

Dying in times of the coronavirus: An online survey among healthcare professionals about end-of-life care for patients dying with and without COVID-19 (the CO-LIVE study)

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Abstract

Background: During the COVID-19 outbreak restricting measures may have affected the provision of good end-of-life care for patients with and without COVID-19.

Aim: To describe characteristics of patients who died and the care they received, and to examine how patient characteristics, setting and visiting restrictions are related to provided care and evaluation of the dying process.

Design: An open observational online survey among healthcare professionals about their experience of end-of-life care that was provided to a patient with or without COVID-19 who died between March and July 2020.

Setting/participants: Healthcare professionals (nurses, physicians and others) in the Netherlands from all settings: home ($n = 163$), hospital ($n = 249$), nursing home ($n = 192$), hospice ($n = 89$) or elsewhere ($n = 68$).

Results: Of patients reported on, 56% had COVID-19. Among these patients, 358 (84.4%) also had a serious chronic illness. Having COVID-19 was negatively, and having a serious chronic illness was positively associated with healthcare staff's favourable appreciation of end-of-life care. Often there had been visiting restrictions in the last 2 days of life (75.8%). This was negatively associated with appreciation of care at the end of life and the dying process. Finally, care at the end of life was less favourably appreciated in hospitals and especially nursing homes, and more favourably in home settings and especially hospices.

Conclusions: Our study suggests that end-of-life care during the COVID-19 pandemic may be further optimised, especially in nursing homes and hospitals. Allowing at least some level of visits of relatives seems a key component.

Keywords

COVID-19, palliative care, end of life, quality of care, quality of dying

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What is already known about the topic?

- Death due to COVID-19 occurs in all healthcare settings.
- During the peak of the COVID-19 outbreak, many measures were taken that may restrict possibilities of providing high quality care at the end of life, both for patients with and without COVID-19.
- Until now studies are lacking that give insight in how care at the end of life was given to patients with and without COVID-19 and how such care was affected by COVID-19 measures.

What this paper adds?

- In the Netherlands, in three quarter of cases there had been visitor restrictions in patients' last days of life; this was strongly negatively associated with healthcare staff's appreciation of care at the end of life and the dying process.
- Patients having COVID-19 was negatively associated and patients having a serious chronic illness was positively associated with healthcare staff's appreciation of care at the end of life.
- Healthcare staff appreciated care at the end of life during the COVID-19 pandemic less favourably in hospitals and especially care homes, and more favourably in home settings and especially hospices.

Implications for practice, theory or policy?

- End-of-life care during the pandemic was suboptimal, especially with regard to emotional support and spiritual care, especially in care homes and hospitals.
- Allowing at least some level of visits of relatives is a key component of improving care at the end of life.
- During the pandemic, extra attention is needed for end-of-life care and this should not be limited to patients with COVID-19.

Introduction

In Februari 2020, COVID-19 had infected over 122 million people worldwide and almost two and a half million people died from it.¹ Among prognostic factors for mortality is comorbidity,² and it has been estimated that in England and Wales about one out of five people dying of COVID-19 might have been in their last year of life in absence of the pandemic. Above that, there was a rise in deaths that were not directly linked to COVID-19.³

The COVID-19 pandemic has invoked drastic measures to protect the health of the population, such as economic lockdowns and social distancing. Responses to the outbreak have affected virtually all people in the world. Especially during the peaks of the pandemic, healthcare professionals were confronted with high numbers of seriously chronic ill patients, staff absences due to COVID-19 infection and self-isolation mandates and concerns about the ability to deliver high quality care in these circumstances. Patients in the last stage of life and their families were in particular affected as under these circumstances it is extra difficult to tailor care to their individual needs and preferences, a core value in care in the last stage of life.

Empirical studies about care at the end of life during the COVID-19 pandemic that have been published until now, predominantly focused on symptom burden and management in studies in patients attended by palliative care services in hospitals.⁴⁻⁸ They show that dyspnoea, agitation and pain are prevalent and can generally be controlled relatively well. However, it is known that many people die in other settings, such as care homes, or without involvement of palliative care services.^{3,9} Furthermore,

these studies focus on symptoms, while care at the end of life also involves attention for other aspects, such as emotional support, spiritual care and attendance of family. Research on these aspects is mainly based on expert opinions and lived experiences.^{10,11} Strang et al.¹² studied patients who died of COVID-19 in all settings in Sweden (mainly hospitals and care homes). They found that these patients had less often had end-of-life discussions or consultations by a palliative care team, and more often died alone than patients who died the year before. Finally, the empirical studies done so far tend to focus on patients who died from COVID-19, while care at the end of life for patients who die of other causes may also have been affected by the pandemic.

It can be questioned to what extent the COVID-19 pandemic and the restrictive measures that were taken, non-intentionally resulted in substandard care for patients in the last phase of life with and without COVID-19. In order to learn lessons for future infection waves or other crisis situations, we studied end-of-life care practices as provided during the first peak of the COVID-19 pandemic in different healthcare settings from the perspective of healthcare professionals.

Methods*Research questions*

- What are the characteristics of patients who died during the first COVID-19 wave in the Netherlands and do they differ between patients with and without COVID-19?

- What are the characteristics of end-of-life care in terms of provided care, communication with patient and relatives, treatment limitations and perspectives on patients' dying process and how are these characteristics related to patient characteristics, setting and visiting restrictions.

Design

We performed an open observational online questionnaire survey in which we invited health care professionals to describe their experience with providing end-of-life care to a patient during the first wave of the COVID-19 pandemic, that is, between 1 March and 31 July 2020. The patient could have died either with or without being infected with COVID-19.

