19, and implementation of most of the
84 abovementioned measures (2, 3).

85
86 The situation surrounding COVID-19, affected care at the end of life for both patients
87 and their relatives (4). Measures, such as visiting restrictions and keeping a physical
88 distance changed human contact inherently and influenced the way end-of-life care
89 was provided (5-7). Furthermore, because of the high number of patients with COVID-
90 19 there might be less time for emotional and existential support for patients and their
91 relatives in a time where this support is very much needed (4-6).

92
93 Good quality of end-of-life care asks for a palliative care approach that focusses on the
94 quality of life of patients and their families. It aims to provide person-centered care that
95 not only focuses on the medical condition of the patient, but also takes on a more
96 holistic approach, looking at the psychological, social and spiritual domains of care as
97 well (8). It pays special attention to specific needs and preferences in these domains

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3 98 and it not only provides support to patients, but also to their relatives and includes
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5 99 bereavement counselling (8).
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10 101 It is likely that these domains of the palliative care approach were endangered during
11
12 102 the COVID-19 pandemic. The aim of this study is to better understand how the COVID-
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14 103 19 outbreak impacted the different domains of the palliative care approach to end of
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16 104 life care from the perspective of HCPs (healthcare professionals), working in different
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18 105 health care settings during the COVID-19 outbreak in the Netherlands.
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Methods

107 Design, Setting and Participants

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28 108 An in-depth qualitative interview study was conducted among HCPs of patients who
29
30 109 died between March and July 2020 in different healthcare settings in the Netherland
31
32 110 as part of the CO-LIVE study. CO-LIVE is a mixed-methods study on the experiences
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34 111 of both bereaved relatives and HCPs during the COVID-19 pandemic. Participants
35
36 112 were recruited through an online survey about the last days of life of a patient who died
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38 113 during the first wave of the COVID-19 outbreak (9). Maximum variation sampling was
39
40 114 used in the group of participants that was interested to take part in an interview.
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42 115 Variation was sought in setting, profession, and how HCPs qualified the death of the
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44 116 patient about whom they filled in the survey (both positive and negative qualifications)
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46 117 and potential respondents were approached via e-mail. Since nursing assistants
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48 118 working in nursing homes were underrepresented in the survey, two were recruited via
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50 119 our own network. Eventually, sixteen HCPs were interviewed: nine nurses, two nursing
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52 120 assistants, one coordinator in a hospice and four physicians. Four participants worked
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121 in a special COVID unit in the hospital, two in an intensive care unit (ICU), five in a
 122 nursing home, three in a hospice and two in home/community care (Table 1). Some
 123 participants had cared for COVID-patients only, others had also cared for non-COVID-
 124 patients. We followed the standards for reporting qualitative research (SRQR).

125

126 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

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128 Patient and public involvement

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

130 Data collection

131 Five researchers (MZ: 2, LB: 8, YB: 4, EW: 1 and RP: 1) conducted the interviews.

132 Because of COVID-measures, all interviews were held via (video)calls. The

133 interviewers used a topic list, that included questions about the responses as given in

1
2
3 134 the survey and questions about new experiences (Additional file 1). The interviews
4
5 135 were conducted in Dutch, lasted between 25 and 70 minutes and were audio-recorded.
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8 136 Data analysis

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12 137 Data were transcribed verbatim and analysed using qualitative data analysis software
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14 138 MAXQDA, following the principles of thematic analysis based on a phenomenological
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17 139 approach (10, 11). First LB and RP went through the transcripts and made summaries,
18
19 140 which were discussed with all interviewers and another member of the research group
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21 141 (BOP). After becoming familiar with the data by reading the transcripts, MZ coded the
22
23 142 data. The analyses were discussed with all members of the research group and on
24
25 143 multiple occasions with the different interviewers. Thereafter, MZ, LB, BOP and RP
26
27 144 sorted the codes into groups developing overarching themes (Additional file 2).
28
29
30 145 Themes and corresponding codes were continuously compared, discussed and
31
32 146 categorized. Finally, appropriate quotes were selected by MZ and LB and translated
33
34 147 by a professional translator. The research group consists of researchers with different
35
36 148 backgrounds (health sciences, medical anthropology, nursing, sociology, psychology
37
38 149 and medicine).
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45 151 Ethical considerations

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49 152 Before the interview, participants gave verbal informed consent to participate in the
50
51 153 interview and to have this interview recorded. All data were anonymized to make sure
52
53 154 the participants and their patients were unidentifiable. After transcription, audio
54
55 155 recordings were deleted. The Medical Ethics Committee Erasmus MC of Rotterdam,
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3 156 The Netherlands, assessed that the rules laid down in the Medical Research Involving
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5 157 Human Subjects Act, do not apply (MEC-2020-0254).
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9 158 Results

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13 159 The COVID-19 outbreak led to an impactful and unique situation for healthcare, and
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15 160 HCPs stated that it affected care at the end of life. This was the case for HCPs of all
16
17 161 disciplines and for all care settings, albeit sometimes in different ways. They mentioned
18
19 162 that the care was good 'given the circumstances', but not comparable with their usual
20
21 163 standard of care. They did what they could do, knowing that they could not do
22
23 164 everything they wanted to do (box 1, quote 1). HCPs explained that it was not satisfying
24
25 165 to work under these circumstances and wished they could have done more (box 1,
26
27 166 quote 2). Some said that the quality of care was poor and described (aspects of) it as
28
29 167 "inhumane" (box 1, quote 3 & quote 4). HCPs also felt that there was too much focus
30
31 168 on the medical aspects of care of this new disease compared to emotional and spiritual
32
33 169 care (box 1, quote 5).
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39 170 Several themes arose from the interviews after thematic analysis, that were
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41 171 characteristic for this impactful and exceptional situation and, mostly negatively,
42
43 172 impacted the quality of end-of-life care: COVID-19 being a new disease, the disease
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45 173 leading to a higher workload for HCPs, and the disease being contagious. Both the
46
47 174 positive and negative effects are described in the following paragraphs.
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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)

176

177 New disease – Lack of knowledge to manage symptoms

178 In the first wave of the COVID-19 outbreak, little was known about the course of the
 179 disease, the prognosis, treatment and symptom relief. This led to difficulties in the
 180 physical domain of end-of-life care. HCPs said that their 'clinical view' was not reliable
 181 anymore because the disease course for COVID-19 patients was unpredictable (box
 182 2, quote 1). In some cases, the patient unexpectedly deteriorated very quickly, making
 183 it difficult to anticipate, for instance to timely inform family members. Furthermore, they
 184 said it was hard to relieve symptoms for some dying patients because existing
 185 treatments for similar symptoms in other diseases had no or little effect for COVID-19
 186 patients. (box 2, quote 2).

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

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

200 Due to lack of time and staff, the quality of end-of-life care was hampered. Some HCPs
201 mentioned that they only had time for the essential, physical care, but not enough time
202 for care in the emotional, social and spiritual domains (box 2, quote 5). However,
203 HCPs, specifically in the ICU, also mentioned some difficulties in the physical domain.
204 They mentioned that, because of a lack of staff, HCPs from other disciplines or wards
205 helped them. However, not all of these new colleagues had the right skills or
206 experience and this sometimes negatively impacted the quality of physical care (box
207 2, quote 6). Furthermore, HCPs mentioned that there was a higher chance of mistakes
208 because of the time pressure (box 2, quote 7).

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3 210 Because of the shortage of (skilled) staff, schedules of HCPs were sometimes unclear
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5 211 or constantly changing. Therefore, HCPs saw a lot of different patients and did not see
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7 212 one particular patient as often as usual. A respondent mentioned that this led to poor
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9 213 continuity of care because individual HCPs were not as involved with and informed
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11 214 about their patients as usual, which made it difficult to be aware of personal needs and
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13 215 preferences (box 2, quote 8).
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19 217 Due to the staff shortage and higher workload, there was also less time for another
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21 218 important part of the palliative care approach: supporting relatives. HCPs mentioned
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23 219 that they could not spend as much time on supporting the relatives as they were used
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25 220 to and that it was unsatisfying for them (box 2, quote 9). In some cases, HCPs in the
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27 221 ICU were limited in the time they could give relatives to say goodbye to their loved
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29 222 ones. (box 2, quote 10).
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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)

225 Contagiousness – Preventative measures hampered good end- 226 of-life care

227 In healthcare settings, different measures were taken to prevent the spread of COVID-
228 19, such as visiting restrictions, keeping physical distance and wearing personal
229 protective equipment (PPE). There was little difference between COVID-19 and non-
230 COVID-19 patients regarding the impact of these measures on care, since most
231 measures applied to everyone. HCPs stated that caregiving at the end of life was
232 hampered, due to the priorities that government and overall healthcare had when
233 dealing with COVID-19. They said that preventing the spread of the virus seemed more
234 important than the quality of end-of-life care and that this impacted, in particular, the
235 emotional and spiritual aspects of care (box 3, quote 1).

