

Serious illness care quality during COVID-19: Identifying improvement opportunities in narrative reports from a National Bereaved Family Survey

Palliative Medicine
2023, Vol. 37(7) 1025–1033
© The Author(s) 2023
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/02692163231175693
journals.sagepub.com/home/pmj



Karleen F Giannitrapani^{1,2} , Matthew D McCaa¹, Bhagvat J Maheta^{1,3},
Isabella G Raspi^{1,4}, Scott T Shreve⁵ and Karl A Lorenz^{1,2} 

Abstract

Background: COVID-19 significantly impacted care delivery to seriously ill patients, especially around including family and caregivers in patient care.

Aim: Based on routinely collected bereaved family reports, actionable practices were identified to maintain and improve care in the last month of life, with potential application to all seriously ill patients.

Design: The Veterans Health Administration's Bereaved Family Survey is used nationally to gather routine feedback from families and caregivers of recent in-patient decedents; the survey includes multiple structured items as well as space for open narrative responses. The responses were analyzed using qualitative content analysis with dual review.

Setting/participants: Between February 2020 and March 2021, there were 5372 responses to the free response questions of which 1000 (18.6%) responses were randomly selected. The 445 (44.5%) responses from 377 unique individuals included actionable practices.

Results: Bereaved family members and caregivers identified four opportunities with a total of 32 actionable practices. Opportunity 1: Facilitate the use of video communication, included four actionable practices. Opportunity 2: Provide timely and accurate responses to family concerns, included 17 actionable practices. Opportunity 3: Accommodate family/caregiver visitation, included eight actionable practices. Opportunity 4: Offer physical presence to the patient when family/caregivers are unable to visit, included three actionable practices.

Conclusion: The findings from this quality improvement project are applicable during a pandemic, but also translate to improving the care of seriously ill patients in other circumstances, such as when family members or caregivers are geographically distant from a loved one during the last weeks of life.

Keywords

COVID-19, palliative care, terminal care, qualitative research, quality improvement

What is already known about the topic?

- COVID-19 disrupted crucial components of quality palliative care, such as good communication and involvement of families and caregivers.

What this paper adds?

- From qualitative analysis of the Veterans Health Administration's Bereaved Family Survey, we identified four overall opportunities and 32 actionable practices to improve serious illness care that apply to remote support of family members/caregivers.

¹VA Quality Improvement Resource Center for Palliative Care, Menlo Park, CA, USA

²Department of Primary Care and Population Health, Stanford University School of Medicine, Stanford, CA, USA

³California Northstate University College of Medicine, Elk Grove, CA, USA

⁴The College of Arts and Sciences, Cornell University, Ithaca, NY, USA

⁵United States Department of Veterans Affairs, VA Palliative Care, Lebanon, PA, USA

Corresponding author:

Karleen F Giannitrapani, VA Quality Improvement Resource Center for Palliative Care, 795 Willow Road, Menlo Park, CA 94025, USA.
Email: Karleen@stanford.edu

Implications for practice, theory or policy

- The actionable practices suggested by family members/caregivers provide opportunities for both healthcare teams and healthcare systems to improve the quality of serious illness care during the COVID-19 context and for including family and loved ones in the modern, more geographically distributed world.

Introduction

Crucial components of quality palliative care, including good communication, continuous pain and symptom management, and involvement of families and caregivers, were disrupted by COVID-19.^{1–3} Beginning in March of 2020, restrictions limited families from visiting hospitalized patients and strained hospital staff and resources to deliver quality palliative care.^{4,5} COVID-19 magnified existing communication gaps between patients, caregivers, and clinicians, heightening the intensity of the already fraught experience of caring for and experiencing the death of seriously ill persons.^{4,6–9}

The United States Veterans Health Administration is a large, comprehensive, integrated health system with over 150 hospitals and community based clinics (throughout the continental United States as well as Hawaii, Guam, and Puerto Rico) that provides care annually to over 9 million United States Veterans, once they have been discharged from service till their death.¹⁰ The Veterans Health Administration serves a population where many patients are plagued with mental health consequences and serious illnesses that result in vulnerability and death, who may benefit from consistent palliative care.¹¹ The insights gained from studying a large, diverse integrated national health system, such as the Veterans Health Administration, can help inform similar large diverse health systems internationally, such as the Australian and Canadian healthcare systems.