Population

We conducted an open online questionnaire survey, to create a convenience sample of health care professionals who had provided end-of-life care from all over the Netherlands. We distinguished three groups of healthcare professionals: physicians, nurses (including nurse specialists and nursing aids) and other healthcare professionals.

Setting

Health care professionals working in all settings, including home care, hospital, nursing home and hospice, could fill out the questionnaire.

Recruitment

The survey was advocated widely through relevant health-care professional organisations (for example oncologists, internal medicine specialists, general practitioners and nurses), palliative care networks and organisations, volunteer networks and personal contacts throughout the Netherlands. These networks and organisations had different approaches to advocate the study: they advertised it on their website, in a newsletter, in a mailing to their members or in a post on social media. All approaches included a link to the survey that was made in an online data collection programme (LimeSurvey).

Data collection

In the questionnaire, respondents were instructed as follows in case they had been involved in the care of more than one patient who had died after March 1, 2020: 'if you experienced more than one death, you can determine for yourself for which deceased patient or client you fill out the questionnaire. You can also choose to fill out the questionnaire more than once'. Respondents were asked to indicate whether it was the first, second or third time they filled out the questionnaire. The questionnaire included an of the international Care Of the Dying Evaluation (iCODE)

questionnaire that focuses on the last 2 days of life and bereavement period, and asks about the characteristics of patient care and family support.^{13,14} From this questionnaire we omitted a question on administration of fluids and replaced a question on death rattle for a question on shortness of breath. Given that healthcare staff were burdened by high numbers of seriously ill patients, lack of staff, moral distress and concerns about their own health and their family's health, we added self-developed questions about the impact of COVID-19 and associated measures; they were based on frequently mentioned concerns in professional and lay media. Furthermore, we asked respondents to select terms that they thought best described the patient's dying trajectory from a predefined list. The Supplemental Appendix shows an overview of the questions used, the way they were categorised for further analyses, and whether they were used as independent or dependent variable.

Analysis

We describe the characteristics of end-of-life care during the COVID-19 epidemic, as assessed by healthcare staff. We distinguished three groups of healthcare staff: physicians, nurses (including nurse specialists and nursing aids) and other healthcare professionals. Patient characteristics, setting and terms best describing how a person died are summarised for the total population and for patients with and without COVID-19 separately. We tested differences between these two groups with χ^2 -tests. Associations between patient characteristics and setting as independent variables and aspects of (evaluation of) care as dependent variables were analysed with univariable and multivariable logistic regression analyses. All univariable analyses were controlled for the profession of the respondent (nurse, physician or other). In multivariable logistic analyses all independent variables were entered that were significantly ($p < 0.10$) associated with the dependent variable in the univariable analysis, while controlling for profession of the respondent. In the analyses, missing observations were not imputed; numbers of missing observations are reported in the footnotes of tables. Finally, we selected some experiences as described by respondents in an open box at the end of a questionnaire.

Ethical issues

Respondents explicitly had to consent to their answers being used for research, before being given access to the questionnaire. Respondents who were willing to participate in later additional interviews or follow-up questionnaires provided their email address. This personal data is stored at a separate location. Otherwise no personal data was collected. The Medical Ethics Committee Erasmus MC of Rotterdam, The Netherlands, has assessed that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply (MEC-2020-0254).

Results

Patient and care characteristics

The online questionnaire was completed for 761 cases by 747 respondents (13 respondents filled out two and 1 respondent filled out three questionnaires): 544 by nurses, 114 by physicians and 99 by healthcare providers from other disciplines, such as spiritual counsellors and volunteers. The characteristics of the patients about whom they filled in the questionnaire and their care are described in Table 1. The data concerned 327 patients without and 427 patients with a COVID-19 infection (of seven patients this was not reported). The

majority of patients were over 75 years old in both groups. Of all patients, 89.7% had one or more serious chronic illness. Pain, breathlessness and agitation were common symptoms during the last 2 days of life, with pain being less frequently reported for patients with COVID-19 (41.4% vs 58.5%), and breathlessness (79.1% vs 44.2%) and agitation (63.9% vs 57.7%) more frequently.

Within our sample, compared to patients without COVID-19, patients with COVID-19 more often died in the hospital (47.1% vs 14.1%) or nursing home (29.3% vs 19.6%), and less often at home (11.0% vs 35.5%) or in an inpatient hospice (2.6% vs 23.2%).

Table 1. Background characteristics of patients according to the patient having COVID-19 or not (absolute numbers and rounded %).

	No COVID-19		COVID-19		Total ^c	
	N = 327		N = 427		N = 761	
	abs	%	abs	%	abs	%
Respondent^a						
Nurse	230	70.8	310	72.9	544	72.9
Physician	38	11.7	74	17.4	114	15.1
Other	57	11.5	41	9.6	99	13.1
Patient characteristics						
Sex^a						
Man	138	42.5	239	56.2	382	50.5
Woman	197	57.5	186	43.8	375	49.5
Age						
≤65 years	68	21.3	72	17.0	144	18.9
66–75 years	70	21.9	90	21.2	161	21.4
76–85 years	97	30.3	162	38.2	261	34.8
>85 years	85	26.6	100	23.6	185	24.6
COVID-19						
Certainly	0		356	83.4	356	47.2
Probably	0		71	16.6	71	9.4
Probably not	101	30.9	0		101	13.4
Certainly not	218	66.7	0		218	28.9
Don't know	8	2.4	0		8	1.1
Serious (chronic) illness^{a,b}						
Cancer ^a	200	61.3	50	11.8	253	33.4
Heart disease ^a	69	21.2	120	28.3	189	25.0
Lung disease ^a	53	16.3	96	22.6	151	19.9
Diabetes ^a	28	8.6	92	21.7	122	16.1
Dementia ^a	51	15.6	121	28.5	174	23.0
Other	69	21.2	92	21.7	166	21.9
Symptoms in the last 2 days of life						
Breathlessness ^a	140	44.2	329	79.1	473	63.9
Pain ^a	186	58.5	173	41.4	362	48.7
Agitation	184	57.7	267	63.9	455	61.2
Care characteristics						
Setting^a						
Home	116	35.5	47	11.0	163	21.4
Hospital	46	14.1	201	47.1	249	32.7
Nursing home	64	19.6	125	29.3	192	25.2

