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Providing End-of-Life Care for Patients Dying of COVID-19 and Their Families in Isolated Death During the Pandemic in Japan

The Providing End-of-life Care for COVID-19 Project

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BACKGROUND: Death resulting from COVID-19 in a hospital during the pandemic has meant death in isolation. Although many health-care providers (HCPs) have struggled with end-of-life (EOL) care for these patients, the various strategies across hospitals are not well known.

RESEARCH QUESTION: What EOL care did HCPs give patients dying of COVID-19 and their families in hospitals during the COVID-19 pandemic? What were the key themes in care?

STUDY DESIGN AND METHODS: This qualitative study used individual, semistructured, internet, and face-to-face interviews. We recruited HCPs who provided EOL care to patients with COVID-19 dying in hospitals and their families. Purposive sampling was used through the academic networks at the School of Public Health, Kyoto University. Anonymized verbatim transcripts were analyzed thematically.

RESULTS: Fifteen doctors and 18 nurses from 23 hospitals in 13 regions across Japan participated; 16 participants (48%) were women, with an age range of 20 to 59 years (most were 30-39 years of age). Participants described 51 strategies, including providing physical and psychological-spiritual care, making connections, providing death care, and arranging care environments and bereavement care for patients and their families. Four themes emerged as prominent efforts in COVID-19 EOL care: maintaining relationships with isolated patients, connecting patients and families, sharing decision-making in isolation, and creating humanistic episodes.

INTERPRETATION: Proper application and awareness of the four themes may help HCPs to implement better EOL care. To compensate for limited memories resulting from isolation and rapid progression of the disease, communicating and creating humanistic episodes are emphasized. ICU diaries and the HCPs' arrangements based on cultural funerary procedures could be provided as grief care for the family and to build trust. EOL education and building partnerships among palliative care staff and nonmedical personnel on a regular basis may enhance the capacity to deliver the necessary support for EOL care. CHEST 2022; ■(■):■-■

KEY WORDS: COVID-19; end-of-life care; good death; qualitative research

ABBREVIATIONS: EOL = end-of-life; HCP = health-care provider; PPE = personal protective equipment

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Take-home Points

Study questions: What end-of-life (EOL) care did health-care providers (HCPs) give patients dying of COVID-19 and their families during the COVID-19 pandemic?

Results: The participants described 51 care strategies that emerged as prominent efforts in COVID-19 EOL care within four themes: maintaining relationships with isolated patients, connecting patients and families, sharing decision-making in isolation, and creating humanistic episodes.

Interpretation: To compensate for limited memory in isolation and rapid deterioration, ICU diaries and the HCP's arrangements based on cultural funerary customs could be provided to communicate and to create humanistic episodes.

As of August 2022, 6.4 million people have died of COVID-19 worldwide; this number continues to grow, although the new confirmed number of deaths is declining.^{1,2} Providing end-of-life (EOL) care for patients with COVID-19 and their families is challenging.^{3,4} The tragedy of dying in isolation without saying goodbye to loved ones and foregoing a formal funeral process has received attention in the media and causes patients and bereaved families to feel abandonment, anger, guilt, and dehumanization.⁵ Death in isolation causes constant rumination, leading to severe psychological and emotional distress for patients and their families⁵ as well as for health care providers (HCPs).⁶⁻⁸

Study Design and Methods

A qualitative descriptive study was used with an objective idealism view based on the recognition of varied shared experiences and the interactive-inseparable nature of human interaction to explore the experiences of HCPs in providing EOL care to patients with COVID-19 and their families.²³⁻²⁷ This study was conducted as part of the Providing End-of-Life Care for COVID-19 project exploring HCPs' experiences with their patients facing death as a result of COVID-19. We report this study following the Consolidated Criteria for Reporting Qualitative Research guidelines.²⁸

Participants, Sampling, and Recruitment

HCPs providing EOL care to patients with COVID-19 from March 2020 through December 2021 in Japan were included. The exclusion criteria were HCPs who had psychiatric problems such as depression or sleep disturbances or HCPs who might feel distressed when recalling their experiences. Using mailing lists from the School of Public Health at Kyoto University, we asked the graduate students and alumni to introduce potentially eligible participants from among

Traditionally, so-called good death studies have explored the concepts of ideal EOL care and death and have contributed to developing EOL care models, assessments, and guidelines.⁹⁻¹⁵ Recent systematic reviews have identified components of good death, such as the absence of physical pain and symptoms. Regarding the spiritual aspect of dying, good relationships with others, respected autonomy, a sense of life completion, and religious procedures and rituals are important.^{15,16} However, patients with COVID-19 often experience difficulty breathing, uncomfortable treatments, challenges in communication, extreme loneliness, no choice of location, and restrictions on cultural and religious rituals.^{5,17-19} From the perspective of good death studies, the process of dying of COVID-19 is far from a good death.

