A Review of Web-Based COVID-19 Resources for Palliative Care Clinicians, Patients, and Their Caregivers

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Palliative and end-of-life care has been pushed to the forefront of medical care during the pandemic caused by the coronavirus-2019 (COVID-19). Palliative care organizations have responded to the growing demand for the rapid dissemination of research, clinical guidance, and instructions for care to clinicians, patients with COVID-19, and their caregivers by creating COVID-19 resource Web pages. Here, end users can access resources that can be updated in real time. These Web pages, however, can be variable in what resources they offer and for whom they are designed for (clinicians, patients, caregivers). Therefore, this project was conducted to consolidate these resources via summary tables of specific contents available through each Web page grouped by palliative care domains (eg, care discussion and planning, communication, symptom management, care access) and to identify the target audience. This environmental scan was conducted by compiling a comprehensive list of COVID-19 resource Web pages of palliative care organizations generated by reviewing previously published research studies and consulting with palliative care research experts. Snowballing techniques were used to identify resource Web pages not captured in the initial scan. Two reviewers independently evaluated eligible Web pages for content via a form developed for the study, and Cohen κ statistic was calculated to ensure interrater reliability. The final κ statistic was 0.76. Of the 24 websites screened, 15 websites met our eligibility criteria. Among the eligible resource Web pages, most (n = 12, 80%) had specific target audiences and care settings, whereas the rest presented information targeted to all audiences. Although 11 Web pages offered resources that addressed all 4 domains, only 1 Web page conveyed all 12 subdomains. We recommend the use of this guide to all frontline clinicians who require guidance in clinically managing patients with COVID-19 receiving palliative care and/or end-of-life care.

KEY WORDS
advance care planning, COVID-19, online resources, palliative care

Since the identification of the novel coronavirus disease (COVID-19) in December 2019, the number of confirmed COVID-19 cases has grown exponentially, reaching more than 76.9 million global cases to date (December 2020). The United States has the highest absolute number of cases, accounting for nearly a quarter of global cases. The situation has forced many to adapt to a new normal, and the US health care system was not an exception. Patients in ambulatory and/or outpatient settings experienced profound disruptions in care, and several hospitals were forced to care for an increasing volume of COVID-19–positive patients with dwindling resources such as personal protective equipment, health care personnel, and an overall decreased capacity to accommodate the increasing COVID-19 load. With profound changes in infrastructure, which are deemed necessary to minimize viral transmission, many clinicians and interdisciplin ary care teams had to rapidly adapt and...
implement the most up-to-date evidence regarding risk stratification and evidence-based management of patients with COVID-19 to clinical practice. Many were encouraged to think of outside-the-box solutions to conduct ongoing assessments, perform essential duties for their patients, and, most importantly, stay connected to those who are most vulnerable. This resulted in the redesigning of existing care models, from face-to-face to telehealth modalities, and application of interdisciplinary team-based care approaches.

Amidst the pandemic, a particular specialty that has experienced a surge in demand is palliative and end-of-life (EoL) care. A growing body of evidence suggests that patients living with comorbidities, frailties, and terminal illnesses have a greater risk of severe COVID-19 infection and are, consequently, at an increased risk for poor patient-reported health outcomes such as high symptom burden and poor quality of life. Palliative care (PC), an approach that aims to improve quality of life among patients and families experiencing life-threatening illnesses through early identification, assessment, and treatment of pain and other related symptoms, is undoubtedly being recognized as a key player in the management of patients and their caregivers impacted by COVID-19.

To adapt to the PC needs of particular patients in the midst of an increased flux of seriously ill patients, several research articles have been recently published to disseminate evidence-based recommendations and guidance for PC and hospice services during the pandemic, international consensus-based guidelines concerning remote communication, advance care planning (ACP), symptom management and holistic approach in PC, and a synthesis of national and international guidance documents regarding PC in nursing homes (NHs). Although peer-reviewed literature and resources available in scientific journals should be adequate for clinicians, patients receiving PC, and their families, they carry certain drawbacks. These resources can be time-consuming to find and rapidly go out-of-date given the unprecedented rate of publishing research related to COVID-19, and clinicians and families may frequently encounter paywalls when accessing much needed information. This presents a significant problem as clinicians/patients and families need to be able to rapidly access up-to-date information that can be implemented in real time to ensure that patients are continually receiving high-quality care and that clinicians and families have resources to turn to if they have questions about caregiving or PC-specific COVID-19-related questions.