(Continued)

Table 1. (Continued)

	No COVID-19		COVID-19		Total ^c	
	N = 327		N = 427		N = 761	
	abs	%	abs	%	abs	%
Hospice	76	23.2	11	2.6	89	11.7
Other	25	7.6	43	10.1	68	8.9
At a Covid ward or institution ^a	31	9.5	243	56.9	275	36.1
Visitors allowed in last 2 days ^a						
Yes, without restrictions	103	34.0	67	17.0	170	24.1
Yes, with restrictions	186	61.4	280	71.1	472	67.0
No	14	4.6	47	11.9	62	8.8
Terms best describing how somebody died ^b						
Quiet ^a	233	74.7	240	58.3	479	65.5
Good ^a	122	39.1	110	26.7	237	32.4
Sad ^a	63	20.2	185	44.9	249	34.1
Hectic ^a	10	3.2	36	8.7	46	6.3
Shocking ^a	11	3.5	33	8.0	44	6.0
Painful ^a	11	3.5	41	10.0	53	7.3
Intimate ^a	54	17.3	35	8.5	89	12.2
Degrading ^a	7	2.2	59	14.3	66	9.0
Touching ^a	41	13.1	83	20.1	125	17.1
Dignified ^a	119	38.1	96	23.3	217	29.7
Restless ^a	14	4.5	63	15.3	79	10.8
Peaceful ^a	128	41.0	103	25.0	234	32.0
Use of positive and negative terms to describe how the patient died ^a						
Only negative terms	24	7.9	78	19.7	103	14.6
Positive and negative terms	61	20.0	166	42.0	228	32.2
Only positive terms	220	72.1	151	38.2	376	53.2

^aDifference between the non-COVID-19 and the COVID-19 group is statistically significant (χ^2 -test, $p < 0.05$).

^bMore than one answer possible.

^cMissing observations: COVID-19 7, respondent 4, sex 4, age 10, serious diseases 4, breathlessness 21, pain 18, agitation 17, visits allowed 57, terms describing how patient died 54.

While relatives in the Netherlands were often not allowed to visit patients admitted to health care institutions during the first wave of the pandemic, we found that visitors had been allowed without restrictions during the last 2 days of life for 24.1% of all patients. In 67.0%, restrictions had been imposed, either in number or in the time that could be spent with a patient, and in 8.8% visitors were not at all allowed during the last 2 days of life. Visiting restrictions were more common for patients with than patients without COVID-19 (83.0% vs 66.0%).

Respondents selected only 'positive' terms (e.g. quiet, good, peaceful, dignified) to describe the death of the patient involved in 53.2% of all cases, and only 'negative' terms (e.g. restless, degrading, painful) in 14.6%.

Appreciation of medical, nursing and personal care

Most respondents (86.2%–88.1%) thought that there had been enough medical, nursing and personal care in the last 2 days of life of the patient they reported on (Table 2). The likelihood that medical care was rated as sufficient was

higher for patients with a serious chronic illness (OR 2.17), and patients dying in a hospice as compared to patients dying at home (OR 4.12), and lower for patients dying in a nursing home as compared to patients dying at home (OR 0.52). The likelihood that nursing care and personal were rated as sufficient was also higher for patients dying in a hospice as compared to patients dying at home (OR 5.16 and OR 4.34, respectively).

Appreciation of emotional support, spiritual care and sharing prognosis

Respondents thought that there had been sufficient emotional support in 65.8% and sufficient spiritual support for the patient and relatives in 58.9% of all cases (Table 3). Multivariable logistic regression analyses showed that sufficient emotional support was more common for patients with a serious chronic illness (OR 2.14), and less common for patients with COVID-19 (OR 0.62), patients dying in a nursing home as compared to patients dying at home (OR 0.36) and patients for whom there had been restricted (OR 0.46) or no (OR 0.23)

Table 2. Patient and care characteristics related to care for people who died during the Corona crisis being sufficient (n = 761).^a