236 Limited family visits and goodbyes

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

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246 According to the HCPs the limited family visits and goodbyes impacted the patients
247 greatly. Some participants mentioned that dying patients could not see everyone they

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2
3 248 wanted to see and that some patients were completely alone in the last days of their
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5 249 life (box 3, quote 2). One nurse described a case where a patient did not want to die
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7 250 in a hospital setting, because of their visitation restrictions. However, this sudden
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9
10 251 transfer to her home led to chaotic last days of life (box 3, quote 3). Furthermore, the
11
12 252 visiting restrictions impacted to what extent HCPs could get to know their patients and
13
14 253 therefore impacted end-of-life care. If unconscious or very ill patients were not able to
15
16 254 talk, care became less personal, because no family was around to share the patients'
17
18 255 preferences and wishes. (box 3, quote 4 and quote 5). Furthermore, a nurse working
19
20 256 in homecare mentioned that the restrictions were used as a good excuse when patients
21
22 257 did not want a specific person to visit them and say goodbye (box 3, quote 6). In some
23
24 258 cases, there were new digital ways for patients to contact their relatives (e.g. video
25
26 259 calls) and HCPs were mostly positive about the usage of these resources, although it
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28 260 did not fully replace the physical family visits (box 3, quote 7).
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35 262 Because of visitation restrictions, HCPs did not see relatives (as much) making it
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37 263 difficult for HCP's to give emotional support to families (box 3, quote 8). Even if the
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39 264 distance could be bridged using digital communication, HCP's felt they could not
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41 265 support the relatives sufficiently from a distance (box 3, quote 9).
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47 267 **Physical distance between HCPs and patients and their relatives**

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50 268 When providing good end-of-life care in all domains of palliative care, the contact and
51
52 269 connection of HCPs with patients and their relatives is really important. Physical
53
54 270 distance hampered the care and connection in all settings for patients with and without
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56 271 COVID-19. Some HCPs felt detached from the patient, mostly because they could not
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58 272 touch the patient, apart from when they performed medical procedures. They explained
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3 273 that touching patients is an important part of emotional support (box 3, quote 10). In
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5 274 some cases, spiritual counselors were not allowed to be physically present with
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8 275 patients anymore and this impacted the spiritual domain of the end-of-life care (box 3,
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10 276 quote 11). Furthermore, when a patient had died, HCPs mentioned that they were not
11
12 277 allowed to take care of the deceased patient to prepare them for relatives to say
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14 278 goodbye (box 3, quote 12 & quote 13). Finally, the physical distance also limited HCPs
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17 279 in providing emotional support to relatives, because they could not get near to the
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19 280 relatives or touch them to console them (box 3, quote 14).
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23 24 282 Feelings of detachment due to personal protective equipment

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27 283 Another measure that created distance between HCPs and patients and their relatives,
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29 284 was the personal protective equipment HCPs needed to wear under certain
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32 285 circumstances. When wearing PPE, they were unrecognizable for patients, and it was
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34 286 sometimes difficult for patients to hear them (box 3, quote 15). Furthermore, some
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36 287 HCPs mentioned that it was scary for patients with dementia or psychological problems
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38 288 to be cared for by staff wearing PPE (box 3, quote 16). However, HCPs also said that
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40 289 they were happy to be wearing PPE, because it allowed them to touch their patients
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42 290 and to them come closer (box 3, quote 17). Some HCPs had experienced a shortage
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44 291 of PPE, or had to economize PPE to prevent a shortage and this made HCPs more
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46 292 reluctant to come near to patients, because it would cost extra PPE (box 3, quote 18).
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48 293 In specific COVID-wards, it was not necessary to change PPE all the time which was
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50 294 seen as an advantage of working in such wards.
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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)

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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)

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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)

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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)

300 Positive effects of the exceptional situation for the long term

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

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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)

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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)
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Discussion

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

331

332 Strength and limitations

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

341
342 Because the situation of the COVID-19 pandemic was hectic and unique, five
343 researchers started with interviewing respondents. Each interviewer did one interview
344 and thereafter they discussed the used topic list with, to see if it was sufficient and if
345 adjustments were needed. By continuously discussing of the topic list and findings,
346 uniformity was guaranteed.

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

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4 353 Psychosocial and spiritual care for patients and relatives was most at stake and
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7 354 affected all care settings
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10 355 Care at the end of life was hampered in all domains of palliative care, but especially
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12 356 impacted the psychosocial and spiritual domain. This already arose from our
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14 357 quantitative study among HCPs (9), but the in-depth interviews have provided a better
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17 358 understanding of this finding. HCPs mentioned they were limited in their possibilities to
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19 359 provide end-of-life care in these domains because they could not get to know the
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21 360 patient well, but predominantly because they were limited in their care due to the
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23 361 measures and lack of time. Furthermore, the situation affected the care for the
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25 362 relatives. Because they were not always allowed to visit, HCPs were not able to take
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28 363 care of them too and support them in this difficult time.
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33 365 The results of the current study echo the findings of studies from different countries, in
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35 366 which several aspects of end-of-life care in times of COVID-19 were studied (12-17),
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37 367 Similar to our findings, they too found staff believed that they fell short in care at the
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39 368 end of life due to the lack of physical contact, wearing of PPE and visiting restrictions.
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42 369 In Hanna et al. and Mitchinson et al., HCPs also mentioned that there was more of a
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44 370 focus on essential physical care, and less focus on the other domains of end-of-life
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46 371 care, mostly because of the increased workload (12, 15). As in our study, Mitchinson
47
48 372 et al, found that emotional care was hampered because of absence of human
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50 373 connections and distance between HCPs in hospitals and patients (12). Mitchell et al.
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52 374 found that community nurses and GPs indicated they provided less support to family
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54 375 carers than usual during the pandemic (16). Both Kentish-Barnes and Sinding found
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56 376 that HCPs were unable to provide good emotional support to families, due to limited
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3 377 family visits in combination with digital communication not being satisfactory (14, 18).
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5 378 Similar to our study, Mayland et al., found in a study among bereaved relatives of
6
7 379 patients that died during the COVID-19 pandemic, that the quality of end-of-life care
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9 380 could be maintained when healthcare services still prioritize (among other things) the
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11 381 holistic aspects of end-of-life care and acknowledge the significance of individual
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13 382 deaths (19).
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17 383 When comparing our results with the findings of other studies, it shows that there are
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19 384 a lot of similarities within the different situations (and measures) in different countries.
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21 385 Because our study included different settings and focused on the quality of care, we
22
23 386 also could expose similarities and differences between different healthcare setting
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25 387 regarding care.
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28 29 388 **The need for individual assessment and adapting rules and measures** 30

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32 389 From our interviews, it appeared that nursing home and hospital staff felt more limited
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34 390 by the measures that had to be taken than HCPs working in home care or hospice
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36 391 care. This might be related to the fact that staff in hospices and at home more often
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38 392 were able to take individual decisions with regard to the measures in order to tailor
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40 393 care to the individual patient. They possibly had or felt more room to deviate from the
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42 394 measures, for instance to allow more visitors or not always keep their distance.
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48 396 The need for leeway to adapt rules and measures is also acknowledged by the WHO
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50 397 in their updated guidance to implement PHSM in November 2020. One of their key
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52 398 points states: "The decision to introduce, adapt or lift PHSM should be based primarily
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54 399 on a situational assessment of the intensity of transmission and the capacity of the
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56 400 health system to respond, but must also be considered in light of the effects these
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58 401 measures may have on the general welfare of society and individuals." (1). In the
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3 402 Netherlands we already saw some adaptation of the measures during the second wave
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5 403 of COVID-19 (September 2020 – February 2021), aimed at providing better care at the
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7 404 end of life. For instance, in most settings visitors were allowed also outside the terminal
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9 405 phase, but the number of visitors and time of the visits generally remained restricted.
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15 407 COVID-19 provided chances to improve care at the end of life

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18 408 Apart from many negative effects of the COVID-19 outbreak, we also found some
19
20 409 potential positive effects of the crisis to improve care at the end of life in the future.
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22 410 First, the shortage of (mainly nursing) staff was already present and discussed before
23
24 411 the COVID-19 outbreak, but staff in our study mentioned that this shortage was now
25
26 412 more visible and discussed more extensively in the media. The outbreak showed that
27
28 413 good qualified nursing staff is essential for good end-of-life care. This appreciation may
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30 414 lead to awareness for better working circumstances for nurses, and consequently more
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32 415 nursing staff in the future.