Although palliative care as part of physical management is indispensable, the strategies for spiritual EOL care for patients with COVID-19 and their families remain to be clarified.²⁰ Treatment and EOL care for patients with COVID-19 also are performed under pressure, leading to HCP burnout.^{21,22} Although pandemics have occurred throughout human history, the details of how EOL care is provided in the globalized world should be described and discussed. Given this context, we aimed to describe what kinds of EOL care were provided in multiple hospitals and to clarify the meaning and purpose of the provided care from the perspective of HCPs. The key themes of EOL care during the pandemic may provide insights in relationship to previous good death studies.

their colleagues. We then performed purposive sampling, recruiting eligible participants based on occupation, sex, hospital size, and region.²³ We sent e-mails to potential participants directing them to the website that provided an explanation of the research, and participants confirmed their intention to participate by clicking on an icon. Thirty participants had not met the interviewers before the study.

Data Collection

Personal, closed interviews were conducted using the Zoom online video platform by three female researchers (M. T., who holds an MD and a PhD; M. N., who is an occupational therapist and holds an MPH; and M. S., who is a nurse with experience working in the ICU and holds an MHS) who received training on qualitative research from senior researchers. We developed an interview guide based on two pilot interviews with HCPs who had experience with patient deaths resulting from COVID-19 (e-Table 1). The main questions were as follows: (1) What EOL care did you provide for patients with COVID-19 and their families? (2) How did you feel when providing this care? Thirty participants permitted face-to-face video

221 Q24 **TABLE 1] Participant and Hospital Characteristics**

Characteristic	No.	% ^a
Participant (n = 33)		
Specialty		
Medical doctor	15	45
Registered nurse	18	55
Sex		
Female	16	48
Male	17	52
Age, y		
≥ 50	2	6
40-49	9	27
30-39	15	45
20-29	7	21
Workplace		
ICU	9	27
ED	8	24
High care unit	3	9
Specialized COVID-19 ward	12	36
Infection control team	1	3
Hospital (n = 23)		
Region		
Hokkaido	1	4
Yamagata	1	4
Chiba	2	9
Tokyo	2	9
Kyoto	1	4
Osaka	2	9
Nara	3	13
Wakayama	1	4
Hyogo	4	17
Okayama	2	9
Hiroshima	1	4
Fukuoka	1	4
Okinawa	2	9
No. of beds		
≥ 1,000	3	13
800-999	4	17
600-799	4	17
400-599	5	22
200-399	6	26
< 200	1	4
No. of available beds for patients with COVID-19		
≥ 30	3	13
20-29	3	13
10-19	8	35

(Continued)

TABLE 1] (Continued)

Characteristic	No.	% ^a
1-9	7	30
Unknown ^b	2	9

^aThe total does not add up to 100% because of rounding of decimals to the first decimal place.

^bTwo participants did not know the maximum number of beds in their hospitals for patients with COVID-19 because they had moved to different hospitals.

recordings, and three participants agreed to audio recordings. Field notes were made during and after the interviews. Data saturation was achieved when no new codes were found in the interviews.²⁹

Data Analysis

All interviews were conducted in Japanese, were anonymized, and were transcribed verbatim. Inductive thematic analysis was used with semantic interpretation focusing on the meaning of care.^{30,31} Two independent researchers (M. T. and M. N.) coded the first 10 interviews. Through multiple discussions, they developed coding strategies; subsequently, M. N. continued coding and categorizing all transcriptions, and M. T. checked all labeling and quotations. Any disagreements were resolved through discussion with a third reviewer (H. M., a female academic researcher who holds a PhD).³² To enhance credibility, triangulation was performed by M. S., H. I. (a doctor and infectious diseases researcher working clinically with patients with COVID-19), and A. K. (a doctor and intensive care researcher working clinically with patients with COVID-19). We repeatedly refined the themes and referred to interview quotations to achieve a final consensus.³² Transcriptions were not returned to the participants, and the participants did not provide feedback on the findings. Most researchers of this study had medical backgrounds, which might have led to our empathic stances for HCPs throughout this study. Data were managed using NVivo 12.

Ethical Considerations

Before beginning the interviews, the interviewers orally reconfirmed the agreement to participate and the participants' right to withdraw at any time. The study was approved by the ethics committee of the Graduate School and Faculty of Medicine, Kyoto University (Identifier: R3027; July 12, 2021).

Results

Thirty-three individuals, including 16 women (48%), were enrolled from 23 hospitals in 13 regions across Japan, including Tokyo, Osaka, Hyogo, and Okinawa, which had massive numbers of cases of COVID-19 (Table 1). Of the 37 participants recruited, one did not participate because of time commitments and three did not respond to our e-mails. Finally, 33 individuals (89%) were interviewed for 50 min on average (SD, 10.6 min), and one was interviewed twice.