The Veterans Health Administration's Bereaved Family Survey provides insights into opportunities to improve palliative care from the patient's perspective.^{12,13} The Veterans Health Administration routinely administers the Bereaved Family Survey to bereaved family members to support the quality of inpatient care.¹⁴ Feedback is directly utilized by Veterans Health Administration program managers, who can evaluate the success of practices in impacting overall quality of palliative care.¹⁴ Bereaved family surveys are also useful in hospice and have the potential to improve patient-family outcomes by giving family members a voice to suggest improvements in patient care.^{15–18}

The Bereaved Family Survey has been used to evaluate patient care in the context of COVID-19. Using the Bereaved Family Survey, one study found that respondents emphasized the importance of improving communication quality, while another study found that effective remote communication led to improved overall experience of end-of-life care.^{4,19} A systematic review found that

quality palliative care could be improved during COVID-19 by enhancing communication with family and finding strategies for telehealth communication to promote family engagement.²⁰ These studies demonstrate areas of improvement for quality palliative care, however, actionable practices to implement these changes need to be further researched.

In a previous study, narratives informed 98 actionable practices related to improving general inpatient palliative and serious illness care.^{16,21} This study found three main domains for improvement: patient needs (adhering to patient wishes and physical presence in the patient's final hours), family needs (communication with the patient's care team and displays of respect and gratitude for the patient's life), and facility and organizational characteristics. Facilitating improvements in these domains became difficult due to the restrictions imposed by COVID-19, so to identify specific actionable opportunities to improve palliative care delivery during and after COVID-19, we qualitatively analyzed COVID-19 related narrative responses from the Veterans Health Administration's Bereaved Family Survey. The insights gained from this analysis will build on the current literature by providing detailed actionable practices that could be applied by healthcare workers and healthcare systems post-pandemic to improve palliative care through the support and engagement of remote family members and caregivers in inpatient and home settings.

Methods

Research question

What opportunities and actionable practices can be identified from the Bereaved Family Survey to improve End-of-Life palliative care post-pandemic?

Population

The Veterans Health Administration's Bereaved Family Survey is administered by mail, telephone, or online to the families of all patients treated within the Veterans Health Administration healthcare system (171 medical centers in the United States), who die in acute care, intensive care, inpatient hospice units, or nursing homes.¹⁰ A family member of the decedent is surveyed unless the patient died by suicide or was an inpatient for less than 24 h in the last month of life.

Design

The survey consists of 17 structured and closed-ended items that require family members to rate the care the veteran received in the last month of life as well as two open-ended items which asked for any additional comments to improve End-Of-Life care (Supplemental Appendix 1).¹⁴

Data collection

The survey has a 45% response rate with minimal response bias.^{14,22} Between February 2020 and March 2021, there were 5372 responses, defined as at least one word written in response to two open-ended questions and one open share space in the survey. Although the regulations for COVID-19 were officially enforced in March 2020, we broadened our inclusion date to February 2020 since the media had started informing the public of this virus by February.

Data analysis

We conducted a qualitative narrative content analysis of the responses to the Veterans Health Administration's Bereaved Family Survey to identify opportunities and actionable practices, using methods of previous work.^{16,21} The research team included a PhD trained qualitative methodologist (KG) who trained, prepared, and supervised two clinician qualitative research assistants (MM and BM). For feasibility, of these 5372 responses, 1000 (18.6%) responses were randomly selected through a random sequence generator by MM for analysis. This approach is based on previous work, where after reviewing a 1000 examples, no new practices were identified after review of an additional 300 examples.^{16,21} Microsoft Excel was used for all the data analysis. Responses were de-identified and those relevant to COVID-19 (445/1000, 44.5%) were selected for further analysis. MM and BM each reviewed all output to identify actionable practices through open coding with a dual-review.^{23,24} Actionable practices were defined as specific actions that can be taken by healthcare providers or systems.¹⁶ Comments that only included generic praise or concern without any specific actionable recommendations or suggestions were not included.¹⁶ If the actionable practices recommended were described by more than one individual we only include it as one practice; and we include the frequency of how often practices were suggested to characterize how some practices were important to multiple unique respondents. We then sorted all the actionable practices into grouped opportunities. Each opportunity and actionable practice was reviewed with the coding team and the wording was determined through consensus to best represent the quotes it encompasses. We addressed

Table 1. Bereaved Family Survey respondents demographics.