	Sufficient medical care ^b			Sufficient nursing care ^b			Sufficient personal care ^b		
	Row-%	OR		Row-%	OR		Row-%	OR	
		Univariate	Multivariable		Univariate	Multivariable		Univariate	Multivariable
Total	87.4			86.2			88.1		
Patient characteristics									
Gender									
Male (n = 382)	88.1	1.00		86.9	1.00		88.2	1.00	
Female (n = 375)	87.1	0.93 (0.60–1.44)		86.0	0.93 (0.61–1.42)		88.2	1.01 (0.65–1.57)	
Age									
≤65 years (n = 144)	89.6	1.00		85.4	1.00		84.0	1.00	
66–75 years (n = 161)	87.0	0.788 (0.39–1.61)		89.4	1.43 (0.72–2.84)		90.1	1.70 (0.86–3.37)	
76–85 years (n = 261)	89.6	1.01 (0.52–1.96)		85.8	1.04 (0.58–1.86)		88.1	1.42 (0.79–2.55)	
>85 years (n = 185)	84.2	0.62 (0.32–1.20)		85.3	1.01 (0.54–1.87)		89.1	1.58 (0.83–3.02)	
COVID-19									
(Probably) not (n = 327)	89.3	1.00		88.6	1.00		91.1	1.00	
(Probably) yes (n = 427)	86.4	0.70 (0.45–1.11)		84.7	0.73 (0.47–1.13)		85.7	0.59 (0.37–0.95)	0.67 (0.39–1.14)
Serious (chronic) illness									
No (n = 78)	78.2	1.00	1.00	80.8	1.00	1.00	80.8	1.00	
Yes (n = 679)	88.6	2.12 (1.17–3.83)	2.17 (1.16–4.05)	87.1	1.69 (0.91–3.11)	1.85 (0.98–3.50)	88.9	1.98 (1.07–3.66)	1.92 (1.00–3.69)
Care characteristics									
Setting									
Home (n = 163)	88.9	1.00	1.0	85.1	1.00	1.00	87.6	1.00	1.00
Hospital (n = 249)	87.1	0.84 (0.45–1.58)	0.95 (0.50–1.81)	88.4	1.41 (0.78–2.53)	1.54 (0.85–2.81)	88.8	1.18 (0.64–3.29)	1.61 (0.81–3.19)
Nursing home (n = 192)	81.2	0.53 (0.28–0.98)	0.52 (0.28–0.98)	81.2	0.81 (0.46–1.44)	0.81 (0.46–1.44)	83.8	0.79 (0.43–1.45)	0.90 (0.47–1.71)
Hospice (n = 89)	96.6	4.20 (1.17–15.0)	4.12 (1.15–14.7)	96.6	5.24 (1.51–18.2)	5.16 (1.48–17.9)	96.6	4.34 (1.23–15.3)	3.99 (1.12–14.2)
Other (n = 68)	92.6	1.67 (0.58–4.78)	1.70 (0.59–4.90)	85.3	1.09 (0.48–2.45)	1.11 (0.49–2.51)	88.2	1.15 (0.47–2.79)	1.39 (0.55–3.47)
At a Covid ward or institution									
No (n = 486)	87.2	1.00		86.3	1.00		87.6	1.00	
Yes (n = 275)	88.4	1.09 (0.69–1.71)		86.9	1.04 (0.67–1.61)		89.1	1.15 (0.72–1.83)	

Row values indicate Odds Ratio's that significantly differ from 1.0.

^aMissing observations: medical care 2, nursing care and personal care 3, respondent. Gender and serious illness 4, COVID-19 7, age 10, restlessness 17, pain 18, shortness of breath 21.

^bCare is considered sufficient when the respondent indicated to agree or strongly agree with a statement that it was sufficient.

access for visitors. Spiritual care was less often rated as sufficient for patients dying in a nursing home as compared to patients dying at home (OR 0.46), and for patients for whom visitors were not allowed in the last 2 days of life (OR 0.21), but it was more often rated as sufficient for patients who died in a designated COVID-19 ward (OR 1.87).

Agreement on treatment limitations

Treatment limitations were common: agreements not to resuscitate were present in 82.5% of all patients, agreements not to transfer patients to an intensive care unit (ICU) in 73.0%, and agreement not to hospitalise patients in 49.6% (Table 4). No-ICU agreements were more common for patients aged between 76 and 85 years as compared to patients under 65 (OR 1.78), patients with COVID-19 (OR 1.60), patients with a serious chronic illness (OR 2.87), and patients dying in the hospital (OR 2.44). No-hospitalisation agreements were especially common in patients with a serious chronic illness (OR

3.57), and less common in patients dying in designated COVID-19 wards (OR 0.46).

Evaluation of the dying process

Of all respondents, 41.2% thought that the patient's care or treatment had been restricted due to the COVID-19 pandemic. This was positively associated with having COVID-19 (OR 1.77) and visitors not being allowed in the last 2 days (OR 3.74) (Table 5).

Just over half of our respondents (53.2%) used only positive terms to describe the patient's death. This was positively associated with patients' age, especially with the patient being older than 85 years compared to being 65 or younger (OR 1.90), and with having a serious chronic illness (OR 1.93) and negatively associated with the patient having COVID-19 (OR 0.35), dying in the hospital (OR 0.42) and no access for visitors in the last 2 days of life (OR 0.46) (Table 5). Box 1 provides examples of what type of situations lie behind the experiences of providing care for patients in the first wave of the COVID-19 pandemic.

Box 1. Examples of experiences with the care for patients in the first wave of the COVID-19 pandemic.

What we did well, is that we were able to let the wife of the patient be present despite the restrictions around family visiting patients with COVID-19 in the hospital. We saw the end-of life approaching and already had a discussion about that he possibly might not survive with the patient and his wife in the week before he died (physician about a man with COVID-19 (76–85 years) in hospital).

What I missed in this case is a physician clearly indicating to the client that she was in the terminal phase. This resulted in the client fighting against and suffering from the symptoms of COVID-19 unnecessary long (nurse about a woman with COVID-19 (>85 years) in care home).

We cared for this man as part of a Corona team; we made a home visit every 4 h and were on call for the partner. We had good contact with the man's general practitioner. We started a terminal care pathway, and the client died in the presence of his partner and a nurse while his favourite music was playing on the background (nurse about a man with COVID-19 (76–85 years) at home).

I think that given the circumstances we tried to do everything that was essential for the client. However, due to the work load we received signals later than desirable. There was too little time to go into his room more often (nurse about a man with COVID-19 (76–85 years) in care home).