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36 416 Second, another potentially positive effect is the increased attention for
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38 417 weighing the pros and cons of medical treatment for frail patients and the increased
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40 418 awareness of the importance of advance care planning and focusing on individual
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42 419 needs and preferences of patients. In the Netherlands, this resulted in the development
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44 420 of a national guidance for advance care planning that was supported by relevant Dutch
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46 421 professional and scientific organizations (20).

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50 422 Last, HCPs mentioned that the importance is psychosocial care and the value
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52 423 of participation of relatives in at the end of life has been emphasized. This may provide
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54 424 fertile ground for efforts to improve palliative care, by e.g. promoting consulting
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56 425 palliative care teams or following palliative care vocational training.
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427 Conclusion

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

436 List of abbreviations

437 HCP: Healthcare professional

438 WHO: World Health Organization

439 PHSM: Public health and social measures

440 ICU: Intensive care unit

441 PPE: Personal protective equipment

442

443 Declarations

444 **Ethics approval and consent to participate**

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

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3 448 **Consent for publication**
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6 449 Not applicable since this manuscript does not contain any details about individuals.
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10 450 **Availability of data and materials**
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13 451 The datasets used and/or analyzed during the current study are available from the
14
15 452 corresponding author on reasonable request.
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19 453 **Conflicts of interest**
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22 454 The authors declare that they have no conflicts of interests.
23
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25

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31

32 457 **Authors' contributions**
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34

35 458 All authors contributed to the design of the study. Interviews were conducted by MZ,
36
37 459 LB, YB, EW and RP. Analysis was done by MZ, LB, RP and BOP and discussed with
38
39 460 all member of the research group. Quotes were selected by MZ and LB. MZ drafted
40
41 461 the manuscript. All authors provided critical comments on drafts of the manuscripts
42
43 462 and approved the final manuscript.
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47

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53 465 the organizations that helped with the recruitment of participants for the questionnaire.
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14 523 pandemie. 2020.

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Additional file 1: Interviewguide

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8 1. Start the interview: introduce yourself, ask if it is a convenient moment for the interview. Ask if
9 the interviewee gives permission to record the interview: if yes, start recording. Explain that
10 anonymity is guaranteed, that personal data is not stored and that everything discussed is
11 handled with confidence. Ask if the interviewee has any questions and agrees.
12
13

14 2. Ask about the interviewee recent experience of end-of-life care.
15

16 Probes:
17

- 18 • How many patients have you cared for during the last days of their lives?
- 19 • What protective measures are taken in your care setting?
- 20 • What is your experience of those measures?
- 21
- 22
- 23
- 24
- 25

26 3. Ask if the interviewee can remember the patient from the questionnaire.
27

28 a. If not, go to 4.
29

30 b. If yes, ask about this patient's story.
31

32 Refer if necessary to answers in the questionnaire, as in: You indicated in the questionnaire
33 that ...: can you tell me more about that? What do you mean by that? What did you miss?
34 What would you rather have seen? Etc.
35

36 Pay attention to:
37

- 38 • Symptoms and symptom management
- 39 • Treatment restrictions
- 40 • Influence of the Corona measures, including visits
- 41 • Place of death
- 42 • How death was characterized in the questionnaire
- 43 • Experiences after the moment of dying
- 44
- 45
- 46
- 47
- 48

49 Probes:
50

- 51 • What did this patient's disease trajectory look like?
- 52 • What care dilemmas did you experience?
- 53 • What did you like in this case and what not?
- 54
- 55
- 56
- 57
- 58
- 59
- 60

- 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/>

Page/line no(s).

Title and abstract

<p>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>	<p>p. 1/ l. 1-2</p>
<p>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>	<p>p. 2-3 / l. 27-57</p>

Introduction

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

Methods

<p>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>	<p>p. 5 / l. 108 p. 7 / l. 137 - 139</p>
<p>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>	<p>p. 7 / l. 147 - 149</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>p. 5 / l. 120 - 122</p>
<p>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>	<p>p.5 / l. 113 - 119</p>
<p>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>	<p>p. 7 / l. 152 - 157</p>
<p>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>	<p>p. 6 / l. 131 - 135</p>

1		
2	Data collection instruments and technologies - Description of instruments (e.g.,	
3	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	
4	collection; if/how the instrument(s) changed over the course of the study	p. 6 / l. 131 - 135
5		
6	Units of study - Number and relevant characteristics of participants, documents, or	
7	events included in the study; level of participation (could be reported in results)	P. 5-6 / l. 119 - 126
8		
9	Data processing - Methods for processing data prior to and during analysis, including	
10	transcription, data entry, data management and security, verification of data integrity,	
11	data coding, and anonymization/de-identification of excerpts	p. 7 / l. 137 - 149 p. 7 / l.152 - 157
12		
13	Data analysis - Process by which inferences, themes, etc., were identified and	
14	developed, including the researchers involved in data analysis; usually references a	
15	specific paradigm or approach; rationale**	p. 7 / l. 137 - 149
16		
17	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and	
18	credibility of data analysis (e.g., member checking, audit trail, triangulation);	
19	rationale**	p. 7 / l. 137 - 149 p.20 / l. 342 - 346
20		

Results/findings

23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	
24	themes); might include development of a theory or model, or integration with prior	
25	research or theory	p. 8- 18 / l. 158 – 310
26		
27		
28		p. 9 / l. 175
29		p. 12 / l. 224
30	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs)	
31	to substantiate analytic findings	p. 16 / l. 296 p. 18 / l. 311
32		

Discussion

35	Integration with prior work, implications, transferability, and contribution(s) to the	
36	field - Short summary of main findings; explanation of how findings and conclusions	
37	connect to, support, elaborate on, or challenge conclusions of earlier scholarship;	
38	discussion of scope of application/generalizability; identification of unique	
39	contribution(s) to scholarship in a discipline or field	p.19-23/ l. 313 - 435
40		
41	Limitations - Trustworthiness and limitations of findings	p.19-20 / l. 332 - 351
42		

Other

45	Conflicts of interest - Potential sources of influence or perceived influence on study	
46	conduct and conclusions; how these were managed	p.24/ l. 454
47		
48	Funding - Sources of funding and other support; role of funders in data collection,	
49	interpretation, and reporting	p. 25/l. 456
50		

*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.

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

7
8 **Reference:**

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

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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Public health, Qualitative research
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH, PUBLIC HEALTH

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3 1 **The impact of COVID-19 during the first months of the pandemic on care at the**
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5 2 **end of life from the perspective of healthcare professionals from different**
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7 3 **settings; a qualitative interview study (the CO-LIVE study).**
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10 4

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52 24

53
54 25 Word count: 3855
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56 26 Number of tables / boxes: 1 table / 3 boxes
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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) 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.

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

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

59

60 Strengths and limitations:

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

70

71 Introduction

72 The COVID-19 pandemic confronted the world with an unknown disease, which had
73 an impact on care in all healthcare settings. To limit transmission and reduce mortality
74 and morbidity from COVID-19, the World Health Organization (WHO) published
75 guidelines to take public health and social measures (PHSM) (1). These measures

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3 76 included, among others, personal protective measures, such as wearing masks, and
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5 77 physical distancing measures, such as maintaining distance in public or workplaces.
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8 78 As other countries, the Netherlands were also confronted with high numbers of patients
9
10 79 with COVID-19, excess mortality due to COVID-19, and implementation of most of the
11
12 80 abovementioned measures (2, 3).

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17 82 The situation surrounding COVID-19, affected care at the end of life for both patients
18
19 83 and their relatives during the first months of the pandemic (4). Measures, such as
20
21 84 visiting restrictions and keeping a physical distance changed human contact inherently
22
23 85 and influenced the way end-of-life care was provided (5-7). Furthermore, because of
24
25 86 the high number of patients with COVID-19 there might be less time for emotional and
26
27 87 existential support for patients and their relatives in a time where this support is very
28
29 88 much needed (4-6).

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35 90 Good quality of end-of-life care asks for a palliative care approach that focusses on the
36
37 91 quality of life of patients and their families. It aims to provide person-centered care that
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39 92 not only focuses on the medical condition of the patient, but also takes on a more
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41 93 holistic approach, looking at the psychological, social and spiritual domains of care as
42
43 94 well (8). It pays special attention to specific needs and preferences in these domains
44
45 95 and it not only provides support to patients, but also to their relatives and includes
46
47 96 bereavement counselling (8).

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53 98 It is likely that these domains of the palliative care approach were endangered during
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55 99 the COVID-19 pandemic. The aim of this study is to better understand how the COVID-
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57 100 19 outbreak impacted the different domains of the palliative care approach to end of
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3 101 life care from the perspective of HCPs (healthcare professionals), working in different
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5 102 health care settings during the first months of the COVID-19 outbreak in the
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7 103 Netherlands.
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104 Methods

105 Design, Setting and Participants

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

124 only, others had also cared for non-COVID-patients. We followed the standards for
 125 reporting qualitative research (SRQR).