Because COVID-19-related deaths were considered a circumstance requiring strict infection control policies, the three actors—the patients, their families, and their HCPs—were “isolated” from one another despite their

331 increasing need for contact. HCPs struggled to provide
 332 care and respond to specific needs related to death in
 333 isolation. Among the 51 care strategies that were used
 334 during this time (Fig 1), four themes emerged:
 335 maintaining relationships with isolated patients,
 336 connecting patients and families, sharing decision-
 337 making in isolation, and creating humanistic episodes.
 338 Although some overlap occurred, the doctors tended to
 339 talk more about connecting patients and families and
 340 sharing decision-making in isolation, whereas the nurses
 341 tended to discuss maintaining relationships with isolated
 342 patients and creating humanistic episodes. Table 2
 343 depicts the themes and narrative data. Quotations were
 344 translated by the authors with the help of a professional
 345 language editor.

348 **Maintaining Relationships With Isolated Patients**

349 Infection control measures such as wearing personal
 350 protective equipment (PPE) and limiting contact time
 351 interfered with HCPs in creation and maintenance of
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relationships with patients. Given the limited
 opportunities for contact, HCPs attempted to maintain
 relationships with isolated patients by addressing the
 patients' loneliness, listening to them, talking to them,
 meeting their needs, and staying nearby when they died.

Addressing Patients' Loneliness: HCPs recognized that
 patients felt loneliness and emptiness and wished to end
 the situation.

"He was alone without doing anything, just waiting to
 die. . . . He said he wanted to commit suicide because he
 knew that his condition was worsening day by day."
 (participant 1, doctor)

HCPs tried to heal patients' loneliness. For example,
 doctors listened to them, and nurses positively
 communicated with patients during daily care, such as
 eating (participant 19, nurse) or playing songs and
 opening the windows so patients could enjoy the scenery
 (participant 28, nurse). A hospital advocated that staff
 should wear PPE so they could visit the patients in a

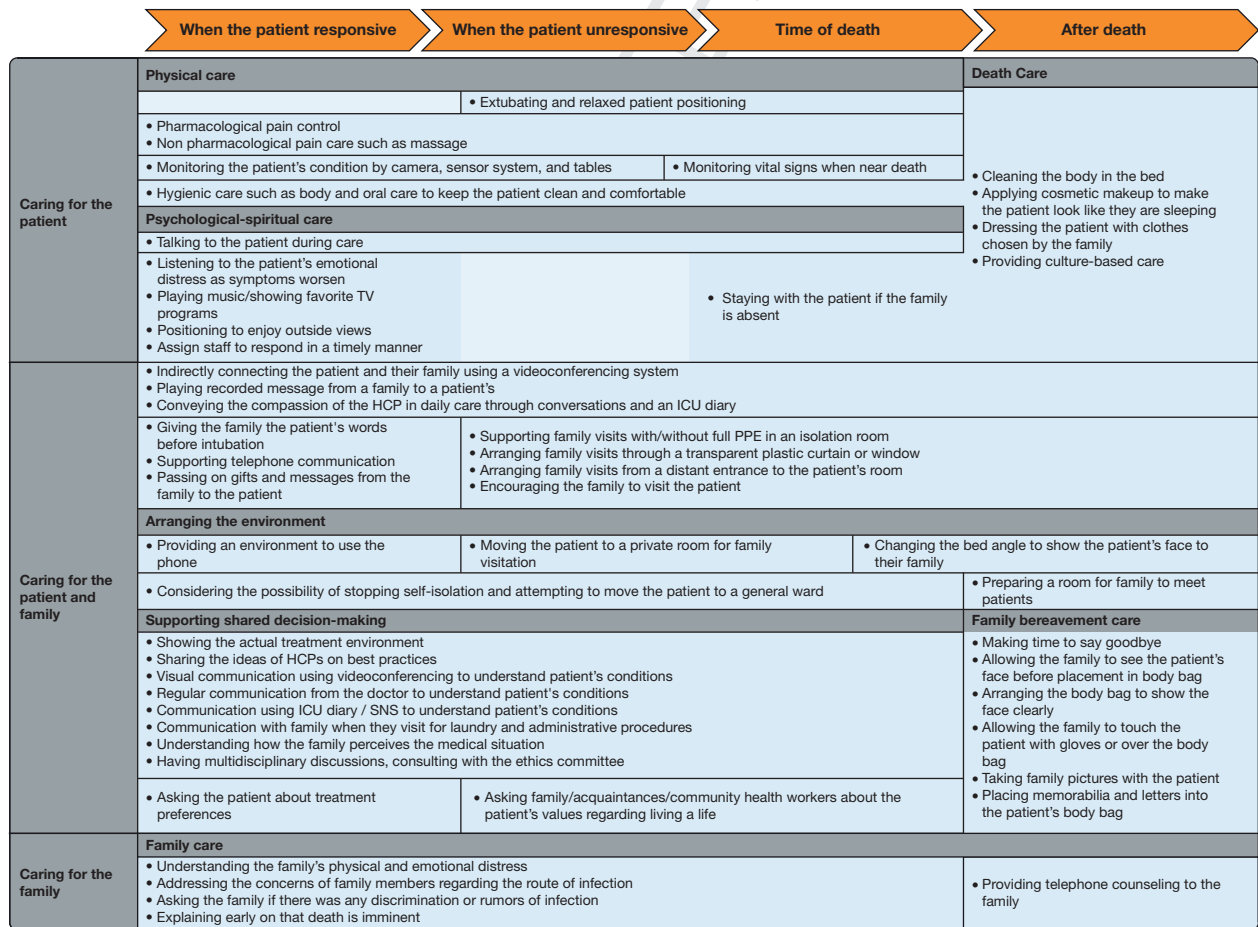


Figure 1 – Diagram showing end-of-life care provided to patients with COVID-19 and their families by health-care providers in Japan, displayed in chronological order. HCP = health-care provider; PPE = personal protective equipment.