The husband was present 24/7 during the 5 days dying phase. Luckily, every now and then one of the children was allowed to stay (overnight). To support him; the patient was no longer responsive due to palliative sedation (nurse about a woman without COVID-19 (≤65 years) in hospice).

What I found most sad about the situation is that he was rather lonely in the last phase of his life because his wife, who had just lost her mother to Corona, was afraid to visit her husband. They had many phone calls, but that remains sad (physician about a man with COVID-19 (<65 years of age) in hospital).

The medical specialist gave the bad news per telephone 2 weeks ago and handed over medical care to the general practitioner. The general practitioner followed the patient by telephone for a long time. She felt less supported due to this, both by the medical specialist and the general practitioner (nurse about a woman without COVID-19 (≤65 years) at home).

Due to the restrictions around COVID-19 the care staff was not allowed to take care of the client after she had died; she was removed very quickly from the nursing home. This was shocking and sad for the care staff who had cared for her for over 10 years (other caregiver about a woman without COVID-19 (>85 years) in care home).

It hurt me to see the daughter sitting at the bed of the resident fully protected and that, because of that, the resident did not recognise her daughter. The partner was standing at the other side of the window (grieving a lot). In my opinion he was not able to say farewell to his wife in a dignified way (nurse about a woman with COVID-19 (75–85 years) in care home).

It was sad to see the daughter of the deceased being sad and not being able to do more than trying to express this feeling in words at one and half meters distance. This gave some connection, but one would mean to do more during a farewell process (other caregiver about a man without COVID-19 (75–85 years) in hospice).

Table 3. Patient and care characteristics related to emotional and spiritual support and sharing prognosis with patient and relatives in the last 2 days of life of people who died during the Corona crisis being sufficient (n = 761).^a

	Sufficient emotional support ^b			Sufficient attention for spiritual needs ^b			Informed that patient was likely to die soon ^b		
	Row-%	OR		Row-%	OR		Row-%	OR	
		Univariate	Multivariable		Univariate	Multivariable		Univariate	Multivariable
Total	65.8			58.9			86.7		
Patient characteristics									
Gender									
Male (n = 382)	62.7	1.00	1.00	58.6	1.00	1.00	85.5	1.00	1.00
Female (n = 375)	69.3	1.33 (0.97–1.81)	1.27 (0.90–1.79)	59.1	1.03 (0.75–1.41)	1.03 (0.75–1.41)	87.9	1.28 (0.82–1.99)	1.28 (0.82–1.99)
Age									
≤65 years (n = 144)	64.0	1.00	1.00	56.1	1.00	1.00	81.5	1.00	1.00
66–75 years (n = 161)	70.7	1.35 (0.82–2.23)	1.22 (0.74–2.01)	60.6	1.22 (0.74–2.01)	1.22 (0.74–2.01)	88.4	1.67 (0.86–3.27)	1.67 (0.86–3.27)
76–85 years (n = 261)	64.0	0.99 (0.65–1.54)	1.22 (0.78–1.90)	60.4	1.22 (0.78–1.90)	1.22 (0.78–1.90)	87.0	1.53 (0.86–2.71)	1.53 (0.86–2.71)
>85 years (n = 185)	64.6	1.03 (0.64–1.65)	1.09 (0.67–1.75)	57.6	1.09 (0.67–1.75)	1.09 (0.67–1.75)	89.0	1.80 (0.94–3.43)	1.80 (0.94–3.43)
COVID-19									
(Probably) not (n = 327)	76.7	1.00	1.00	70.3	1.00	1.00	90.5	1.00	1.00
(Probably) yes (n = 427)	57.5	0.42 (0.30–0.59)	0.62 (0.40–0.96)	50.3	0.43 (0.31–0.60)	0.59 (0.30–1.15)	83.8	0.51 (0.32–0.81)	0.86 (0.46–1.78)
Serious (chronic) illness									
No (n = 78)	46.4	1.00	1.00	41.0	1.00	1.00	73.5	1.00	1.00
Yes (n = 679)	67.8	2.51 (1.52–4.15)	2.14 (1.23–3.71)	60.7	2.36 (1.37–4.05)	1.78 (0.99–3.20)	88.2	2.50 (1.38–4.53)	1.51 (0.76–2.97)
Care characteristics									
Setting									
Home (n = 163)	78.7	1.00	1.00	70.4	1.00	1.00	90.9	1.00	1.00
Hospital (n = 249)	63.1	0.46 (0.29–0.74)	0.67 (0.34–1.32)	57.2	0.56 (0.36–0.89)	0.59 (0.30–1.15)	78.2	0.37 (0.20–0.70)	0.38 (0.15–0.94)
Nursing home (n = 192)	48.9	0.26 (0.16–0.43)	0.36 (0.21–0.63)	47.5	0.38 (0.23–0.61)	0.46 (0.27–0.80)	90.3	0.95 (0.45–2.01)	0.88 (0.39–2.02)
Hospice (n = 89)	84.7	1.45 (0.71–2.97)	1.38 (0.65–2.94)	71.3	0.99 (0.54–1.83)	0.79 (0.41–1.59)	95.3	2.51 (0.79–8.00)	1.68 (0.50–5.63)
Other (n = 68)	66.2	0.51 (0.27–0.97)	0.64 (0.28–1.47)	51.6	0.44 (0.24–0.83)	0.36 (0.16–0.82)	85.7	0.66 (0.27–1.63)	0.62 (0.19–2.00)
At a Covid ward or institution									
No (n = 486)	68.6	1.00	1.00	60.9	1.00	1.00	90.8	1.00	1.00
Yes (n = 275)	61.3	0.74 (0.54–1.01)	1.26 (0.72–2.20)	55.9	0.81 (0.59–1.12)	1.87 (1.04–3.35)	80.3	0.41 (0.26–0.63)	1.16 (0.53–2.51)
Visitors allowed in last 2 days									
Yes, without restrictions (n = 170)	82.4	1.00	1.00	72.9	1.00	1.00	91.2	1.00	1.00
Yes, with restrictions (n = 472)	63.1	0.36 (0.23–0.56)	0.46 (0.29–0.75)	57.6	0.51 (0.34–0.77)	0.67 (0.43–1.03)	89.4	0.81 (0.44–1.49)	0.94 (0.50–1.79)
No (n = 62)	42.6	0.16 (0.08–0.30)	0.23 (0.12–0.45)	30.4	0.15 (0.08–0.30)	0.21 (0.10–0.42)	56.5	0.13 (0.06–0.27)	0.17 (0.08–0.36)