Demographic characteristic (N = 377)	N (%) or Mean \pm SD
<i>Veteran decedent</i>	
Age at death, in years	77 \pm 11
Gender	
Female	9 (2.4)
Male	368 (97.6)
Ethnicity	
Non-Hispanic or Latino	344 (91.2)
Hispanic or Latino	22 (5.8)
Declined/unknown	11 (2.9)
Race	
African American	72 (19.1)
White	275 (72.9)
American Indian or Alaska Native	1 (0.2)
Asian	3 (0.8)
Native Hawaiian or other Pacific Islander	3 (0.8)
Declined/unknown	23 (6.1)
<i>BFS respondent</i>	
Relationship to decedent	
Spouse or partner	176 (46.7)
Child	120 (31.8)
Sibling	41 (10.9)
Parent	6 (1.6)
Friend	6 (1.6)
Other	27 (7.2)
POA/legal guardian/caretaker	1 (0.2)

inter-coder agreement through discussion and consensus. The practices may overlap but the four higher level opportunities are distinct. All practices fit into at least one of the opportunities.

Ethical issues

Since this research did not include animal and/or human subjects directly, and only used de-identified survey responses, no ethics approval or patient consent was required.

Results

From the 1000 randomly selected responses, which represented 18.6% of the total 5372 responses available, the 445 (44.5%) responses (from 377 individuals) that mentioned topics related to the COVID-19 pandemic were analyzed. The demographic information for the data analyzed is shown in Table 1. Through standard qualitative content analysis with dual review, four opportunities were identified to improve palliative care with a total of 32 actionable practices. Table 2 shows all of the opportunities and actionable practices created based on the data collected. The labels for each of the actionable practices are mapped to the text of the results.

Table 2. Family/caregiver-identified practices.

Opportunities	Actionable practice (number of quotes supporting it)
Opportunity 1: Facilitate use of video communication	1a. Assist patients in participating in video communication (provide the patient with technical assistance, offer them devices, hold the phone for the patient). Provide staff with training so that they can assist patients in participating in video communication. (32) 1b. Provide technology with video capabilities rather than just voice. Ensure the technology is working effectively. (24) 1c. Facilitate frequent, consistent, and scheduled video conversations between patients and remote family members and caregivers. (15) 1d. Install a video system in each of the hospice care and intensive care units. (2)
Opportunity 2: Provide timely and accurate responses to family concerns	2a. Proactively call family members and caregivers and keep them informed about the patient's condition. (60) 2b. Answer phone calls from family members and caregivers in a timely manner. (22) 2c. Remain knowledgeable about the patient's condition and be able to answer family member/caregiver questions. (10) 2d. Kindly explain everything to patients and their family members and caregivers. (6) 2e. Be professional, supportive, approachable, and easy to talk to. (5) 2f. Maintain consistency with communication to family members and caregivers. (5) 2g. Attend conference calls with patients and family members/caregivers to keep everyone informed about the patient's situation. (3) 2h. Respect and understand family/caregiver situations. (3) 2i. Listen to patients, family members, and caregivers. (3) 2j. Offer patients a (teletypewriter) TTY machine. (2) 2k. Allow time for the healthcare team to update the family on the patient's condition. (1) 2l. Allow for video communication with doctors/healthcare team, not just audio calls. (1) 2m. Ensure family member/caregiver accessibility to talk to the healthcare team. (1) 2n. Provide comfort to family members and caregivers. (1) 2o. Allow family members and caregivers to ask questions during the conversations. (1) 2p. Allow family members and caregivers to participate in healthcare decisions. (1) 2q. Have interpreters available. (1)
Opportunity 3: Accommodate family/caregiver visitation	3a. Allow frequent and consistent visitation for family members/caregivers throughout the patient's hospital stay. (103) 3b. Prioritize visitation ability to allow family members/caregivers to visit when there are anticipated or significant life-threatening changes. (98) 3c. Give an early warning about anticipated or significant life-threatening changes for a patient so family members and caregivers can come visit the patient on time (prior to death). (11) 3d. Allow family members/caregivers to visit/call prior to the patient becoming unresponsive. (10) 3e. Allow window visits for family members/caregivers to still see the patient. (7) 3f. Allow all family members and caregivers to visit in-person. (9) 3g. Allow family members/caregivers to provide patient care, translation, and support when appropriate. (5) 3h. Bring patients outside the hospital to meet with family members and caregivers to allow for in-person interaction while continuing to abide by hospital COVID regulations. (4)
Opportunity 4: Offer physical presence when family/caregivers were unable to visit	4a. Support patients to not feel alone by offering physical presence to the patients. (11) 4b. Care for the patient as if they were family. (2) 4c. Spend time with the patients and listen to them. (2)