126

127 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

128

129 Patient and public involvement

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

131

132 Data collection

133 Five researchers (MZ: 2, LB: 8, YB: 4, EW: 1 and RP: 1) conducted the interviews.

134 Because of COVID-measures, all interviews were held via (video)calls. The

135 interviewers used a topic list, that included questions about the responses as given in

136 the survey and questions about new experiences (Additional file 1). The interviews

137 were conducted in Dutch, lasted between 25 and 70 minutes and were audio-recorded.

138 Data analysis

139 Data were transcribed verbatim and analysed using qualitative data analysis software
140 MAXQDA. We followed the principles of thematic analysis based on a
141 phenomenological approach; focusing on the lived experiences from the respondents
142 (10, 11). First LB and RP went through the transcripts and made summaries, which
143 were discussed with all interviewers and another member of the research group (BOP).
144 After becoming familiar with the data by reading the transcripts, MZ coded the data.
145 The analyses were discussed with all members of the research group and on multiple
146 occasions with the different interviewers. Thereafter, MZ, LB, BOP and RP sorted the
147 codes into groups developing overarching themes (Additional file 2). During the
148 process of sorting the codes into themes, MZ, LB, BOP and RP continuously compared
149 and discussed their decisions. Finally, appropriate quotes were selected by MZ and
150 LB and translated by a professional translator. The research group consists of
151 researchers with different backgrounds (health sciences, medical anthropology,
152 nursing, sociology, psychology and medicine).

154 Ethical considerations

155 Before the interview, participants gave verbal informed consent to participate in the
156 interview and to have this interview recorded. After transcription, audio recordings were
157 deleted and all data were anonymized to make sure the participants and their patients
158 were unidentifiable. Personal information and transcripts were saved in separate
159 folders that both could only be accessed by the researchers. The Medical Ethics
160 Committee Erasmus MC of Rotterdam, The Netherlands, assessed that the rules laid

1
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3 161 down in the Medical Research Involving Human Subjects Act, do not apply (MEC-
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5 162 2020-0254).
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9 163 Results

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13 164 The COVID-19 outbreak led to an impactful and unique situation for healthcare, and
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15 165 HCPs stated that it affected care at the end of life. This was the case for HCPs of all
16
17 166 disciplines and for all care settings, albeit sometimes in different ways.
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20 167 Several themes arose from the interviews after thematic analysis, that were
21
22 168 characteristic for this impactful and exceptional situation and, mostly negatively,
23
24 169 impacted the quality of end-of-life care during the first months of the COVID-19
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26 170 pandemic: COVID-19 being a new disease, the disease leading to a higher workload
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28 171 for HCPs, the disease being contagious and the long-term positive impact of the
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30 172 COVID-19 pandemic on end-of-life care.
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5 174 **New disease – Lack of knowledge to manage symptoms**
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9 175 In the first months of the COVID-19 outbreak, little was known about the course of the
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11 176 disease, the prognosis, treatment and symptom relief. This led to difficulties in the
12
13 177 physical domain of end-of-life care. HCPs said that their 'clinical view' was not reliable
14
15 178 anymore because the disease course for COVID-19 patients was unpredictable (box
16
17 179 1, quote 1). In some cases, the patient unexpectedly deteriorated very quickly, making
18
19 180 it difficult to anticipate, for instance to timely inform family members. Furthermore, they
20
21 181 said it was hard to relieve symptoms for some dying patients because existing
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23 182 treatments for similar symptoms in other diseases had no or little effect for COVID-19
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25 183 patients. (box 1, quote 2).
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30 184 **High workload – Lack of time and staff for good end-of-life care**
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34 185 The COVID-19 outbreak led to a great influx of patients with COVID-19 on top of the
35
36 186 regular patients, resulting in a high workload for HCPs, especially at the ICU and
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38 187 COVID-wards in hospitals. Besides, HCPs in nursing homes also had a higher
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40 188 workload since they had to isolate residents with COVID-19 from residents without
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42 189 COVID-19. This created more wards than usual, that they had to distribute the same
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44 190 amount of HCPs over. Furthermore, because of a lack of knowledge on how to prevent
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46 191 COVID-19 infections, many HCPs mentioned how (especially in the first months of the
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48 192 pandemic) measures and rules about visitation or protective equipment were unclear
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50 193 or kept changing. Being updated on the rules took a lot of time, creating a higher
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52 194 workload. These aspects were mentioned by HCPs from all settings, also those who
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54 195 had not cared for COVID-19 patients.
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3 197 Due to the great influx of patients, the quality of end-of-life care was hampered. HCPs
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5 198 mentioned degrading situations for patients where there were crowded wards with little
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7 199 privacy and work that felt like a production line (box 1, quote 3). Some HCPs mentioned
8
9 200 that they only had time for the essential, physical care, but not enough time for care in
10
11 201 the emotional, social and spiritual domains (box 1, quote 4). However, HCPs,
12
13 202 specifically in the ICU, also mentioned some difficulties in the physical domain. They
14
15 203 mentioned that, because of a lack of staff, HCPs from other disciplines or wards helped
16
17 204 them. However, not all of these new colleagues had the right skills or experience and
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19 205 this sometimes negatively impacted the quality of physical care (box 1, quote 5).
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21 206 Furthermore, HCPs mentioned that medication safety was an issue because of the
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23 207 time pressure.
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31 209 Because of the shortage of (skilled) staff, schedules of HCPs were sometimes unclear
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33 210 or constantly changing. Therefore, HCPs saw a lot of different patients and did not see
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35 211 one particular patient as often as usual. A respondent mentioned that this led to poor
36
37 212 continuity of care because individual HCPs were not as involved with and informed
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39 213 about their patients as usual, which made it difficult to be aware of personal needs and
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41 214 preferences (box 1, quote 6).
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47 216 Due to the staff shortage and higher workload, there was also less time for another
48
49 217 important part of the palliative care approach: supporting relatives. HCPs mentioned
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51 218 that they could not spend as much time on supporting the relatives as they were used
52
53 219 to and that it was unsatisfying for them (box 1, quote 7). In some cases, HCPs in the
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55 220 ICU were limited in the time they could give relatives to say goodbye to their loved
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57 221 ones. (box 1, quote 8).
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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)

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8 224 Contagiousness – Preventative measures hampered good end-9
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17 226 In healthcare settings, different measures were taken to prevent the spread of COVID-
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19 227 19, such as visiting restrictions, keeping physical distance and wearing personal
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21 228 protective equipment (PPE). There was little difference between COVID-19 and non-
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23 229 COVID-19 patients regarding the impact of these measures on care, since most
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25 230 measures applied to everyone. HCPs stated that caregiving at the end of life was
26
27 231 hampered, due to the priorities that government and overall healthcare had when
28
29 232 dealing with COVID-19. They said that preventing the spread of the virus seemed more
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31 233 important than the quality of end-of-life care and that this impacted, in particular, the
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33 234 emotional and spiritual aspects of care (box 2, quote 1).

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38 235 Limited family visits and goodbyes

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41 236 All HCPs mentioned that family visits and goodbyes were limited to smaller or greater
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43 237 extent which impacted end-of-life care for both patients and their relatives. There were
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45 238 restrictions in the number of people who were allowed to visit patients, the number of
46
47 239 visits per day, and the amount of time relatives were allowed to visit a patient. Visiting
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49 240 restrictions varied between settings; HCPs from hospitals and especially nursing
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51 241 homes mentioned that these restrictions were very strict and that it was difficult to
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53 242 deviate from them. In homecare, patients or HCPs could decide themselves on
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55 243 visitation (restrictions).