TABLE 2] Themes, Definitions, Subthemes, Categories, and Quotations Regarding End-of-Life Care

Category	Quotation (Participant's Identification, Specialty, Sex)
Theme: Maintaining relationships with isolated patients	
Definition: Efforts to form and maintain relationships between patients with COVID-19 and HCPs	
Subtheme: Addressing patient's loneliness	
Identifying issues regarding how to spend time alone at the end of life	"My biggest dilemma was that I wondered if there was anything else I could do for them. Hmm . . . The COVID-19 patient's mental activity is functioning well, and I think their time until the end is valuable in itself. If the patient could find value in it, the time spent there would be meaningful. It is not about prolonging life. [Did you find any meaning?] No, I did not find any." (participant 14, doctor, male)
Addressing the feelings of isolation experienced by the patient	"I tried not to make time for loneliness. It is not just about having the TV on. I tried taking the initiative in helping with meals. I talked to them as I could when I was helping them eat." (participant 16, nurse, female)
Responding in a timely manner	"When he wanted to see the scenery outside, I only helped him look out through the window." (participant 28, nurse, female)
Subtheme: Talking to unresponsive patients	"It is tough working in the red zone, but we set up a nurse staffing system to respond to patients immediately while still wearing PPE. We allocated nurses to be in charge and made efforts to increase the frequency of nurses' visits to the rooms as much as possible." (participant 29, nurse, female)
Talking to the patients while providing care	"Of course, just because the patient is already intubated does not mean I'm going to skip certain procedures. I talked to the patient: 'How are you doing? I'm going to take a look at you.' And I would explain what's going on while talking to the patient." (participant 26, doctor, female)
Subtheme: Preventing death alone	
Preparing for the time of death	"The pulse wave form looked like PEA. I prepared by wearing PPE, calling his wife and other nurses." (participant 27, nurse, male)
Staying with patient if the family is absent	"He died on the night shift. We tried to stay by his side as much as possible, but we were very busy at that time, so when we could not, we asked a care worker to stay by his side for a while." (participant 15, nurse, female)
Theme: Connecting patients and families	
Definition: Efforts to connect the patient with their family members under circumstances of separation	
Subtheme: Messaging between patients and families	
Giving messages from the family to the patient	"Some people brought letters to the patients. Some people brought food that the patients could not eat, but they said, 'Please let her eat this if she wants.' I would take their gifts so that their feelings could be conveyed." (participant 29, nurse, female)
Giving messages from the patient to the family	"I asked the patient and his family to talk to each other because it would be the last time that they could have a conversation. Even a casual conversation was enough. Then, we intubated the patient." (participant 19, nurse, female)
Describing the patient's condition using photographs and messages	"It is like an ICU diary. Every day we take pictures of the patients, and the nurses on the day shift write a brief note of what happened today. The nurses on the day shift would take photographs of the patient every day and would keep a brief diary of what happened. The doctors and rehabilitation staff would sometimes add information. The social

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TABLE 2] (Continued)