Opportunity 1: Facilitate the use of video communication

A frequently mentioned opportunity to improve quality of care was for the healthcare team to facilitate the use of video communication, which has four actionable practices within it. Caregivers expressed the importance of the healthcare team using Zoom, FaceTime, Teams, or any other form of video communication to allow patients to talk with loved ones when physical communication was

not allowed. Specifically, many caregivers appreciated when the healthcare team assisted patients in participating in video communication (such as providing the patient with technical assistance, offering them devices, holding the phone for the patient) (actionable practice 1a). A family member said "[I] also want to thank the nurses for holding the phone next to his ear when I called" while another family member said "the nurses were awesome. They went out of their way to facetime in the end." The family members really appreciated that the healthcare

team went above and beyond to ensure that the patient was able to interact and communicate with family and friends.

Another priority for family members was for the patients to have access to video rather than just voice only capabilities (actionable practice 1b). A family member recalled *“the only thing was not being able to visit Mr. [patient’s name] because of Covid-19, we had the webcam, but it never work[ed] for us to see him by face, we did talk to him on the phone, but would have liked to see his face.”* Although phone calls were fruitful in connecting family members with the patients, having adequate video communication available would further enhance this experience. Incorporation of video calls is also helpful for the caregivers themselves since a caregiver mentioned *“video conferencing would have made it easy for me. I wasn’t able to see him transition.”* This caregiver would have been more content if they had the opportunity to see their loved one as they died (“transition”).

Opportunity 2: Provide timely and accurate responses to family concerns

Another opportunity for healthcare teams to improve palliative care was providing timely and accurate responses to family concerns, which included 17 distinct actionable practices. Families appreciated when healthcare teams were open to questions and answered them quickly (actionable practice 2b). Families indicated staff should be knowledgeable about the patient’s condition and be able to refer to the correct personnel if needed so that the family can get answers in a timely manner (actionable practice 2c). A caregiver mentioned, *“each day I was able to talk to his nurse and felt 100% that he was receiving excellent, loving care. His nurses and the aides were so kind and patient with me and my calls and questions.”* Caregivers felt that patients were given good quality of care when there was good communication between the patient’s caregivers and the healthcare team.

Caregivers also appreciated when physicians/nurses proactively called to inform caregivers about the patient’s status and any updates (actionable practice 2a). *“However, I was able to talk with his nurse every time I called and was kept updated on his condition. His doctors called me at least 1 time per day to give me his up to the minute condition. All of the staff was very helpful to me every time I called.”* Other helpful practices that caregivers suggested were having scheduled conference calls between the healthcare team and family members to give updates (actionable practice 2g), using video conferencing with the healthcare team instead of just audio calls (actionable practice 2l), and involving family members and caregivers in patient healthcare decisions (actionable practice 2p). When the healthcare team was knowledgeable about the patient’s condition

and were professional and approachable during conversations with caregivers, caregivers felt comfortable and became more trusting of clinicians (actionable practices 2c and 2e). The demeanor with which the healthcare team interacted with caregivers was important as a caregiver expressed, *“some of the staff were great, and others were not. A lot of work can be done as how the interns and/or doctors speak to the family. Some were almost abrasive which was contradictory to the doctor that gives you the facts and walks you through a situation.”*