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3 245 According to the HCPs the limited family visits and goodbyes impacted the patients
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5 246 greatly, mostly in the psychological and social domains. Some participants mentioned
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7 247 that dying patients could not see everyone they wanted to see and that some patients
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9 248 were completely alone in the last days of their life (box 2, quote 2). One nurse described
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11 249 a case where a patient did not want to die in a hospital setting, because of their visiting
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13 250 restrictions. However, this sudden transfer to her home led to chaotic last days of life.
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15 251 Furthermore, the visiting restrictions impacted to what extent HCPs could get to know
16
17 252 their patients and therefore impacted end-of-life care. If unconscious or very ill patients
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19 253 were not able to talk, care became less personal, because no family was around to
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21 254 share the patients' preferences and wishes. (box 2, quote 3). Furthermore, a nurse
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23 255 working in homecare mentioned that the restrictions were used as a good excuse when
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25 256 patients did not want a specific person to visit them and say goodbye (box 2, quote 4).
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27 257 In some cases, there were new digital ways for patients to contact their relatives (e.g.
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29 258 video calls) and HCPs were mostly positive about the usage of these resources,
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31 259 although it did not fully replace the physical family visits.
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40 261 When providing good end-of-life care in all domains of palliative care, the contact and
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42 262 connection of HCPs with patients and their relatives is really important. Because of
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44 263 visitation restrictions, HCPs did not see relatives (as much) making it difficult for HCP's
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46 264 to provide emotional support to families (box 2, quote 5). Even if the distance could be
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48 265 bridged using digital communication, HCP's felt they could not support the relatives
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50 266 sufficiently from a distance (box 2, quote 6).
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268 Physical distance between HCPs and patients and their relatives

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

282 Feelings of detachment due to personal protective equipment

283 Another measure that created distance between HCPs and patients and their relatives,
284 was the PPE HCPs needed to wear under certain circumstances. A HCP described
285 how they felt it was degrading for patients to provide care when being unrecognizable
286 due to wearing PPE (box 2, quote 11). Furthermore, some HCPs mentioned that it was
287 scary for patients with dementia or psychological problems to be cared for by staff
288 wearing PPE and therefore hindered care in the psychological domain (box 2, quote
289 12). However, HCPs also said that they were happy to be wearing PPE, because it
290 allowed them to touch their patients and to them come closer. Some HCPs had
291 experienced a shortage of PPE, or had to economize PPE to prevent a shortage and

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3 292 this made HCPs more reluctant to come near to patients, because it would cost extra
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5 293 PPE, hindering care in all domains (box 2, quote 13). In specific COVID-wards, it was
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7 294 not necessary to change PPE all the time which was seen as an advantage of working
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For peer review only

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)

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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)

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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)

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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)

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303 Positive impact of the exceptional situation for the long term

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

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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 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)

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Discussion

316
317 This interview study, held in the first months of the COVID-19 pandemic, shows that
318 care at the end of life was seriously hampered by the exceptional situation and led to
319 a combination of challenges in all domains of end-of-life care: uncertainty about how
320 to best treat patients with this unknown disease, a high workload for HCPs, and strict
321 preventive measures to prevent the spread of this contagious disease. However, the
322 situation also brought some potential long-term positive impact on care, such as
323 awareness of the importance of talking about advance care planning and potentially
324 futile treatments, and of the importance of good care at the end of life within all the
325 domains.

326 327 Strength and limitations

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

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337 Because the situation of the COVID-19 pandemic was hectic and unique, five
338 researchers started with interviewing respondents. Each interviewer did one interview
339 and thereafter they discussed the used topic list with, to see if it was sufficient and if

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3 340 adjustments were needed. By continuously discussing of the topic list and findings,
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5 341 uniformity was guaranteed.
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10 343 During the last interviews in this study, no new topics came up in comparison to the
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12 344 earlier interviews. However, since the situation of COVID-19 was so complex, unique
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14 345 in every healthcare setting and kept changing so quickly, we cannot say with certainty
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16 346 that we reached saturation.
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22 348 Psychosocial and spiritual care for patients and relatives was most at stake and
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25 349 affected all care settings
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28 350 The situation impacted the care in all domains. This already arose from our quantitative
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30 351 study among HCPs (9), however the in-depth interviews have provided a better
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32 352 understanding of this finding. The impact varied in degree, in all settings and for both
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34 353 COVID-19 and non-COVID-19 patients, from annoying (e.g. wearing masks hindered
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36 354 patients to hear staff very well), to falling short in care (e.g. there was no time to support
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38 355 family, or not getting to know the patient) to degrading or inhumane care (e.g. patients
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40 356 dying without relatives being present).
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47 358 The fact that COVID-19 was a new unknown disease seems to mostly impacted care
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49 359 in the physical domain. However, the other themes related predominately to the
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51 360 psychosocial and spiritual domain of care. The high workload hindered physical care,
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53 361 but mostly care in the psychosocial and spiritual domain (for both patients and
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55 362 relatives), since there was not enough staff or time and physical care was prioritized.
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58 363 The preventative measures taken, impact all the domains of care in different ways It
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3 364 is notable that a social intervention as visit restrictions, did not only impact the social
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5 365 domain of end-of-life care, but also personalized care in the psychological domain and
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7 366 that the physical distance measure, had an impact on all domains, including spiritual
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14 369 The results of the current study echo the findings of studies from different countries, in
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16 370 which several aspects of end-of-life care during the first months of the COVID-19
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18 371 pandemic were studied (12-17), Similar to our findings, they too found staff believed
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20 372 that they fell short in different domains of palliative care at the end of life due to the
21
22 373 lack of physical contact, wearing of PPE and visiting restrictions. Other studies also
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24 374 showed that HCPs in different settings found it difficult to provide good emotional
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26 375 support to families due to limited family visits and not being able to touch them, in
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28 376 combination with digital communication not being satisfactory (14, 16, 18, 19) .
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35 378 As in our study, HCPs and bereaved relatives in other studies emphasized the
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37 379 importance of holistic care (in all domains of the palliative approach) and mentioned
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39 380 that there often was a focus on physical care compared to the psychosocial and
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41 381 spiritual domain (12, 20, 21). Bradshaw et al., described how the measures to prevent
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43 382 the spread of the virus hindered HCPs in providing person-centered and holistic care,
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45 383 in accordance to their professional values (22).
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52 53 54 386 [COVID-19 provided chances to improve care at the end of life](#)

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57 387 Our study presents findings about the first months of the COVID-19 pandemic. Since
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59 388 then, there were a lot of changes that could have improved or changed the care in all

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3 389 domains at the end of life during the pandemic. For example, we learned that the
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5 390 lockdown of nursing homes was very harmful for the residents and measures became
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7 391 less restrictive. However, studies about experiences of HCPs after the first year of the
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10 392 pandemic are at date still scarce. We do not know if the problems highlighted in our
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12 393 study or previously mentioned studies persisted after the first months of the pandemic,
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14 394 even with more knowledge on the disease (and the prevention of the disease), less
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16 395 restrictive measures and enough PPE. We have a do know that new problems arose,
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18 396 such as more aggression of visitors, but most importantly, the shortage of healthcare
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20 397 staff (due to for example long-covid and burn-out) which is still very evident. Research
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22 398 about the later phases of the pandemic probably will shed more light on this.
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28 400 In our study, we found that HCPs thought that the pandemic could have a long-term
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30 401 positive impact on end-of-life care. Despite the challenges mentioned earlier, we
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32 402 believe that the pandemic provides chances to improve care at the end of life. The
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34 403 outbreak showed that good qualified nursing staff is essential for good end-of-life care.
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36 404 This appreciation may lead to awareness for good education in palliative and end-of-
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38 405 life care in all care settings, better working circumstances for nurses, and consequently
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40 406 more nursing staff in the future.
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44 407 Second, another mentioned potentially positive effect is the increased attention
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46 408 for weighing the pros and cons of medical treatment for frail patients and the increased
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48 409 awareness of the importance of advance care planning and focusing on individual
49
50 410 needs and preferences of patients. In the Netherlands, this resulted in the development
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52 411 of a national guidance for advance care planning that was supported by relevant Dutch
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54 412 professional and scientific organizations (23). Bradshaw et al., discussed how HCPs
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3 413 are now more often involved in ACP and more involved in advising and educating about
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5 414 ACP in response to the pandemic (24).
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8 415 Last, HCPs mentioned that the importance is psychosocial care and the value
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10 416 of participation of relatives in at the end of life has been emphasized. This may provide
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12 417 fertile ground for efforts to improve palliative care, by e.g. promoting consulting
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14 418 palliative care teams or following palliative care vocational training.
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18 19 20 420 Conclusion

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23 421 The palliative care approach, key for good care at the end of life, was often negatively
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25 422 influenced in the first months of the COVID-19 outbreak, and seriously harmed patients
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27 423 and relatives. This predominantly concerned the emotional, social and spiritual
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29 424 domains of care, and was related to an emphasis on essential physical care and
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31 425 prevention of the spread of COVID-19. Negative effects could be limited when
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33 426 professionals feel room to adapt to rules and measures in individual cases. However,
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35 427 the pandemic and the restrictive measures shed light on the importance of
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37 428 multidimensional care at the end-of-life. These lessons learned can potentially improve
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39 429 care at the end of life in the future.
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45 430 List of abbreviations

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49 431 HCP: Healthcare professional

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51 432 WHO: World Health Organization

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53 433 PHSM: Public health and social measures

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55 434 ICU: Intensive care unit

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57 435 PPE: Personal protective equipment
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437 **Declarations**

438 **Ethics approval and consent to participate**

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

442 **Consent for publication**

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

444 **Availability of data and materials**

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

447 **Conflicts of interest**

448 The authors declare that they have no conflicts of interests.

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451 **Authors' contributions**

452 MZ, LB, YB, EW, AH, LL, AG, IK, BOP and RP contributed to the design of the study.

453 Interviews were conducted by MZ, LB, YB, EW and RP. Analysis was done by MZ, LB,

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3 454 RP and BOP and discussed with YB, EW, AH, LL, AG and IK. Quotes were selected
4
5 455 by MZ and LB. MZ drafted the manuscript. MZ, LB, YB, EW, AH, LL, AG, IK, BOP and
6
7 456 RP provided critical comments on drafts of the manuscripts and approved the final
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9 457 manuscript.