Category	Quotation (Participant's Identification, Specialty, Sex)
	worker would send this information to the family's address. My patients' families were pleased about that." (participant 21, nurse, female)
Subtheme: Indirectly connecting patients and families	
Connecting the patient and family members synchronously	"The nurse in charge of the patient holds an electronic tablet device like this, saying, 'Well, I will start now. Yes, Mrs. [redacted], can you see me? Mr. [redacted] cannot speak right now, but he is doing his best like this.' Then, the family would reply, 'Oh, Dad, you are doing your best.' I would respond for him with something like, 'Yes, I'm doing my best.' Yeah." (participant 11, nurse, male)
Moving the patient and family members closer to each other	"The patient was the only one in the room, so I extended the ambu bag forcibly and brought him over to us. I moved the patient's bed to the glass door. The distance from the family was probably approximately 50 centimeters, right? I made it so that the family could see the patient up close." (participant 7, nurse, male)
Subtheme: Directly connecting patients and families	
Coordinating a family meeting under a high risk of infection	"At that time, PPE was very limited, and we were treating patients while wearing garbage bags or something. However, there were a few sets of PPE, so when I said, 'I want his family to visit with him when he is near death,' everyone said, 'Let's do that.' Only for patients who I thought may not be able to recover, I did [family] visits with PPE since last May or June [in 2019]." (participant 12, doctor, female)
Coordinating a family meeting under a low risk of infection	At present, all patients are released from isolation after 21 days from the onset of illness and are moved to the general ward. In that case, they are allowed to meet with their families in the same way as regular patients in the general ward." (participant 22, doctor, male)
Subtheme: Combining multiple communication tools	
Coordinating a family meeting using different tools	"At that time [May 2019, when PPE was in short supply in Japan], the patient's husband was already infected, so when he came down from the ward, he entered the ICU without any protective clothing. His daughter was not infected, so I had her go in there wearing full PPE. I had them meet the dying patient directly, and I removed the ventilator." (participant 10, doctor, male)
Theme: shared decision-making in isolation	
Definition: Efforts in sharing common care goals addressing the family's and patient's care preferences under isolation or separation and communication difficulties	
Subtheme: Understanding the families' distress	
the family for death	"I said to the family, 'If this treatment doesn't work anymore, I don't think he will survive.' Well, if I didn't tell them, I don't think they would be able to accept death suddenly. I tried to allow the family to prepare for death." (participant 12, doctor, female)
Addressing the family members' distress without direct visitation	"Nurses are used to family communication and usually ask, 'How are you doing? Are you okay?' Additionally, since there can be harmful rumors, we asked the family if they had any problems." (participant 11, nurse, male)
Confirming families' understanding of medical explanations	"Additionally, the nurses could see and talk with the families personally when we met with them on the tablets, so we asked them if they were well-rested . . . or, 'What did the doctor say about this? How was the explanation from the doctor?'" (participant 2, nurse, female)
Subtheme: Helping families understand patients' medical status	
Visual communication	

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TABLE 2] (Continued)

Category	Quotation (Participant's Identification, Specialty, Sex)
	"While on the videophone, the family can see how the patient's body has been damaged. Some families accept the end-of-life care plan saying, 'Yes, my father did his best.'" (participant 14, doctor, male)
Regular communication	"I made it a rule to call the family at least twice a week. Additionally, if the patient's condition suddenly changed or became critical, we would call." (participant 20, doctor, male)
Irregular communication	"[The family] brought the patient's laundry. Although they could not enter the patient's room, nurses could meet the family at the nurse's station, so I told them about the patient's condition." (participant 30, nurse, female)
Subtheme: Meticulous exploration of hidden preferences	
Addressing the patient's treatment preferences	"He indicated that he did not want to be reintubated. Since he clearly expressed this intention, I realized he have felt so hard during the treatment. So, he passed away without reintubation." (participant 5, doctor, male)
Asking about the patient's preferences	"When the patients have no relatives, I called the public health nurse who knows the person before, and asked if he wanted to fully live longer or if they have ever had that kind of conversation." (participant 26, doctor, female)
Consulting with multidisciplinary team	"We created a system to have regular multidisciplinary conferences to discuss patients who have already been hospitalized for a long time or when we need to review the current treatment plan using the Jensen's four-box model of clinical ethics." (participant 10, doctor, male)
Subtheme: Conveying the HCPs' compassionate care	
Conveying the staff's efforts to provide the best care for patients to families	"I wrote about the patient's condition and what I thought about the patient today for the family members at home. I thought, well, writing this is meaningful. I wanted to tell the family that we are doing our best with our belief in the patient's recovery." (participant 21, nurse, female)
Suggesting what they can do during the dying period	"I said to the families that we can support [them] wearing gloves and a gown, so I encouraged them to visit the [dying] patients." (participant 19, nurse, female)
Theme: Creating humanistic episodes	
Definition: Efforts to promote families' emotional recovery by providing humanistic episodes during care	
Subtheme: Promoting family involvement	
Allowing the family to touch the patient or over the body bag using gloves	"We allowed families to touch the patient using gloves and masks in the yellow zone." (participant 5, doctor, male)
Taking photographs with the patient	"I do not know if it was a good idea or not, but well, the body would be cremated soon, so I allowed them, if they wanted, to take a picture with him." (Participant 12, doctor, female)
Placing memorabilia and letters into the patient's body bag	"I put the letters, photos, and other things from the families into the body bags so that the deceased would not be lonely when the body was cremated." (participant 19, nurse, female)
Dressing the patient with clothes chosen by the family	"The nurses cleaned the body and applied makeup to the patient. Yes. So they dressed the patient in clothes that family brought and she liked when she was alive, like the kind of cloth she has worn on festive occasions, because it is culture in this region." (participant 5, doctor, male)
Creating mourning opportunities for families	"Since the deceased passed away from COVID-19, the funeral director would not touch the body at all. Therefore, we decided to set up a memorial service with the family at the hospital, like a small funeral, even though we could not hold one." (participant 19, nurse, female)

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TABLE 2] (Continued)

