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Original Article

Palliative Care Practice During the COVID-19 Pandemic: A Descriptive Qualitative Study of Palliative Care Clinicians



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Abstract

Context. COVID-19 created unprecedented demand for palliative care at a time when in-person communication was highly restricted, straining efforts to care for patients and families.

Objectives. To qualitatively explore the challenges presented by the COVID-19 pandemic from the perspective of palliative care clinicians. Specifically we sought to: 1) Describe the strategies adopted by palliative care clinicians to cope with new challenges including patient and clinician isolation, prognostication of an emergent disease, and rapidly rising numbers of severely ill patients; 2) Identify additions or adjustments to in-person and system-related palliative care training, methods, and tools made during pandemics.

Methods. This descriptive qualitative study utilized a thematic approach for data analysis of individual, semi-structured interviews with palliative care clinicians ($n = 25$). Codes, categories, and emerging themes were identified through an iterative, comparative method. Methods align with the Consolidated Criteria for Reporting Qualitative Research (COREQ)

Results. A theme of “Expanding the reach of palliative care for today and the future” was identified with three subthemes: 1) Redefining attitudes and hardship due to collective uncertainty, 2) Breaking with the past towards integrated concept of palliative care, and 3) Building capacity through primary palliative care training.

Conclusion. COVID-19 forced hospital systems to consider the inclusion of palliative care in unforeseen ways due to an uncontrollable, unpredictable disease. Faced with unprecedented uncertainty, palliative care clinicians utilized strategies for integration and innovation across hospitals, particularly in intensive care units and emergency departments. A need to build capacity through increased primary palliative care access and training was identified. *J Pain Symptom Manage* 2021;62:1111–1116. © 2021 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative, COVID, qualitative, interdisciplinary, training, culture

Key Message

COVID-19 has demonstrated palliative care skills are essential to quality care, should be integrated with ICU and ER teams, and primary palliative care training should be incorporated into providers’ training.

What is already known?

- COVID-19 ushered in a new level of uncertainty, isolation, and collective grief for patients, families, and clinicians.

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- Interdisciplinary collaboration is foundational to effective palliative care across all levels of health care to respond to COVID-19.
- Resources, policies, and practices of palliative care vary greatly across institutions with limited integration and capacity.

What this paper adds

- First-hand perspectives of palliative care team members and their efforts to provide care, comfort, and support to patients, families and colleagues during a pandemic.
- Evidence that specialty-level palliative care should be further integrated into medicine, including standardizing primary palliative care training as a fundamental skill for providers and increasing its presence in the intensive care units (ICU) and emergency departments.(ED).

Implications for practice, theory, or policy

- Implications for practice today include expansion of quality guidelines to include integrating palliative care professionals across specialties and institutions, foremost within the ICU and ED, as well as increasing primary palliative care training across specialties.
- Implications for policy for the future include the expectation of adequate planning, resources, and personnel to meet palliative care needs during future unforeseen crises at the institutional, state, and national level.

Introduction

The number of daily deaths in the United States due to COVID-19 rose from 16 persons dead on March 15th, 2020 to 6,489 persons dead on April 15, 2020.¹ The rapidly growing number of seriously ill persons created an unprecedented demand for expert symptom management and patient-family-clinician communication at a time when patient access and in-person communication were highly restricted, constraining clinicians' efforts to care for and comfort patients and families. Palliative care teams were essential to meet the need for symptom management and communication.² Visitor and contact restrictions caused patients, families, and clinicians to experience isolation, grief, and exhaustion.^{3,4}

The purpose of this qualitative study was to explore the perspective and experiences of palliative care

clinicians during the COVID-19 pandemic. The findings from this study inform the growing body of knowledge on the role of palliative care during a pandemic and within medicine at-large.⁵

Methods

Study Design

This study utilized a qualitative methodology with a thematic analysis approach. Twenty-five semi-structured interviews were conducted with palliative care clinicians from June 12 to July 31, 2020. Methods align with the Consolidated Criteria for Reporting Qualitative Research (COREQ).⁶ The Institutional Review Board at the University of Kansas Medical Center approved this study in April 2020 (STUDY00145700). Team members for this study included three second-year medical students, one third-year medical student, a second-year PhD student in clinical psychology, a qualitative researcher in nursing science, and a palliative care physician.

Participants

Clinician interviews were conducted by JR, RM, IE, and AD, with the majority of interviews being conducted by JR. No prior relationship existed between participants and interviewers. Palliative care clinicians who provided direct patient care were recruited via emails to palliative care clinical sites, hospitals, academic medical centers, and direct contacts using the snowball recruitment method. Eligibility criteria included participants working as physicians, nurses, nurse practitioners, social workers, clinical psychologists, or chaplains who were currently practicing palliative care in the United States. The exclusion criterion was lack of fluency in English.