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Additional file 1: Interviewguide

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8 1. Start the interview: introduce yourself, ask if it is a convenient moment for the interview. Ask if
9 the interviewee gives permission to record the interview: if yes, start recording. Explain that
10 anonymity is guaranteed, that personal data is not stored and that everything discussed is
11 handled with confidence. Ask if the interviewee has any questions and agrees.
12
13

14 2. Ask about the interviewee recent experience of end-of-life care.
15

16 Probes:
17

- 18 • How many patients have you cared for during the last days of their lives?
- 19 • What protective measures are taken in your care setting?
- 20 • What is your experience of those measures?
- 21
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- 25

26 3. Ask if the interviewee can remember the patient from the questionnaire.
27

- 28 a. If not, go to 4.
- 29
- 30 b. If yes, ask about this patient's story.
- 31

32 Refer if necessary to answers in the questionnaire, as in: You indicated in the questionnaire
33 that ...: can you tell me more about that? What do you mean by that? What did you miss?
34 What would you rather have seen? Etc.
35

36 Pay attention to:
37

- 38 • Symptoms and symptom management
- 39 • Treatment restrictions
- 40 • Influence of the Corona measures, including visits
- 41 • Place of death
- 42 • How death was characterized in the questionnaire
- 43 • Experiences after the moment of dying
- 44
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49 Probes:
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- 51 • What did this patient's disease trajectory look like?
- 52 • What care dilemmas did you experience?
- 53 • What did you like in this case and what not?
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- 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 (-)
		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/>

Page/line no(s).

Title and abstract

<p>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>	<p>p. 1/ l. 1-2</p>
<p>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>	<p>p. 2-3 / l. 27-57</p>

Introduction

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

Methods

<p>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>	<p>p. 5 / l. 108 p. 7 / l. 137 - 139</p>
<p>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>	<p>p. 7 / l. 147 - 149</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>p. 5 / l. 120 - 122</p>
<p>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>	<p>p.5 / l. 113 - 119</p>
<p>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>	<p>p. 7 / l. 152 - 157</p>
<p>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>	<p>p. 6 / l. 131 - 135</p>

1 2 3 4 5	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
6 7 8	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
9 10 11 12	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
13 14 15 16	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
17 18 19 20	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

23 24 25 26	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
27 28 29 30 31 32	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

35 36 37 38 39 40 41	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
42	Limitations - Trustworthiness and limitations of findings	p.19-20 / l. 332 - 351

Other

45 46 47	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p.24/ l. 454
48 49	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.

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

7
8 **Reference:**

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

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)

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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Public health, Qualitative research
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH, PUBLIC HEALTH

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3 1 **The impact of COVID-19 on care at the end of life during the first months of the**
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5 2 **pandemic from the perspective of healthcare professionals from different**
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7 3 **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 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

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3 51 awareness of advance care planning and the importance of end-of-life care that
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5 52 includes all the domains.
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10 54 **Conclusion:** The palliative care approach, which is key to good end-of-life care, was
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12 55 often negatively influenced by the COVID-19 pandemic, predominantly in the
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14 56 emotional, social and spiritual domains. This was related to a focus on essential
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16 57 physical care and prevention of the spread of COVID-19.
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19 58 **Keywords:** COVID-19, Palliative Care, End-of-life Care, Quality of Care, Qualitative
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21 59 Research
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26 61 Strengths and limitations:

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28 62 - This study describes a broad range of perspectives since it includes healthcare
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30 63 professionals from all care settings and different professions who cared for
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32 64 COVID-19 patients and non-COVID-19 patients.
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35 65 - Respondents were eager to share their experiences despite the fact that the
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37 66 interviews were held via (video) calls.
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40 67 - Despite the fact that five researchers interviewed respondents, uniformity was
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42 68 guaranteed by continuously discussing the topic list and findings.
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44 69 - We cannot say with certainty that data saturation was reached, since the
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46 70 COVID-19 situation was so complex and kept changing so quickly.
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53 72 Introduction

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57 73 The COVID-19 pandemic confronted the world with an unknown disease, which had
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59 74 an impact on care in all healthcare settings. To limit transmission and reduce mortality
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3 75 and morbidity from COVID-19, the World Health Organization (WHO) published
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5 76 guidelines on what public health and social measures should be taken (PHSM) (1).
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7 77 These measures included personal protective measures, such as wearing masks, and
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10 78 physical distancing measures, such as maintaining distance in public spaces or
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12 79 workplaces. As other countries, the Netherlands was also confronted with high
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14 80 numbers of patients with COVID-19 and excess mortality due to COVID-19, and most
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16 81 of the above-mentioned measures were implemented (2, 3).
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21 83 The situation surrounding COVID-19 affected care at the end of life for both patients
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23 84 and their relatives during the first months of the pandemic (4). Measures such as
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25 85 visiting restrictions and keeping a physical distance changed human contact inherently
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27 86 and influenced the way end-of-life care was provided (5-7). Furthermore, because of
28
29 87 the high number of patients with COVID-19, there may have been less time for
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31 88 emotional and spiritual support for patients and their relatives during a period where
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33 89 this support was very much needed (4-6).
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39 91 Good-quality end-of-life care requires a palliative care approach that focusses on the
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41 92 quality of life of patients and their families. It aims to provide person-centred care that
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43 93 not only considers the patient's medical condition, but also takes a more holistic
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45 94 approach, looking at the psychological, social and spiritual domains of care as well (8).
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47 95 Special attention is paid to specific needs and preferences in these domains and
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49 96 support is provided not only to patients, but also to their relatives; this includes
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51 97 bereavement counselling (8).
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3 99 It is likely that these domains of the palliative care approach were endangered during
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5 100 the COVID-19 pandemic. The aim of this study is to better understand how the COVID-
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7 101 19 outbreak impacted the different domains of the palliative care approach to end-of-
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9 102 life care from the perspective of healthcare professionals (HCPs) working in different
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11 103 healthcare settings during the first months of the COVID-19 outbreak in the
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13 104 Netherlands.

18 105 Methods

23 106 Design, Setting and Participants

27 107 An in-depth qualitative interview study was conducted among HCPs caring for patients
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29 108 who died between March and July 2020 in different healthcare settings in the
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31 109 Netherland as part of the CO-LIVE study. CO-LIVE is a mixed-methods study of the
32
33 110 experiences of both bereaved relatives and HCPs during the COVID-19 pandemic.
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35 111 Participants were recruited through an online survey on the last days of life of patients
36
37 112 who died during the first wave of the COVID-19 outbreak. This survey was distributed
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39 113 via relevant healthcare professional organizations, palliative care networks and
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41 114 organizations, volunteer organizations and personal contacts throughout the
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43 115 Netherlands (9). Maximum variation sampling was used in the group of participants
44
45 116 who were interested in taking part in an interview. Variation was sought in setting,
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47 117 profession and how HCPs qualified the death of the patient about whom they filled in
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49 118 the survey (both positive and negative qualifications). Potential respondents were
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51 119 approached via e-mail. Since nursing assistants working in nursing homes were
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53 120 underrepresented in the survey, two were recruited via our own network. Eventually,
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55 121 sixteen HCPs were interviewed: nine nurses, two nursing assistants, one coordinator

122 in a hospice and four physicians. Four participants worked in a special COVID unit in
 123 a hospital, two in an intensive care unit (ICU), five in a nursing home, three in a hospice
 124 and two in home/community care (Table 1). Some participants had cared for COVID
 125 patients only, while others had also cared for non-COVID-patients. We followed the
 126 standards for reporting qualitative research (SRQR).

127

128 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

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130 Patient and Public Involvement

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

132

133 Data Collection

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

139 Data Analysis

140 The interviews were transcribed verbatim and analysed using the qualitative data
141 analysis software MAXQDA. We followed the principles of thematic analysis based on
142 a phenomenological approach, focussing on the lived experiences of the respondents
143 (10, 11). First LB and RP went through the transcripts and made summaries, which
144 were discussed with all interviewers and another member of the research group (BOP).
145 After becoming familiar with the data by reading the transcripts, MZ coded the data.
146 The analyses were discussed with all members of the research group and on multiple
147 occasions with the different interviewers. Thereafter, MZ, LB, BOP and RP sorted the
148 codes into groups to develop overarching themes (Additional File 2). During the
149 process of sorting the codes into themes, MZ, LB, BOP and RP continuously compared
150 and discussed their decisions. Finally, appropriate quotes were selected by MZ and
151 LB and translated by a professional translator and checked by a second professional
152 translator. The research group consisted of researchers with different backgrounds
153 (health sciences, medical anthropology, nursing, sociology, psychology and medicine).