Bold values indicate Odds Ratio's that significantly differ from 1.0.

^aMissing observations: emotional support 45, attention for spiritual care 118 (15.6%), told likely to die soon 54, shortness of breath 21, pain 18, restlessness 17, respondent and gender 4, COVID-19 7, age 10, visitors allowed 57 (7.5%).

^bA symptom is considered present when the respondent reported that it was present all of the time or some of the time during the last 2 days of life.

Table 4. Patient and care characteristics related to agreements about treatment limitations in the last 2 days of life of people who died during the Corona crisis being sufficient (n = 761).^a

	Do not resuscitate ^b			No admittance to intensive care unit ^b			No hospital admission ^b		
	Row-%	OR	OR	Row-%	OR	OR	Row-%	OR	OR
		Univariate	Multivariable		Univariate	Multivariable		Univariate	Multivariable
Total	82.5			73.0			49.6		
Patient characteristics									
Gender									
Male (n = 382)	82.3	1.00		72.9	1.00		41.9	1.00	
Female (n = 375)	83.0	1.07 (0.71–1.59)		73.3	1.05 (0.74–1.48)		57.4	1.92 (1.41–2.61)	1.31 (0.83–2.06)
Age									
≤65 years (n = 144)	83.1	1.00		66.9	1.00	1.00	37.5	1.00	1.00
66–75 years (n = 161)	83.5	0.99 (0.52–1.88)		71.9	1.20 (0.71–2.03)	1.08 (0.63–1.87)	38.1	0.98 (0.59–1.61)	0.97 (0.46–2.04)
76–85 years (n = 261)	84.8	1.13 (0.63–2.03)		79.7	1.93 (1.18–3.14)	1.78 (1.06–2.99)	52.8	1.84 (1.19–2.86)	1.23 (0.63–2.41)
>85 years (n = 185)	78.7	0.74 (0.41–1.34)		69.5	1.11 (0.67–1.82)	1.21 (0.69–2.11)	63.4	2.84 (1.76–4.58)	1.14 (0.56–2.32)
COVID-19									
(Probably) not (n = 327)	81.7	1.00		67.0	1.00	1.00	62.7	1.00	1.00
(Probably) yes (n = 427)	83.9	1.06 (0.71–1.59)		77.4	1.64 (1.16–2.32)	1.60 (1.01–2.53)	39.7	0.38 (0.27–0.52)	1.44 (0.85–2.43)
Serious (chronic) illness									
No (n = 78)	62.7	1.00	1.00	56.7	1.00	1.00	19.4	1.00	1.00
Yes (n = 679)	84.8	3.23 (1.87–5.58)	4.57 (2.52–8.31)	74.8	2.14 (1.27–3.61)	2.87 (1.62–5.10)	53.1	4.54 (2.43–8.52)	3.57 (1.53–8.34)
Care characteristics									
Setting									
Home (n = 163)	77.1	1.00	1.00	63.9	1.00	1.00	72.9	1.00	1.00
Hospital (n = 249)	87.8	2.18 (1.25–3.81)	2.30 (1.04–5.07)	77.3	2.03 (1.28–3.23)	2.44 (1.23–4.81)	2.6	0.01 (0.00–0.02)	0.01 (0.01–0.04)
Nursing home (n = 192)	80.8	1.25 (0.72–2.17)	1.17 (0.66–2.08)	75.4	1.79 (1.09–2.93)	1.48 (0.85–2.57)	75.4	1.08 (0.64–1.81)	1.02 (0.55–1.86)
Hospice (n = 89)	80.0	1.28 (0.64–2.58)	1.24 (0.61–2.53)	66.7	1.30 (0.71–2.37)	1.37 (0.74–2.56)	76.0	1.33 (0.69–2.58)	1.25 (0.63–2.47)
Other (n = 68)	83.6	1.56 (0.69–3.54)	1.52 (0.54–4.27)	80.0	2.45 (1.16–5.20)	2.79 (1.10–7.06)	69.1	0.83 (0.41–1.66)	1.43 (0.55–3.74)
At a Covid ward or institution									
No (n = 486)	79.8	1.00	1.00	70.3	1.00	1.00	67.4	1.00	1.00
Yes (n = 275)	86.9	1.68 (1.09–2.60)	1.35 (0.68–2.67)	77.2	1.44 (1.01–2.07)	0.75 (0.40–1.41)	21.2	0.13 (0.09–0.18)	0.46 (0.22–0.97)

Bold values indicate Odds Ratio's that significantly differ from 1.0.