Data Collection

Interview Guide: The interview guide was developed in an inductive fashion. We reviewed the Clinical Practice Guidelines for Quality Palliative Care from The National Coalition for Hospice and Palliative Care (NPHCP).⁷ The NPHCP guidelines helped develop our questions, as well as our consulting qualitative expert. The questions were pilot tested during mock interviews with palliative care clinicians to determine face validity and interviewee fidelity to the interview guide. Appendix 1 provides the final interview guide.

Interview Procedure: Participant consent and scheduling was completed using REDCap (Research Electronic Data Capture) electronic data capture tool, a secure, web-based software platform designed to support data capture for research studies, hosted by University of Kansas Medical Center.^{8,9} A link to a REDCap survey was emailed to clinicians that provided the purpose of

our study, informed consent prior to participation, and requested demographics: years of experience, state of practice, and whether the clinician had provided direct care to COVID-19 positive patients. Interviewers included a graduate student from the University of Kansas, three medical students from the University of Kansas, and one medical student from Kansas City University. The students were mentored by faculty experts in palliative care and qualitative research. Guided, one-on-one interviews were conducted using a secure University of Kansas Zoom account; interviews lasted approximately 30 minutes. Zoom interviews were completed with both interviewer and interviewee on camera whenever possible to provide a face-to-face quality. Only one interview was completed with Zoom call capacity alone due to the participant's inability to use their camera at the time. Interviews were audio-recorded and transcribed by a professional transcription service. Transcripts were de-identified and uploaded to a secure KUMC drive. Interviewers remained emotionally neutral by following the agreed upon interview guide to limit personal interjection and possible bias. Study participants could withdraw consent at any time or refuse to answer any question at their discretion. Interviews were conducted until thematic saturation was reached.

Data Analysis

De-identified transcripts were imported into the secure KUMC Dedoose qualitative software platform for analysis. A descriptive, deductive thematic analysis approach was used to interpret the data. Four interviews were coded independently by four different team members to generate a preliminary code book. As analysis continued with subsequent interviews and new ideas emerged from the data, the code book was expanded using an iterative, comparative method. This iterative process continued until the team agreed that thematic saturation with interview data had been reached. Categories were developed across all codes, and emergent themes were identified. Excerpts were reviewed for exemplar quotations. Coding completed by the medical students and PhD student was reviewed by the qualitative researcher. Total time from data collection to final data analysis was approximately eight weeks.

Results

A total of 25 palliative care clinicians from 16 different states participated in this study, including 18 physicians, 3 nurse practitioners, 2 social workers, 1 chaplain, and 1 advanced practice registered nurse. All participants provided direct care to patients during the summer of 2020, and 21 of the 25 provided direct care to patients diagnosed with COVID-19. Clinical

experience ranged from 1 to 5 years to 30 years with the majority of participants having from 1-10 years of experience.

Qualitative data analysis resulted in one overarching theme with three subthemes. The main theme was "Expanding the reach of palliative care for today and the future." The three sub themes were: 1) Redefining attitudes and hardship due to collective uncertainty, 2) Breaking with the past towards an integrated concept of palliative care, and 3) Building capacity through primary palliative care training. Table 1 details exemplars for the each subtheme.

Subtheme 1: Redefining Attitudes and Hardship Due to Collective Uncertainty

Categories leading to the first theme included increased stress, uncertain prognosis, uncertain treatment plans, isolation, and unclear communication. Most clinicians described new levels of hardship for patients, families, colleagues, and themselves. Clinicians spoke of their stress and exhaustion; one said, "I was on that first week that all of this went down. I was in such a stressed space. It was like threat, react, threat, react, threat, react. . . ." More than half of the clinicians discussed the challenges of uncharted treatment plans and unclear prognostication: "It was hard because you had to let family in when someone was actively dying, but you weren't able to always predict that, so there were several instances where family was unable to come because the person died before we had thought they were going to die." Isolation also personally affected study participants as they witnessed families suffer: "One of the hardest things for me was people dying alone. And people dying without their support systems. . . we were all so isolated." Physical isolation was the biggest challenge: ". . . some of these families have been here alone and isolated for a long time and we know the kid's going to die, but until they're actually dying. . . they're very isolated and they're lonely." Participants described how traditional approaches to communicating were found lacking against untested treatment plans, unreliable prognostication, large non-English speaking patient populations, and an exhausting feeling of helplessness.