154

155 Ethical Considerations

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

163 Results

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

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

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5 174 **New Disease – Lack of Knowledge about How to Manage**6
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9 175 **Symptoms**

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13 176 In the first months of the COVID-19 outbreak, little was known about the course of the
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15 177 disease, the prognosis, treatment and symptom relief. This led to difficulties in the
16
17 178 physical domain of end-of-life care. HCPs said that their 'clinical view' was not reliable
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19 179 anymore because the disease course for COVID-19 patients was unpredictable (box
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21 180 1, quote 1). In some cases, the patient unexpectedly deteriorated very quickly, making
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23 181 it difficult to take anticipatory action, for instance to inform family members in good
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25 182 time. Furthermore, HCPs said it was hard to relieve symptoms for some dying patients
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27 183 because existing treatments for similar symptoms in other diseases had little or no
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29 184 effect for COVID-19 patients (box 1, quote 2).

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34 185 **High Workload – Lack of Time and Staff for Good End-of-life**35
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39 186 **Care**

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43 187 The COVID-19 outbreak led to a great influx of patients with COVID-19 on top of the
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45 188 regular patients, resulting in a high workload for HCPs, especially on the ICU and
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47 189 COVID wards in hospitals. Besides, HCPs in nursing homes also had a higher
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49 190 workload since they had to isolate residents with COVID-19 from residents without
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51 191 COVID-19. This created more wards than usual, which then had to be staffed using
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53 192 the same number of HCPs. Furthermore, because of a lack of knowledge on how to
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55 193 prevent COVID-19 infections, many HCPs mentioned how (especially in the first
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57 194 months of the pandemic) measures and rules about visits or protective equipment were

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3 195 unclear or kept changing. Being updated on the rules took a lot of time, creating a
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5 196 higher workload. These aspects were mentioned by HCPs in all settings, including
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8 197 HCPs who had not cared for COVID-19 patients.
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12 199 The great influx of patients adversely affected the quality of end-of-life care. HCPs
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14 200 mentioned degrading situations for patients on crowded wards with little privacy, and
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17 201 work that felt like a production line (box 1, quote 3). Some HCPs mentioned that they
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19 202 only had time for the essential, physical care, but not enough time for care in the
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21 203 emotional, social and spiritual domains (box 1, quote 4). However, HCPs (especially
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24 204 in ICUs) also mentioned some difficulties in the physical domain. They said that,
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26 205 because of a lack of staff, HCPs from other disciplines or wards helped them. However,
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28 206 not all of these new colleagues had the right skills or experience and this sometimes
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30 207 negatively impacted the quality of physical care (box 1, quote 5). Furthermore, HCPs
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33 208 mentioned that medication safety was an issue because of the time pressure.
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37 210 Because of the shortage of skilled staff, HCPs' schedules were sometimes unclear or
38
39 211 were constantly changing. Therefore, HCPs saw a lot of different patients and did not
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42 212 see particular individual patients as frequently as usual. A respondent mentioned that
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44 213 this led to poor continuity of care because individual HCPs were not as involved with
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47 214 their patients and as well-informed about them as usual, which made it difficult to be
48
49 215 aware of personal needs and preferences (box 1, quote 6).
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53 217 Due to the staff shortage and higher workload, there was also less time for another
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55 218 important part of the palliative care approach: supporting relatives. HCPs said that they
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58 219 could not spend as much time on supporting the relatives as they were used to and
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3 220 that this was unsatisfying for them (box 1, quote 7). In some cases, HCPs in the ICU
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5 221 were limited in the time they could give relatives to say goodbye to their loved ones
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8 222 (box 1, quote 8).
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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)

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8 225 **Contagiousness – Preventative Measures Hampered Good**9
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13 226 **End-of-life Care**

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17 227 In healthcare settings, various measures were taken to prevent the spread of COVID-
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19 228 19, such as visiting restrictions, keeping physical distance and wearing personal
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21 229 protective equipment (PPE). There was little difference between COVID-19 and non-
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23 230 COVID-19 patients regarding the impact of these measures on care, since most
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25 231 measures applied to everyone. HCPs stated that caregiving at the end of life was
26
27 232 hampered due to the priorities that government and the healthcare service had when
28
29 233 dealing with COVID-19. They said that preventing the spread of the virus seemed more
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31 234 important than the quality of end-of-life care and that this impacted, in particular, on
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33 235 the emotional and spiritual aspects of care (box 2, quote 1).

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38 236 **Limited family visits and goodbyes**

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41 237 All HCPs said that restrictions were placed on family visits and goodbyes to a greater
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43 238 or lesser extent, which impacted end-of-life care for both patients and their relatives.
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45 239 There were restrictions on the number of people who were allowed to visit patients, the
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47 240 number of visits per day, and the amount of time relatives were allowed for visiting a
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49 241 patient. Visiting restrictions varied between settings; HCPs in hospitals and, especially,
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51 242 nursing homes mentioned that these restrictions were very strict and that it was difficult
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53 243 to deviate from them. In home care, patients or HCPs could decide themselves on what
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55 244 to do about visits (restrictions).

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3 246 According to the HCPs, the restrictions on family visits and goodbyes impacted the
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5 247 patients greatly, mostly in the psychological and social domains. Some participants
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7 248 mentioned that dying patients could not see everyone they wanted to see and that
8
9 249 some patients were completely alone in the last days of their life (box 2, quote 2). One
10
11 250 nurse described a case where a patient did not want to die in a hospital setting because
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13 251 of the visiting restrictions. However, the sudden transfer to her home led to a chaotic
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15 252 last few days of life. Furthermore, the visiting restrictions affected the extent to which
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17 253 HCPs could get to know their patients and therefore impacted end-of-life care. If
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19 254 unconscious or very ill patients were not able to talk, care became less personal
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21 255 because no family was around to share the patients' preferences and wishes (box 2,
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23 256 quote 3). However, a nurse working in home care said that the restrictions were used
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25 257 as a good excuse when patients did not want a specific person to visit them and say
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27 258 goodbye (box 2, quote 4). In some cases, there were new digital ways for patients to
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29 259 contact their relatives (e.g. video calls) and HCPs were mostly positive about the usage
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31 260 of these resources, although they were not a perfect substitute for the physical family
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33 261 visits.

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42 263 When providing good end-of-life care in all domains of palliative care, the contact and
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44 264 connection between HCPs and patients and their relatives is really important. Because
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46 265 of visiting restrictions, HCPs did not see relatives as much, making it difficult for HCPs
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48 266 to provide emotional support to families (box 2, quote 5). Even if the distance could be
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50 267 bridged using digital communication, HCPs felt they could not support the relatives
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52 268 sufficiently from a distance (box 2, quote 6).

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270 Physical distance between HCPs and patients and their relatives

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

284 Feelings of detachment due to personal protective equipment

285 Another measure that created distance between HCPs and patients and their relatives
286 was the PPE HCPs needed to wear under certain circumstances. An HCP described
287 how they felt it was degrading for patients to have care provided by someone who was
288 unrecognizable due to wearing PPE (box 2, quote 11). Furthermore, some HCPs said
289 that it was scary for patients with dementia or psychological problems to be cared for
290 by staff wearing PPE and this therefore hindered care in the psychological domain (box
291 2, quote 12). However, HCPs also said that they were happy to be wearing PPE
292 because it allowed them to touch their patients and to come closer. Some HCPs had
293 experienced a shortage of PPE or had to economize on PPE to prevent a shortage

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3 294 and this made HCPs more reluctant to come close to patients, because that would cost
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5 295 extra PPE, which hindered care in all domains (box 2, quote 13). On wards for only
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7 296 COVID patients, it was not necessary to change the PPE all the time, which was seen
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10 297 as an advantage of working in such wards.
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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)

299

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)

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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)

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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)

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305 Positive Impact of the Exceptional Situation in the Long Term

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

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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)

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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)
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Discussion