^aMissing observations: do not resuscitate, no admittance to ICU and no hospital admission 91, shortness of breath 21, pain 18, restlessness 17, respondent and gender 4, COVID-19 7, serious illness 4, age 10, visitors allowed 57 (7.5%).

^bA symptom is considered present when the respondent reported that it was present all of the time or some of the time during the last 2 days of life.

Table 5. Patient and care characteristics related to evaluation of the end of life of the patient who died during the Corona crisis being sufficient (*n* = 761).^a

	Care or treatment restricted due to COVID-19 pandemic ^b			Died at the right place ^b			Only positive terms to describe how patient died ^b		
	Row-%	OR	Univariate	Row-%	OR	Univariate	Row-%	OR	Univariate
			Multivariable			Multivariable			Multivariable
Total	41.2			81.8			53.2		
Patient characteristics									
Gender									
Male (<i>n</i> = 382)	44.8	1.00		78.5	1.00		48.7	1.00	
Female (<i>n</i> = 375)	37.7	0.756 (0.56–1.02)		85.0	1.60 (1.07–2.38)		58.0	1.44 (1.07–1.95)	1.11 (0.79–1.56)
Age									
≤65 years (<i>n</i> = 144)	38.5	1.00		74.6	1.00		45.2	1.00	
66–75 years (<i>n</i> = 161)	39.7	1.01 (0.63–1.63)		80.7	1.36 (0.76–2.41)		53.4	1.35 (0.84–2.17)	1.54 (0.90–2.61)
76–85 years (<i>n</i> = 261)	42.4	1.17 (0.76–1.80)		80.9	1.42 (0.85–2.38)		52.5	1.32 (0.86–2.02)	1.54 (0.94–2.52)
>85 years (<i>n</i> = 185)	44.3	1.28 (0.81–2.01)		88.8	2.65 (1.42–4.92)		59.8	1.82 (1.15–2.87)	1.90 (1.09–3.29)
COVID-19									
(Probably) not (<i>n</i> = 327)	32.6	1.00		90.5	1.00		72.1	1.00	
(Probably) yes (<i>n</i> = 427)	48.1	1.95 (1.43–2.67)		74.7	0.30 (0.19–0.47)		38.2	0.24 (0.17–0.33)	0.35 (0.23–0.53)
Serious (chronic) illness									
No (<i>n</i> = 78)	52.2	1.00		71.9	1.00		29.4	1.00	
Yes (<i>n</i> = 679)	40.0	0.61 (0.37–1.01)		83.0	1.81 (1.01–3.26)		55.6	3.06 (1.76–5.30)	1.93 (1.05–3.54)
Care characteristics									
Setting									
Home (<i>n</i> = 163)	36.5	1.00		96.7	1.00		66.7	1.00	
Hospital (<i>n</i> = 249)	43.3	1.35 (0.89–2.06)		59.2	0.05 (0.02–0.12)		34.2	0.24 (0.16–0.38)	0.42 (0.22–0.78)
Nursing home (<i>n</i> = 192)	49.2	1.70 (1.09–2.06)		91.2	0.35 (0.12–0.98)		51.4	0.49 (0.31–0.77)	0.70 (0.42–1.19)
Hospice (<i>n</i> = 89)	26.5	0.61 (0.33–1.10)		97.6	1.50 (0.28–7.93)		78.8	1.76 (0.94–3.31)	1.74 (0.88–3.44)
Other (<i>n</i> = 68)	41.5	1.26 (0.69–2.30)		76.6	0.11 (0.04–0.32)		59.4	0.66 (0.36–1.21)	0.83 (0.38–1.83)
At a Covid ward or institution									
No (<i>n</i> = 486)	39.1	1.00		92.1	1.00		62.3	1.00	
Yes (<i>n</i> = 275)	44.7	1.27 (0.94–1.73)		65.1	0.16 (0.10–0.24)		38.9	0.38 (0.28–0.52)	1.24 (0.71–2.15)
Visitors allowed in last 2 days									
Yes, without restrictions (<i>n</i> = 170)	32.7	1.00		87.1	1.00		65.9	1.00	1
Yes, with restrictions (<i>n</i> = 472)	41.2	1.41 (0.97–2.04)		83.0	0.71 (0.42–1.19)		51.5	0.53 (0.36–0.76)	0.67 (0.44–1.01)
No (<i>n</i> = 62)	64.5	3.74 (2.03–6.91)		57.6	0.21 (0.10–0.42)		32.3	0.24 (0.13–0.45)	0.46 (0.23–0.91)

Bold values indicate Odds Ratio's that significantly differ from 1.0.

^aMissing observations: care or treatment restricted due to corona crisis 43, died in the right place 81, only positive terms used 54, shortness of breath 21, pain 18, restlessness 17, respondent and gender 4, COVID-19 7, age 10, visitors allowed 57 (7.5%).

^bA symptoms is considered present when the respondent that it was present all of the time or some of the time during the last 2 days of life.

Discussion

Summary

We gathered healthcare professionals' experiences with care of patients with and without COVID-19 who died during the first wave of the COVID-19 pandemic. Most patients with COVID-19 who died also had an underlying serious chronic illness. Having COVID-19 was negatively associated, and having a serious chronic illness was positively associated with healthcare staff's appreciation of care at the end of life. Often there had been restrictions in relatives being allowed to visit the patient in the last 2 days of life: in 67.0% visits were restricted in number or time; in 8.8% no visits were allowed. Restrictions in visits were strongly negatively associated with healthcare staff's appreciation of care at the end of life and the dying process. Finally, care at the end of life was less favourably appreciated in hospitals and especially care homes, and more favourably in home settings and especially hospices.