Opportunity 3: Accommodate family/caregiver visitation

Accommodating family/caregiver visitation, which had eight actionable practices, is an opportunity that was especially emphasized in light of the isolation caused by the COVID-19 pandemic. Families appreciated when the healthcare team allowed for them to visit during the time of COVID-19 regulations (actionable practice 3a). Many hospitals had policies that at least allowed families to visit during the last stages of life (actionable practice 3b). Whether it was going into the patient’s room or bringing the patient outside the hospital (actionable practice 3h), the ability to say goodbyes in person and with adequate time was meaningful for the bereaved family (actionable practice 3c). Allowing family members to be present when there are anticipated or significant life-threatening changes (actionable practice 3b) was especially meaningful for families as one caregiver recalled, *“What a great memory for our children & for me. I had a phone call early the next morning from the doctors telling me he had gotten worse & wanted our family to come to the hospital. We were able to be with him as he took his last breath. We were so very thankful we were able to be with him.”*

In some cases, notifying family members to visit when there are anticipated or significant life-threatening changes in the patient was too late as the patient may already have been intubated or in a condition where they cannot properly understand or communicate with the family (actionable practice 3d). An example response for this was, *“[NAME] died of Covid and I was not allowed to be with him prior to [being] put on a ventilator. By that time, he was sedated, and we could not communicate. I feel that the rules should be changed allowing the spouse to come up when the doctors are pretty sure the patient is headed to the ventilator. We both deserved the opportunity to say our final ‘I love you.’”* Allowing family to visit prior to death is important, but family members crave spending as much time as possible with their loved ones (actionable practice 3a). A caregiver wrote, *“Because of Covid 19 I understand the dangers but, it would’ve been better if I could [have sat] with him a little more, he never wanted me to leave. I was his caregiver the last 7 [months] of his life.”* An emphasis was placed by caregivers on

allowing all of the family members to visit, rather than having a cap of one or two caregivers that are allowed (actionable practice 3f).

Even with strict regulations to prevent the spread of the COVID-19 virus, creative solutions can be found to allow for patients to see their family while still adhering to the rules. One of these solutions was to bring the patient outside the hospital to meet their family (actionable practice 3h). A caregiver mentioned in the Bereaved Family Survey, *"We were not allowed in to see him, but they brought him outside. They had a tent set up with chairs, so we were able to say goodbye. It was the most special thing."* Another solution that may be beneficial if implemented is adding a large window for family members to see and talk to the patients in-person (actionable practice 3e). One of the caregivers mentioned, *"I was not allowed to visit with him, but I did see him through a window,"* while another suggested, *"at least some face time between glass / partitions during Covid-19 [would be helpful]."* These practices can be used to reduce the spread of pathogens and adhere to salient policy while nevertheless allowing patients and caregivers some measure of personal contact and intimacy.

Opportunity 4: Offer physical presence to the patient when family/caregivers are unable to visit

Another opportunity for healthcare teams is offering physical presence to the patient when family/caregivers cannot visit, which included three actionable practices. Family members appreciated when healthcare teams spent time with patients when family and friends were unable to visit (actionable practice 4a). A caregiver mentioned, *"He was never alone. The staff cared and loved him as if he was their own family member. I was very comforted in knowing this."* Caregivers were grateful when the staff would sit and listen to the patients, play cards or other games with them, play music for them, or spend time with the patients in any way (actionable practice 4c). In the situation where caregivers cannot visit patients, staff presence can benefit both patients and caregivers; a caregiver said, *"I got comfort from the nurse that stayed with him and held his hand while he [passed]."*