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

328

Strength and limitations

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

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5 340 Because the situation with the COVID-19 pandemic was hectic and unique, we started
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7 341 with five researchers interviewing respondents. Each interviewer did one interview,
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9 342 after which they discussed the topic list together to see if it was sufficient and if
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11 343 adjustments were needed. By continuously discussing the topic list and findings, they
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13 344 were able to guarantee uniformity.
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19 346 No new topics came up during the last interviews in this study when compared to the
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21 347 earlier interviews. However, since the COVID-19 situation was so complex and unique
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23 348 in every healthcare setting and kept changing so quickly, we cannot say with certainty
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25 349 that we reached saturation.
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31 351 Psychosocial and spiritual care for patients and relatives were the domains most
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34 352 severely affected in all care settings
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38 353 The situation impacted the care in all domains. This was already shown by our
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40 354 quantitative study among HCPs (9); however, the in-depth interviews have provided a
41
42 355 better understanding of this finding. In all settings and for both COVID-19 and non-
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44 356 COVID-19 patients, the impact varied in degree from an annoyance (e.g. wearing
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46 357 masks meant patients could not hear staff very well) to care that fell short (e.g. there
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48 358 was no time to support the family or to get to know the patient) to care that was
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50 359 degrading or inhumane (e.g. patients dying without relatives being present).
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56 361 The fact that COVID-19 was a new, unknown disease seems to have mostly impacted
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58 362 care in the physical domain. However, the other themes related predominately to the
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3 363 psychosocial and spiritual domains of care. The high workload hindered physical care,
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5 364 but had an even greater effect on care in the psychosocial and spiritual domains (for
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7 365 both patients and relatives), since there was not enough staff or time and physical care
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10 366 was prioritized. The preventative measures taken impacted all the domains of care in
11
12 367 different ways. It is notable that a social intervention such as visiting restrictions not
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14 368 only affected the social domain of end-of-life care, but also personalized care in the
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16 369 psychological domain. Similarly, the physical distancing measure had an impact on all
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19 370 domains, including spiritual care.
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24 372 The results of the current study echo the findings of studies from different countries, in
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26 373 which several aspects of end-of-life care during the first months of the COVID-19
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28 374 pandemic were studied (12-17), Similar to our findings, they too found staff believed
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30 375 that they fell short in different domains of palliative care at the end of life due to the
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32 376 lack of physical contact, having to wear PPE and visiting restrictions. Other studies
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35 377 also showed that HCPs in different settings found it difficult to provide good emotional
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37 378 support to families due to limited family visits and not being able to touch them, in
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39 379 combination with digital communication not being satisfactory (14, 16, 18, 19) .
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44 381 As in our study, HCPs and bereaved relatives in other studies emphasized the
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46 382 importance of holistic care (in all domains of the palliative approach) and mentioned
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48 383 that there was often a focus on physical care rather than the psychosocial and spiritual
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50 384 domains (12, 20, 21). Bradshaw et al., described how the measures to prevent the
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52 385 spread of the virus hindered HCPs in providing person-centred and holistic care in
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54 386 accordance with their professional values (22).
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6 389 COVID-19 provided chances to improve care at the end of life

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9 390 Our study presents findings about the first months of the COVID-19 pandemic. Since
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11 391 then, there were a lot of changes that could have improved or changed the care in all
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13 392 domains at the end of life during the pandemic. For example, we learned that the
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15 393 lockdown of nursing homes was very harmful for the residents, and as a consequence
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17 394 measures became less restrictive. However, studies of the experiences of HCPs after
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19 395 the first year of the pandemic are still scarce at present. We do not know if the problems
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21 396 highlighted in our study or the studies mentioned above persisted after the first months
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23 397 of the pandemic, despite the greater knowledge about the disease (and the prevention
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25 398 of the disease), the less restrictive measures and the end to PPE shortages. We do
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27 399 know that new problems arose, such as more aggression among visitors, but most
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29 400 importantly, a shortage of healthcare staff (due for example to long COVID and burn-
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31 401 out), which is still very much a problem. Research on the later phases of the pandemic
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33 402 will probably shed more light on this.

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41 404 In our study, we found that HCPs thought that the pandemic could have a long-term
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43 405 positive impact on end-of-life care. Despite the challenges mentioned earlier, we
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45 406 believe that the pandemic provides chances to improve care at the end of life. The
46
47 407 outbreak showed that well-qualified nursing staff are essential for good end-of-life care.
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49 408 This appreciation may lead to an awareness of the need for good education in palliative
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51 409 and end-of-life care in all care settings, better working conditions for nurses, and
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53 410 consequently more nursing staff in the future.

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57 411 Another potentially positive effect that was mentioned is the increased attention
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59 412 paid to weighing the pros and cons of medical treatment for frail patients and the

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3 413 increased awareness of the importance of advance care planning and focussing on
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5 414 patients' individual needs and preferences. In the Netherlands, this resulted in the
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7 415 development of national guidance for advance care planning that was supported by
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9 416 the relevant Dutch professional and scientific organizations (23). Bradshaw et al.
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11 417 discussed how HCPs are now involved more often in ACP and are more involved in
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13 418 advising others about ACP in response to the pandemic (24).
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17 419 Lastly, HCPs stressed the importance of psychosocial care and the value of
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19 420 involving relatives at the end of life. This may provide fertile ground for efforts to
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21 421 improve palliative care, by e.g. promoting consulting palliative care teams or giving
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23 422 HCPs palliative care vocational training.
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27 28 29 424 Conclusion

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32 425 The palliative care approach, which is key for good care at the end of life, was often
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34 426 negatively affected in the first months of the COVID-19 outbreak, and this had a serious
35
36 427 adverse impact on patients and relatives. The emotional, social and spiritual domains
37
38 428 of care were predominantly affected, which was related to an emphasis on essential
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40 429 physical care and prevention of the spread of COVID-19. Negative effects could be
41
42 430 limited when professionals felt they had room to adapt the rules and measures in
43
44 431 individual cases. On the positive side, the pandemic and the restrictive measures shed
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46 432 light on the importance of good end-of-life care in all domains of the palliative care
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48 433 approach. of multidimensional care at the end-of-life. These lessons can potentially
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50 434 improve care at the end of life in the future.
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435 List of abbreviations

436 HCP: Healthcare professional

437 WHO: World Health Organization

438 PHSM: Public health and social measures

439 ICU: Intensive care unit

440 PPE: Personal protective equipment

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442 Declarations

443 Ethics approval and consent to participate

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

447 Consent for publication

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

449 Availability of data and materials

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

452 Conflicts of interest

453 The authors declare that they have no conflicts of interests.

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456 **Authors' contributions**

457 MZ, LB, YB, EW, AH, LL, AG, IK, BOP and RP contributed to the design of the study.

458 Interviews were conducted by MZ, LB, YB, EW and RP. Analysis was done by MZ, LB,

459 RP and BOP and discussed with YB, EW, AH, LL, AG and IK. Quotes were selected

460 by MZ and LB. MZ drafted the manuscript. MZ, LB, YB, EW, AH, LL, AG, IK, BOP and

461 RP provided critical comments on drafts of the manuscripts and approved the final

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Additional file 1: Interviewguide

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8 1. Start the interview: introduce yourself, ask if it is a convenient moment for the interview. Ask if
9 the interviewee gives permission to record the interview: if yes, start recording. Explain that
10 anonymity is guaranteed, that personal data is not stored and that everything discussed is
11 handled with confidence. Ask if the interviewee has any questions and agrees.
12
13

14
15 2. Ask about the interviewee recent experience of end-of-life care.
16

17 Probes:

- 18 • How many patients have you cared for during the last days of their lives?
- 19 • What protective measures are taken in your care setting?
- 20 • What is your experience of those measures?
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26 3. Ask if the interviewee can remember the patient from the questionnaire.
27

- 28 a. If not, go to 4.
- 29
- 30 b. If yes, ask about this patient's story.
- 31

32 Refer if necessary to answers in the questionnaire, as in: You indicated in the questionnaire
33 that ...: can you tell me more about that? What do you mean by that? What did you miss?
34 What would you rather have seen? Etc.
35

36 Pay attention to:

- 37
- 38 • Symptoms and symptom management
- 39 • Treatment restrictions
- 40 • Influence of the Corona measures, including visits
- 41 • Place of death
- 42 • How death was characterized in the questionnaire
- 43 • Experiences after the moment of dying
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50 Probes:

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

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- 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/>

Page/line no(s).

Title and abstract

<p>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>	<p>p. 1/ l. 1-2</p>
<p>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>	<p>p. 2-3 / l. 27-57</p>

Introduction

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

Methods

<p>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>	<p>p. 5 / l. 108 p. 7 / l. 137 - 139</p>
<p>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>	<p>p. 7 / l. 147 - 149</p>
<p>Context - Setting/site and salient contextual factors; rationale**</p>	<p>p. 5 / l. 120 - 122</p>
<p>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>	<p>p.5 / l. 113 - 119</p>
<p>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>	<p>p. 7 / l. 152 - 157</p>
<p>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>	<p>p. 6 / l. 131 - 135</p>

1 2 3 4 5	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
6 7 8	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
9 10 11 12	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
13 14 15 16	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
17 18 19 20	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

23 24 25 26	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
27 28 29 30 31 32	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

35 36 37 38 39 40 41 42	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
43 44	Limitations - Trustworthiness and limitations of findings	p.19-20 / l. 332 - 351

Other

45 46 47	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p.24/ l. 454
48 49 50	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.

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

7
8 **Reference:**

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