Subtheme 2: Breaking With the Past Towards An Integrated Concept of Palliative Care

Categories leading to the second theme included new-found levels of appreciation for palliative care and integration of palliative care into intensive care units (ICU) and emergency departments (ED). A clinician described new appreciation for palliative care saying, ". . . for clinicians who are not palliative care trained, [the pandemic] has highlighted the importance of needing access to palliative care services. . . just how

Table 1
Exemplars

Category	Subtheme
Increased Unknowns/ Uncertainty	Redefining Attitudes and Hardship Due to Collective Uncertainty
Increased stress	“there’s no aspect of life that has been unchanged. . .and thinking about home life and our children and our parents, and all of these ways in which the world is really different and challenging.”- (ID05) “It was challenging because so much was unknown about the virus and the toll that it was going to take on patients and where we were headed.” – (ID03)
Uncertain prognosis	“We are seeing people who are incredibly sick all of a sudden get better. We’ve seen people who we thought we got better, they go home; they get sick; they come back; they die. . . . We don’t like to appear in the medical field like we don’t know what we’re doing, but being very honest and saying this is new. . . .”-(ID38)
Uncertain treatment plans	“We change recommendations. . .Whatever the best decision is today might turn out to be wrong tomorrow. And that’s always been true, but people are more cognizant of that, and so I think they feel much more vulnerable.”-(ID04)
Isolation	“The realization of how many people would be dying alone, the realization of how difficult it was going to be for families to grieve the death of their loved one, . . .I grieved that in a pretty anxious way.”-(ID08)
Unclear communication	“ . . .communicating with people with face shields and masks on. It’s really hard to read the face. And so much of what we do is also nonverbal communication.”- (ID09)
Palliative Care Integration Across Hospital	Breaking with the Past Towards an Integrated Concept of Palliative Care
Appreciation for palliative care	“[COVID] demonstrated the importance of palliative care because there’s been so much death and so much fear of death associated with COVID that I think it’s really made clear how important palliative care is in the spectrum of care that is provided for patients, all patients, and especially patients with a serious illness.”- (ID14)
Integration of PC into ICU and ED	“ED clinicians . . . said the reason they did not feel morally distressed is because we [palliative care clinicians] had their back. And that was really powerful. . . it just made me realize how many places there are in the institution that could benefit from partnership with us. I always knew they were there.” - (ID18)
Future Training/Planning for Pandemics	Building Resiliency Through Primary Palliative Care Training
Importance of advanced care planning	“Dying is a big part of medicine, too, and the fact that we can help people do that with dignity and without any kind of suffering and kind of guide those conversations. . . being trained to have those conversations in a time when it was extremely necessary was extremely helpful. . .I never thought I would be in a part of the pandemic, but I was grateful for my training to be able to be useful in such a dire time for the country and especially for our hospital.” – (ID20)
Importance of primary palliative care	“primary palliative care and having conversations especially about advance directive is so important as early as possible. . .we were having those conversations almost too late. if you had that conversation with your family or with your primary care physician prior, we would know your advance directives but not everyone had, which made it just so very clear how necessary it is for palliative care to [be a] part of primary care and primary palliative care takes us.”- (ID12)
Effectiveness of primary palliative care training	“So I think that that was one thing that helped our hospital a lot is that lot of our residents and our attendings get a lot of primary palliative care teaching. . . in any pandemic, the number of cases will be much higher than a palliative care team can handle. . . .how do we teach our hospitalists and our intensivists to have these conversations in advance of the next pandemic.” - (ID35)
Future training	“Palliative care is the medical specialty, but it’s also a set of principles and approaches to serious illness that are not consigned and should not be consigned to those who practice palliative care as a medical specialty. There are things that everybody should be doing. . . by hospitalists and cardiologists and oncologists and intensivists and surgeons and all of the different specialties.”- (ID05)

needed palliative care clinicians are and how essential they are to a well-functioning health care system.” Clinicians reported expanded palliative care presence in intensive care units and emergency departments, often long-term: “There was a concerted effort to integrate palliative care. . . in the care of all ICU patients and all patients in the hospital who had taken a turn for the

worse. . . it was like 10 years’ worth of culture change in probably 2 days.” No one interviewed reported negative feelings about this new level of integration and several clinicians recounted positive feedback from their non-palliative care colleagues: “We wouldn’t know how to have done what we are doing if [palliative care] weren’t here. . . We wouldn’t have known what to

do. . . We're so glad that you were here to help have those conversations."

Subtheme 3: Building Capacity Through Primary Palliative Care Training

Categories leading to the third subtheme included reaffirmation of the importance of advanced care planning, increased need for development of palliative care skills across all specialties, and the importance of palliative care training for COVID-19 and possible future pandemics. Clinicians recognized the necessity of end-of-life planning and described increased willingness to engage in those often-daunting end-of-life conversations: "The pandemic was the easiest advance care planning I ever did. . . literally everybody was thinking about dying. . . And I think that was true of the doctors too. A number of clinicians noted a reawakened conviction to advocate for advanced care planning: "I want to double down on my efforts to have people understand advance directives and goals. . . had they been in place and fully utilized, [they] could have prevented so much suffering."