Discussion

Main findings

From responses to the Bereaved Family Survey during early COVID-19, we identified opportunities and specific actionable practices to improve palliative care quality. Although described by family members and caregivers in the COVID-19 context, the findings are salient for common situations when family members or friends cannot

physically be with loved ones during illness and the dying process. These opportunities, including facilitating video communication, providing timely and accurate responses to family concerns, accommodating family visitation, and offering physical presence to the patient when family cannot visit, seem straightforward; however, they are often difficult to implement. These findings add to previous research by identifying family/caregiver respondent suggested specific actions that would abet teams in providing comfort to patients and families under such circumstances.^{4,19}

What this study adds

In our previous study analyzing caregiver responses to the Veterans Health Administration's Bereaved Family Survey in pre-COVID 2019, the most frequent themes from caregiver quotes were for healthcare teams to have clear communication about the patient's condition, and to alert and support the family in the patient's final hours.^{16,21} This focus on communication has always been a central aspect of improving serious illness quality of care; the need for facilitating this connection at the onset of the pandemic was heightened when patients could no longer consistently be with their loved ones, as shown by actionable practices 2a, 2b, and 3c.^{19,25}

Other frequent themes to improve serious illness care prior to the onset of the pandemic were maintaining Veterans' hygiene, expressions of staff grief and condolence, and understaffed facilities.¹⁸ In contrast, due to the disruption in serious illness care caused by the COVID-19 context, Bereaved Family Survey narrative responses emphasized allowing family visitation and having healthcare staff offer physical presence to the patient when family is unable to visit. This sentiment of prioritizing family visitation and physical presence has also been found in other studies that have found higher levels of grief during COVID-19 due to social isolation and loneliness, due to the inability to visit and say goodbye at the end of life.^{26,27}

The COVID-19 period challenges, definitionally, what it means to provide good quality end of life care on the subject of including family and friends through physical presence.^{4,19} Hospice and palliative care programs had to figure out how to support connection with family and caregivers while there was simultaneous tension with general hospital visitation policies. To help facilitate connection, recent studies have provided examples and suggestions of effective ways to incorporate telecommunication with healthcare teams and families during the pandemic.^{28,29} Our study adds to this existing literature by covering specific actionable practices to not only improve telecommunication resources, but also facilitate in-person contact while adhering to heightened infection spread protocols or more limited visitations policies.

Communication with caregivers regarding a patient's condition and engaging them in healthcare decisions is an acknowledged attribute of good care^{27,30}; however, implementing this for remote caregivers or family members is difficult. Frontline teams require permission to communicate with family members electronically and to use their often limited time to accommodate remote family members in bedside care and healthcare decisions. Also, healthcare facilities may lack sufficient resources to allow each patient to have access to the appropriate technology, such as an iPad, when needed.^{28,31} Healthcare systems can improve quality of serious illness care by allowing dedicated time to engage around the patient's condition with family shared decision making when needed.³² Although the COVID-19 moment disrupted norms and thus fostered a necessity to innovate rapidly, the challenge now is to standardize the inclusion of caregivers/family members so they become involved in patient care in all medical centers, remotely when needed, as a feature of patient-centered quality, sustainable by clinicians and the system.

Strengths and limitations of the study

These findings set a precedent for future improvements in palliative care for patients based on the opportunities and actionable practices presented in this study; however, it should be considered in light of the following limitations. The sample was limited to Veterans, who were predominantly White males, that received care at the Veterans Health Administration, which is an integrated care system across the US with a robust national hospice and palliative care program. It may be more difficult to apply these findings to hospital systems that lack equally robust supports and services for palliative care (e.g. community medical centers). The analysis was conducted on written responses of caregivers, thus there was no opportunity for follow-up questions or further explanation. Furthermore, it may be challenging to confirm our findings in other health systems because the Veterans Health Administration is unique as a system in routinely surveying bereaved caregivers and family members after a decedent's loss.

Conclusion

In summary, from the Veterans Health Administration's national Bereaved Family Survey of family members and caregivers of recently deceased Veterans, we identified four key opportunities and 32 actionable practices to foster communication, provide support, and engage remote family members and caregivers in the late phases of a Veteran's illness and death. These findings provide opportunities for both healthcare teams and healthcare systems to improve the quality of serious illness care during the COVID-19 context, for example, by fostering inclusion

virtually. These practices are also particularly important in an increasingly mobile society where loved ones or family members may live distantly.³³ The opportunities and actionable practices found in this study build upon the actionable practices identified in our pre-pandemic work and are likely relevant for including family and loved ones in the modern, more geographically distributed world.