Category	Quotation (Participant's Identification, Specialty, Sex)
Subtheme: Sharing patients' EOL periods	
Recording the patient's efforts in an ICU diary	"When I gave the ICU diary to the deceased patient's family, they were truly grateful. The family said, 'I can feel from the diary that my father is doing his best with treatment.'" (participant 25, nurse, female)
Subtheme: Helping families see the patients' corpses	
Creating opportunities for the family to see the patient's face directly	"Two or three nurses helped each family member into PPE. Then, we let them touch the patient, visit with the patient, and put the patient's favorite things in the body bag. The family was very satisfied with this service and thanked me, saying, 'I truly did not expect them to do this for me.'" (participant 11, nurse, male)
Allowing the family to see the patient's face before placement in the body bag	"We transported the bodies to the yellow zone, where family members who had not been infected could see the patient before placing the body into a body bag. Once the body is placed in the body bag, the bag itself looks, well, slightly too oppressive, so . . ." (participant 5, doctor, male)
Arranging body bags to show the patient's face to the family	"The nurses believed that the transparent body bag would give the family a sense of satisfaction because they could see the person. Then, after the patient was placed in the transparent body bag, a blanket was placed over the bag to make it look more natural." (participant 20, doctor, female)

EOL = end-of-life; HCP = health-care provider; PEA = pulseless electrical activity; PPE = personal protective equipment.

timely manner without taking the time to put on PPE (participant 29, nurse). 826
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Talking to Unresponsive Patients: Most HCPs talked to patients during treatment, even when the patients were deeply sedated. Treating the patient as a person maintained the relationship between the patient and the HCP 828
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"Having a patient already intubated does not mean we cut corners in our communication. We asked the patient politely to let us see." (participant 26, doctor) 834
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Preventing Death Alone: When a patient was dying, some HCPs called the family, whereas other HCPs stayed with the patient as much as they could or asked care workers to stay 838
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"I want to prevent patients from dying alone. Always." (participant 14, nurse) 842
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Connecting Patients and Families 845

The HCPs believed that a patient dying in the absence of their family was "abnormal" (participant 4, nurse). Both frontline HCP staff and managers struggled with connecting patients with family members using innovative and traditional approaches, such as family visits and audio and video calls. Direct connection through family visits was preferred by the HCPs; however, the content of communication was valued despite the tools. 846
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Messaging Between Patients and Families: The HCPs facilitated communication between patients and their families by bringing letters and gifts from families to patients and helping patients to have conversations with their families before intubation. 856
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"I wanted patients to talk with their families before being intubated. If the patient's condition worsens, the trajectory is quite short. It is so fast!" (participant 11, nurse) 862
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Indirectly Connecting Patients and Families: HCPs used videoconferencing for synchronous connections between patients and families. Many HCPs considered videoconferencing an unsatisfactory communication tool for patients and families: "I personally wanted them to meet directly" (participant 6, nurse). However, some HCPs found it beneficial 867
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"Before (the COVID-19 pandemic), some families visited but ended up just looking at the monitors in the patients' rooms without touching or saying anything to the patient . . . however, in videoconferencing . . . only the patient's face was shown on the full screen, and the words spoken by the family, you know, it was heartfelt, from their heart." (participant 11, nurse) 875
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881	Directly Connecting Patients and Families: From	“Seeing the damage to the patient, the family agreed	936
882	October through December 2021, as PPE availability	with our suggested care goals.” (participant 14, doctor)	937
883	stabilized and HCPs gained confidence in the preventive	Meticulous Exploration of Hidden Preferences: Some	938
884	measures in place, more hospitals allowed brief family	patients were forced by others to decline medical care or	939
885	visits while wearing PPE. Some HCPs warmly	were hesitant to express their true preferences because of	940
886	encouraged families who hesitated to visit the patient for	the shortage of hospital beds (participant 10, doctor).	941
887	fear of infection	Additionally, some patients’ preferences differed from	942
888		their HCPs’ assumptions.	943
889	“The family’s fear of infection before coming was big. . .		944
890	. However, we encouraged them to see the patient as	“He was single, lived alone, experienced cancer, and did	945
891	much as they could. Regardless of COVID-19, I hope	not call for medical attention after infection. However,	946
892	families visit [them] because it’s the completion of the	his sister said that he wanted to live as he could. Our	947
893	patient’s life.” (participant 19, nurse)	team’s assumption was at fault.” (participant 26, doctor)	948
894	Combining Multiple Communication Tools: One		949
895	doctor arranged direct visits with the family wearing	When a patient’s preferences were difficult to determine	950
896	PPE and simultaneously connected other relatives via	despite efforts to gather information, the HCPs usually	951
897	videoconferencing to enable them to say goodbye, as if	consulted with a multidisciplinary team, ethics	952
898	the patient was surrounded by loved ones	committees, and community officers who knew the	953
899		patient.	954
900	“When the patient was near death, only his daughter	Conveying HCPs’ Compassionate Care: Some HCPs	955
901	entered his room wearing PPE. Simultaneously, his son-	used ICU diaries to describe the patient’s condition to	956
902	-in-law and grandchildren saw the patient from the	the family. The messages in these diaries conveyed the	957
903	hospital’s green zone, calling out, ‘Grandpa, Grandpa’	HCPs’ compassion, and this compassion promoted the	958
904	through a tablet. . . . It was just like the end-of-life care	family’s trust. Reading these diaries, the families realized	959
905	we usually do.” (participant 12, doctor)	that the patients had received all available treatment and	960
906		care, which affected treatment decision-making.	961
907	Shared Decision-Making in Isolation		962
908	The separation of the three actors made it difficult to	“After we started writing (ICU diaries), the family’s	963
909	share patients’ medical conditions and each other’s	distrust decreased. Families realized that the patients	964
910	real intentions. HCPs particularly had to support the	were being treated sufficiently, and there were many	965
911	families in their decision-making and confirm patients’	moments when the families smiled when reading them.”	966
912	wishes. HCPs worked to understand the families’	(participant 20, doctor)	967
913	distress, helping them to understand the medical		968
914	status, meticulously exploring patients’ hidden	Creating Humanistic Episodes	969
915	preferences, and conveying the HCPs’ compassionate	In Japanese culture, families partially join in cleaning,	970
916	care.	washing, and applying cosmetics to the corpse and	971
917		spend 2 days in mourning ceremonies. Relatives visit to	972
918	Understanding the Families’ Distress: The patients’	see the deceased and then eat or talk together, sharing	973
919	families had complex problems, including their own	memories. When patients with COVID-19 died, these	974
920	health concerns, stress resulting from being isolated at	processes were omitted. Funeral companies transported	975
921	home, and guilt for having infected the patient. To build	the corpse from the hospital to the crematorium within	976
922	a trustworthy relationship, addressing the family’s	24 h, and the family received cremated remains without	977
923	distress was emphasized	seeing the face of the patient one last time. HCPs were	978
924		concerned that the lack of memories after a patient’s	979
925	“We had to talk about the patient’s difficult conditions,	death would affect the family’s grief process, and they	980
926	but the family on the phone was suffering from COVID-	attempted to create humanistic episodes.	981
927	19. Therefore, the coordinator listened to the family’s		982
928	situation and contacted the public health center.”	Promoting Family Involvement: The HCPs tried to	983
929	(participant 9, doctor)	involve the family after death. For example, some HCPs	984
930	Helping Families Understand Patients’ Medical	allowed families to touch the patient’s body while	985
931	Status: Videoconferencing and multiple	wearing PPE or masks and plastic gloves. The HCPs also	986
932	communications from doctors were found to be	asked the families to bring items such as letters, pictures,	987
933	beneficial in sharing information about care and	and gifts to put in the body bag (participant 19, nurse).	988
934	patients’ critical conditions with families.		989
935			990