Clinicians expressed the need for palliative care skills to be developed as fundamental (primary skills) across all specialties and disciplines through multiple layers of training. One clinician said: "Making sure that there is a good bedrock of primary palliative care skill sets of talking about making advance directives, and advance care planning, good communication with patients and family members...those things hit at the root of what would make overall good medical care, even not in a pandemic." Three clinicians discussed the benefit of educating other specialties in primary palliative care skills prior to COVID-19: ". . . there's been a lot of work on building primary palliative care skills and teaching the ICUs how to have family meetings. And that's been going on for years and years. . . when COVID hit, the attendings in the ICU didn't really need any specialty level palliative care. . . Primary skills in palliative care must, must, must increase so that when the next pandemic hits, people are ready." Another clinician shared their gratification as over one-thousand primary care clinicians, trained in primary palliative care prior to the pandemic, were empowered to lead a large number of goals of care and end-of-life conversations without the need for a palliative care specialist.

The final interview question asked: "If you had one wish right now for something to help address the challenges you have been talking about, what would that be?" Our themes reflect their responses. Clinicians wished for increased multidisciplinary collaboration, a future of integrated palliative care, and national improvements in primary palliative care education so that their experiences will help guide future pandemics.

Discussion

Our findings show that during the initial months of the COVID-19 pandemic in the United States, clinicians, patients, and families were overwhelmed by stress and isolation in the face of collective uncertainty in treatment, prognosis, and communication. The objective of this study was to qualitatively explore the challenges presented by the COVID-19 pandemic from the perspective of palliative care clinicians including strategies and adjustments clinicians adopted to cope with these new challenges.

A predominant strategy identified through data analysis was that palliative care clinicians adopted to cope with the stress of the pandemic was to foster palliative care skills in members of ED and ICU teams by incorporating palliative care clinicians as part of those teams on a daily basis. To grow this competency, palliative care clinicians called for standardizing primary palliative care training as a fundamental clinical skill across the US healthcare system to build capacity to ensure better day to day care for all patients and in the face of the unforeseen.

One way to formally acknowledge the need to build capacity and expand the reach of palliative care is to expand upon the NCHPC's 4th edition of *Clinical Guidelines for Quality Palliative Care*. Based on our findings from this study, we recommend expansion of quality guidelines to include integrating palliative care professionals across specialties and institutions, foremost within the ICU and ED, as well as increasing primary palliative care training across specialties. These recommendations, along with strategic plans to prepare for future pandemics would bolster the stability, sustainability, and capacity of the structure and process of quality palliative care both during a pandemic or other crises.

Strengths and Limitations

Strengths of this study include being completed shortly after the first peak and most turbulent weeks of the COVID-19 pandemic in spring of 2020. The perspectives shared were formed in response to the onset of the pandemic and were not retrospective reflections. Interviews were informed by the experiences and exposure of each clinician as defined by their various positions and geographical locations. Given the evolving nature of COVID-19 since spring of 2020, this study is limited by its inability to speak to the experiences of clinicians in the waves of COVID-19 that have followed. Limitations of this study also include the team's cumulative experience with qualitative research as new investigators, the number of interviewers and analyzers, lack of specifying each participants practice setting (hospital vs. clinic) and the small number of non-physician participants. Future studies should consider these areas for improvement.

Conclusion

COVID-19 forced hospital systems to consider the inclusion of palliative care in unforeseen ways due to an uncontrollable, unpredictable disease that hit the U S. within a matter of weeks. Specific strategies for integration and innovation emerged during the COVID-19 pandemic.^{10,11} By gathering and analyzing first-hand perspectives and experiences of palliative care clinicians, the value of inclusion of palliative care throughout the health care system becomes obvious, specifically in ED and ICU departments.^{4,10,11} The capacity to increase palliative care training requires monetary investment and endorsement from federal, local, and organizational leadership.¹² This study provides support of the Palliative Care and Hospice Education and Training Act (PCHETA).¹³ Without advocacy for palliative care funding and federal support of PCHETA, efforts towards implementation and integration as outlined in this research will be difficult.¹⁴ Continued research should explore the effect of COVID-19's on the isolation experienced by patients, families, and clinicians. Repeating this study over time to trace the lasting effect of this pandemic would be a worthwhile endeavor. Although our project did not speak to the potential differences in experiences of physicians vs non-physicians it may be beneficial to include that analysis in future studies. Additionally, researchers should investigate the perspectives of emergency medicine and intensive care clinicians on standardizing palliative integration and training.

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Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.jpainsymman.2021.06.013](https://doi.org/10.1016/j.jpainsymman.2021.06.013).

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