Authorship

Karleen F Giannitrapani: Led the concept and design of the work, made a substantial contribution to the acquisition, analysis and interpretation of data, drafted the article and revised it critically for important intellectual content, approved the version to be published, and participated sufficiently in the work to take public responsibility for appropriate portions of the content. Matthew McCaa: Made a substantial contribution to the acquisition, analysis and interpretation of data, revised the article critically for important intellectual content, approved the version to be published, and participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Bhagvat Maheta: Made a substantial contribution to the analysis and interpretation of data, drafted the article and revised it critically for important intellectual content, approved the version to be published, and participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Isabella Raspi: Assisted in drafting the article, approved the version to be published, and participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Scott Shreve: Revised the article critically for important intellectual content, approved the version to be published, and participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Karl A Lorenz: Revised the article critically for important intellectual content, approved the version to be published, and participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Acknowledgements

The authors would like to acknowledge Ariadna Garcia for her help with acquiring the data. Earlier versions of this work have been presented at The Annual Assembly of Hospice and Palliative Care in Montreal, Canada in March, 2023. The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the U.S. Government.

Data sharing

The data can be found in the Veterans Health Administration's Bereaved Family Survey responses. For assistance in requesting permission to access these data, please email Matthew.McCaa@va.gov.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by the Department of Veterans Affairs Office of Geriatrics and Extended Care for the operational palliative care Quality Improvement Resource Center. Dr. Giannitrapani is supported by a Veterans Affairs Career Development Award (19-075).

Ethics and consent

Since this research did not include animal and/or human subjects directly, and only used de-identified survey responses, no ethics approval or patient consent was required.

ORCID iDs

Karleen F Giannitrapani  <https://orcid.org/0000-0003-0987-6204>

Karl A Lorenz  <https://orcid.org/0000-0002-2468-2566>

Supplemental material

Supplemental material for this article is available online.