991 Other HCPs dressed the dead patient in clothes chosen
992 by the family.

993 “We dressed the dead patient in the karate uniform that
994 the family had brought.” (participant 24, nurse)
995

996 **Sharing Patients’ EOL Periods:** The isolation of
997 patients and the rapid progression of the illness limited
998 the time families had to accept the patients’ deaths.
999 Some families wanted to know not only medical
1000 information, but also how the patients were spending
1001 their time. Keeping an ICU diary for the patient and
1002 giving it to the family allowed them to share the patient’s
1003 last weeks.
1004

1005 “The families said that the ICU diary showed the pa-
1006 tients’ great effort to respond to treatments, which
1007 touched them deeply.” (participant 25, nurse)

1008 **Helping Families See the Patients’ Corpses:** National
1009 guidelines recommend that the dead body be placed in a
1010 plastic body bag; however, HCPs were concerned about
1011 the negative impact on families. Some hospitals used
1012 transparent body bags. To show the patient’s face better,
1013 HCPs taped the body bag’s zipper that ran over the
1014 patient’s face to the side and secured it
1015

1016 “I was astonished. Even for us, we thought, ‘Oh, patients
1017 are put in such bags.’ Families would feel sad, so we
1018 arranged the bag.” (participant 28, nurse)
1019

1020 Discussion

1021 This study collected data on 51 practices of EOL care for
1022 patients with COVID-19 and their families from 33
1023 HCPs at 23 hospitals nationwide. Four themes emerged
1024 as prominent features of EOL care resulting from the
1025 rapid progression of the disease and isolated deaths. The
1026 care practices and themes reported from various
1027 hospitals will help in considering specific ways to
1028 provide EOL care in a setting where families, patients,
1029 and medical personnel are separated from one another.
1030

1031 Previous studies on pandemics caused by the Ebola,
1032 H7H9 influenza, and severe acute respiratory syndrome
1033 viruses have recommended palliative care for patients
1034 with COVID-19.^{17,33-35} These recommendations include
1035 controlling symptoms, family visitation when possible,
1036 developing treatment plans that incorporate patient and
1037 family values, making memories, and connecting family
1038 support and are consistent with our themes. In this
1039 study, HCPs used the internet as a new approach, but
1040 strived to achieve the common components of better
1041 EOL care toward a good death.
1042

1043 From our narratives, the reported effort to “connect
1044 patients and families” was important not only because it
1045