Strengths and limitations

Strength of this study is that we collected information on end-of-life care of many patients, with and without COVID-19, during the first wave of the pandemic in all settings where people die. This was achieved by using an open online survey. A limitation of this method is that the data from our convenience sample are not necessarily representative. Comparison to Dutch registry data during the first peak of the pandemic shows that our sample of patients who died with COVID-19 is similar with regard to sex (56% vs 55% men) and also with having cancer (12% vs 15%), but somewhat different in age (63% >75 years vs 75% ≥75 years).¹⁵ It is possible that healthcare professionals were for instance more inclined to describe complex cases. While this means that presented frequencies have to be interpreted with caution, this is not a limitation for the analyses aimed at studying associations. Another limitation is that we only studied the experiences of healthcare professionals, and not those of patients or relatives. Previous research has shown that experiences with end of life care of professionals and bereaved relatives may differ.¹⁶

Symptom burden. Other studies found varying prevalences of pain (20%–57%), breathlessness (48%–84%) and agitation (23%–77%) among patients with COVID-19 in the last phase of life.^{4–7,17} These prevalences are difficult to compare to the prevalence found in this study, due to differences in methodologies, for example using patient records as data source or a focus on patients for whom a palliative care service was involved.

However, all but one of these studies also found that especially breathlessness and agitation were common in patients with COVID-19.^{4–7} Comparable to our study, a study from Sweden suggested that breathlessness occurred more frequently in patients with COVID-19 than patients without COVID-19. This study also found that establishing complete relief for breathlessness and agitation was more difficult in patients with COVID-19 than patients without COVID-19.¹⁷ In several other studies, however, it was concluded that the symptoms of COVID-19 patients could be treated well with similar drugs as used in other patients.^{4–8}

Sufficient medical, nursing and personal care

It is noticeable that in a large majority of cases medical, nursing and personal care were considered to have been sufficient, while at the same time almost half of the respondents stated that care or treatment had been limited due to the COVID-19 pandemic. Possibly respondents considered care to be sufficient given the limited possibilities in this crisis, as can also be seen in the examples given in Box 1. It is also possible that the care and treatment were especially limited in other aspects than medical, nursing and personal care. The appreciation of emotional care for patients and relatives and attention for spiritual needs was less favourable. This is in line with a study during the SARS outbreak that showed that especially the restrictions leading to isolation led to spiritual and psychosocial concerns due to loss of connectedness.¹⁸ Our results also indicate that especially restrictions in visits were associated with healthcare staff's more negative appreciation of end-of-life care. However, Box 1 also shows an example of medical care being hampered by a physician providing care over telephone.

Differences between patient groups

While having COVID-19 was negatively associated with several aspects of care, having a serious chronic illness was positively associated with several aspects of care. This might be related to the experience that patients with COVID-19, especially in the absence of an underlying serious chronic illness, relatively frequently suddenly declined. Above that it was difficult to get to know these patients and provide person-centred care.¹⁹ For patients having a serious chronic illness the end of life may have come more expectedly, which allowed the patient, relatives and professionals to get prepared. This might also explain why respondents were more likely to choose positive terms to describe how a person had died for patients who had a serious chronic illness and less likely when the patient had COVID-19.

Differences between settings

Setting and visiting restrictions were also frequently related to different aspects of care at the end of life. It is clear that care was appreciated less in nursing homes and hospitals and relatively more in hospices and the home setting. In part this is likely to be related to the size of institutions. It has for instance been found that residents of small scale living facilities have better social relations and relations with nursing staff than residents of regular larger scale nursing homes.²⁰ Another study found that hospital size was negatively associated with the ability to deliver care in a manner that is responsive to individual patient needs and preferences.²¹ In the pandemic this might translate to larger institutions setting more stringent restrictions or leaving less room for deviating from rules in specific cases. This while visiting restrictions, and especially allowing no visitors in the last 2 days of life seem to be related negatively to appreciation of care at the end of life. Furthermore, differences between settings can be related to settings differing in the extent to which they are equipped for providing palliative care with attention for all domains of care. Only in hospices this is the main aim of care. At the other end of the spectrum, hospitals are primarily directed at cure, which probably also is reflected in the patient population. This makes the transition to identifying death approaching and adjusting care to it more challenging.²² In nursing homes an extra challenge is that a large part of the nursing home population, for example patients with dementia, does not understand the visiting restrictions, and is not very skilled in using alternatives to have contact, such as telephone or video calls. In addition, especially in nursing homes there was a lack of personal protective equipment for health care staff.

Conclusion

We found that from the perspective of health care professionals the COVID-19 pandemic generally does not seem to have led to substandard care at the end-of-life at a large scale, especially with regard to medical and nursing care, although the small group for which medical and nursing home care was insufficient should not be disregarded. Healthcare providers felt that care especially fell short in the emotional and existential domain. It is recommended that in future waves or pandemics attention is paid to timely identification of the end of life approaching, and giving personal attention to patients and their relatives, among others by having attention for their psychosocial and existential concerns and foremost by, where possible, being flexible in allowing relatives visiting patients in the last phase of life in order to be able to say goodbye properly. Palliative care services are particularly equipped to assist in achieving this.^{4,5,16}

Author contributions

All authors contributed to the design of the study. The analyses were performed by BOP. BOP drafted the article and all other authors revised the article critically for important intellectual content. All authors approved the version to be published, and have participated sufficiently in the work to take public responsibility for appropriate portions of the content. BOP and AvH accept direct responsibility for the manuscript.

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Supplemental material

Supplemental material for this article is available online.

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