References

- Jung MY and Matthews AK. A systematic review of clinical interventions facilitating end-of-life communication between patients and family caregivers. *Am J Hosp Palliat Care* 2021; 38(2): 180–190.
- Sepulveda JMG, Baid D, Johnson FR, et al. What is a good death? A choice experiment on care indicators for patients at end of life. *J Pain Symptom Manag* 2022; 63(4): 457–467.
- Galbadage T, Peterson BM, Wang DC, et al. Biopsychosocial and spiritual implications of patients with COVID-19 dying in isolation. *Front Psychol* 2020; 11: 588623.
- Ersek M, Smith D, Griffin H, et al. End-of-life care in the time of COVID-19: communication matters more than ever. *J Pain Symptom Manag* 2021; 62(2): 213–222.e2.
- Kennedy G. The importance of patient dignity in care at the end of life. *Ulster Med J* 2016; 85(1): 45–48.
- Ghosh D and Gupta B. End-of-life issues in the era of the COVID-19 pandemic. *Korean J Hosp Palliat Care* 2020; 23(3): 162–165.
- Palliative care and the COVID-19 pandemic. *Lancet* 2020; 395(10231): 1168.
- Morris SE, Nayak MM and Block SD. Insights from bereaved family members about end-of-life care and bereavement. *J Palliat Med* 2020; 23(8): 1030–1037.
- Jeitziner MM, Camenisch SA, Jenni-Moser B, et al. End-of-life care during the COVID-19 pandemic—what makes the difference? *Nurs Crit Care* 2021; 26(3): 212–214.
- U.S. Department of Veterans Affairs. Veterans Health Administration, <https://www.va.gov/health/>. 2021; (accessed 11 March 2021).
- Boucher NA, Shapiro A, Van Houtven CH, et al. Needs of care partners of older veterans with serious illness. *J Am Geriatr Soc* 2022; 70(6): 1785–1791.
- Stajduhar KI, Funk L, Cohen SR, et al. Bereaved family members' assessments of the quality of end-of-life care: what is important? *J Palliat Care* 2011; 27(4): 261–269.
- Bussmann S, Muders P, Zahrt-Omar CA, et al. Improving end-of-life care in hospitals: a qualitative analysis of bereaved families' experiences and suggestions. *Am J Hosp Palliat Care* 2015; 32(1): 44–51.
- Smith D, Thorpe JM, Ersek M, et al. Identifying optimal factor scores on the bereaved family survey: implications for practice and Policy. *J Pain Symptom Manag* 2019; 58(1): 108–114.
- Schlesinger M, Grob R, Shaller D, et al. Taking patients' narratives about clinicians from anecdote to science. *N Engl J Med* 2015; 373(7): 675–679.
- Gray C, Yefimova M, McCaa M, et al. Developing unique insights from narrative responses to bereaved family surveys. *J Pain Symptom Manag* 2020; 60(4): 699–708.
- Hawley P. Barriers to access to palliative care. *Palliat Care* 2017; 10: 1178224216688887.
- Rome RB, Luminais HH, Bourgeois DA, et al. The role of palliative care at the end of life. *Ochsner J* 2011; 11(4): 348–352.
- Feder S, Smith D, Griffin H, et al. "Why Couldn't I Go in To See Him?" Bereaved families' perceptions of end-of-life communication during COVID-19. *J Am Geriatr Soc* 2021; 69(3): 587–592.
- Wittenberg E, Goldsmith JV, Chen C, et al. Opportunities to improve COVID-19 provider communication resources: a systematic review. *Patient Educ Couns* 2021; 104(3): 438–451.
- Giannitrapani KF, Yefimova M, McCaa MD, et al. Using family narrative reports to identify practices for improving end-of-life care quality. *J Pain Symptom Manag* 2022; 64(4): 349–358.
- Smith D, Kuzla N, Thorpe J, et al. Exploring nonresponse bias in the Department of Veterans Affairs' Bereaved Family Survey. *J Palliat Med* 2015; 18(10): 858–864.
- Williams M and Moser T. The art of coding and thematic exploration in qualitative research. *Manage Int Rev* 2019; 15(1): 45–55.
- Glaser BG. Open coding descriptions. *Grounded Theory Rev* 2016; 15: 108–110.
- Anderson RJ, Bloch S, Armstrong M, et al. Communication between healthcare professionals and relatives of patients approaching the end-of-life: a systematic review of qualitative evidence. *Palliat Med* 2019; 33(8): 926–941.
- Gerber K, Lemmon C, Williams S, et al. 'There for me': a qualitative study of family communication and decision-making in end-of-life care for older people. *Prog Palliat Care* 2020; 28(6): 354–361.
- Covvey JR, Kamal KM, Gorse EE, et al. Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature. *Support Care Cancer* 2019; 27(5): 1613–1637.
- Ritchey KC, Foy A, McArdel E, et al. Reinventing palliative care delivery in the era of COVID-19: how telemedicine can support end of life care. *Am J Hosp Palliat Care* 2020; 37(11): 992–997.
- Lowe S, Pereira SM and Yardley S. Communication in palliative care during the COVID-19 pandemic: lessons from

- rapidly changing, uncertain, complex, and high-stake interventions. *Palliat Med* 2021; 35(7): 1222–1224.
30. Torrens-Burton A, Goss S, Sutton E, et al. 'It was brutal. It still is': a qualitative analysis of the challenges of bereavement during the COVID-19 pandemic reported in two national surveys. *Palliat Care Soc Pract* 2022; 16: 26323524221092456.
 31. Moyo P, Loomer L, Teno JM, et al. Effect of a video-assisted advance care planning intervention on end-of-life health care transitions among long-stay nursing home residents. *J Am Med Dir Assoc* 2022; 23(3): 394–398.
 32. Graham RNJ and Woodhead T. Leadership for continuous improvement in healthcare during the time of COVID-19. *Clin Radiol* 2021; 76(1): 67–72.
 33. Douglas SL, Mazanec P, Lipson A, et al. Distance caregiving a family member with cancer: a review of the literature on distance caregiving and recommendations for future research. *World J Clin Oncol* 2016; 7(2): 214–219.