1046 enabled families to contact the patients, but also because
1047 it was the final opportunity to encourage their life
1048 completion. According to good death studies, “life
1049 completion” is the central concept of the spiritual
1050 domain of good death.³⁶⁻⁴⁰ Life completion consists of
1051 life review, life closure, forgiveness, acceptance,
1052 generativity, contributing to others, and spending time
1053 with family and relatives. Oriented life completion is
1054 meaningful not only for an individual, but also for the
1055 family, staff, and society.¹³ Connecting the patient and
1056 family is necessary because it is an indispensable
1057 opportunity; however, it is not sufficient for the
1058 achievement of life completion. In other studies,
1059 connecting families and postintubated patients using a
1060 videoconference system was considered controversial,
1061 and some studies reported that seeing intubated patients
1062 had a negative impact on families.^{41,42} In our study,
1063 however, HCPs who focused on the content of
1064 communication described connecting patients and
1065 family as positive. HCPs must recognize that tablets
1066 serve only as a communication tool. They can deepen
1067 the final communication between patients and their
1068 families by promoting a sense of life completion as in
1069 ordinary EOL care, such as by asking, “Could you tell
1070 me what she meant to you?”
1071

1072 The ICU diaries used in the four hospitals in this study
1073 were applied effectively to all four themes. The original
1074 role of the ICU diary was to compensate for patient
1075 memory loss in the ICU; it contained daily medical care,
1076 photographs, and encouraging messages from HCPs and
1077 family members.⁴³⁻⁴⁶ Scofield et al⁴⁶ noted that ICU Q7
1078 diaries help families to cope with their emotions and
1079 problems and to interpret ICU experience as a
1080 humanistic episode. In this study, we highlighted the
1081 usability of ICU diaries after a patient’s death. While
1082 reading the diary, the family may perceive HCPs’ efforts
1083 to establish a relationship with the patient and the
1084 meticulous care as humanistic episodes, which may lead
1085 to the acceptance of the patient’s death. Although
1086 barriers to ICU diary writing exist, such as tight work
1087 shifts, a challenging writing environment, and a lack of
1088 guidance on how to write,⁴⁴ digital technologies using
1089 mobile messenger applications, such as those used by
1090 participants 24 and 25, reduced this burden.
1091

1092 Japanese traditional funeral and ritual processes reaffirm
1093 relationships by allowing the family to spend time with
1094 the corpse and invite relatives to a social ceremony.⁴⁷
1095 HCPs recognized the seriousness of the loss of these
1096 processes, which prevented the family from interacting
1097 with the community. As some studies have indicated,
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bereaved families of patients with COVID-19 experience a high risk of complicated grief, that is, ambiguous loss and disenfranchised grief.^{33,47,48} “Ambiguous loss” means that bereavement itself is unsubstantial, traumatic, and hidden for reasons such as prejudice.^{47,48} “Disenfranchised grief” refers to the experience of a loved one’s death not being publicly acknowledged or socially supported.^{47,49,50} By creating tangible and intangible humanistic episodes, families may recover from complicated grief. In this study, HCPs put letters from families in the body bag or dressed patients in clothes chosen by their families. In Brazil and the United States, patients’ belongings were returned to their families in decorated boxes, and silver key chains with the patient’s fingerprints were given as gifts to show the HCPs’ respect for their patients.^{8,51} As with other efforts, applying the meaning of normal care to alternative care may improve the satisfaction of the bereaved family and HCPs. Bereavement care was performed by volunteers and palliative care staff in Europe and the United States,^{52,53} whereas in this study, HCPs provided bereavement care while treating other patients. Japan has fewer hospices than other countries, and HCPs have limited EOL training opportunities.^{54,55} Furthermore, collaboration between religions and hospitals is limited.⁵⁶ Such an environment may have increased the burden on HCPs.

This study has some limitations. We excluded HCPs who might feel distressed when recalling their

experiences; their perspectives may have been more critical of these practices, or they may have had different care experiences from the present participants. Our interviews started in August 2021, when the number of COVID-19 deaths was the highest and occurred in hospitals.⁵⁷ Currently, most deaths from COVID-19 occur in nursing homes,⁵⁷ and the human resources and professional backgrounds of staff are different from those at the hospitals included in this study. The adaptation of the 51 strategies may be limited, especially with access to opioid use. Despite these limitations, the four identified themes may help HCPs who struggle with what they can do to support patients and their families facing death under isolated circumstances.

Interpretation

As patients with COVID-19 died in isolation, HCPs used existing and new tools to link the concepts of a good death with care practices. The four themes of maintaining relationships with patients, connecting patients and families, sharing decision-making in isolation, and creating humanistic episodes were particularly beneficial in coping with rapid disease progression and death in isolation. ICU diaries and HCPs’ creative arrangements based on cultural funerary procedures promoted caring for families’ grief and building trusted relationships. EOL training for HCPs and establishing an EOL care support system as a normal part of care are urgent issues in Japan.

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