To address this issue, national and international PC agencies have created a suite of COVID-19 resource Web pages that can be easily accessed on the Internet. However, there is significant heterogeneity for whom resources are being offered to and specific resources offered by each Web page. Therefore, our objective for this article was 3-fold: (1) to provide a list of PC organizations/addresses that offer web-based COVID-19 resources, (2) to identify whom the information is designed for (eg, the intended end users) and in which care setting (eg, target audience and care settings, when applicable), and (3) to visually summarize specific contents available through each Web page by domain (eg, care discussion and planning, communication, symptom management, care access).

**METHOD**

Online resources, freely available to end users, were used. A protocol a priori for identification and inclusion of online PC resources that included COVID-19 information was developed. This involved first identifying and compiling a comprehensive list of Web pages of PC/EoL care organizations generated by reviewing previously published research studies and by consulting with PC research experts. Snowballing techniques were used to identify resource Web pages not captured in our initial scan. The final list of PC/EoL Web pages was subsequently screened for the inclusion of COVID-19-related resources (yes/no). When available and deemed potentially eligible to be included, authors investigated further to extract relevant data (eg, target audience, content covered). Inclusion criteria were as follows: PC websites that were free of charge, accessible, and relevant to clinicians, and/or patients receiving PC and their families. In the case where the Web page offered free information along with a “members-only” section, authors only extracted content that was accessible without fees. This was done to ensure that resources presented in this article were readily available to all end users.

A standardized data collection instrument was composed using Qualtrics, a web-based survey system, to extract relevant information and fulfill project objectives (full information available upon request). This data collection instrument contained a total of 17 questions (see Box 1 for specific information extracted and organized per project objectives).

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**Box 1. Data Extracted by Instrument per Project Objectives**

**Objective 1. Provide a list of PC organizations and web addresses (2 items)**
- Name of PC organization
- Web address

**Objective 2. Identify target care settings and audiences (2 items)**
- Target organization
  - Assisted living, long-term care, homecare
  - Inpatient, nursing home, outpatient
- Target audience
  - Clinician, patients receiving palliative care, families (eg, family caregiver)

(continues)
Objective 3. Identify specific contents available on websites (13 items)
- Care discussion and planning domain
  ○ Advance care planning in COVID-19, goals of care
  ○ Treatment preference, medical care priorities
- Communication domain
  ○ Family meetings, care team meetings, sharing last words/legacies, preparing for end of life
- Symptom management domain
  ○ Dyspnea/breathlessness, pain, and other related symptoms
- Access to care domain
  ○ Telehealth visits, virtual office hour sessions, webinars, and podcasts

Data Collection
Data collection occurred in September 2020. Two authors (A.T. and V.K.) independently extracted relevant information from all eligible websites. These 2 data sets of collected information were then reviewed by the team, and any discrepancies were resolved through weekly virtual team meetings. Cohen’s κ statistic was used to ensure that adequate interrater reliability was achieved. The final κ statistic was excellent (κ = 0.76), and the final version of extracted data was collated in table format and shared among additional authors (J.S. and S.C.) to ensure data had been accurately captured.

RESULTS
List of PC Organizations and Web Page Addresses
A total of 15 PC/EoL Web pages met our criteria and were included in this article. Names and web addresses of the COVID-19 resource pages are presented in Table 1. In summary, 13 Web pages were national-level PC/hospice care organizations, and 2 were international. Although open and accessible to all disciplines, 2 national-level organizations were nursing-specific (ie, End-of-Life Nursing Education Consortium, Hospice and Palliative Nursing Association [HPNA]) and 1 was physician assistant-specific (Physician Assistant in Hospice and Palliative Medicine). Both national Physician Orders for Life-Sustaining Treatments and Respecting Choices were organizations that promote ACP for patients and families living with life-limiting illnesses (ie, Physician Orders for Life-Sustaining Treatments offers an actionable, portable ACP tool; Respecting Choices offers EoL decision aids). VitalTalk is a web-based organization that aims to bring communication skills and competencies to clinicians caring for individuals living with serious illnesses. On its Web page, clinicians can access various learning tools (eg, conversation scripts, videos, online courses) designed to provide training and expertise in how to navigate conversations when caring for seriously ill patients.

| Organization Name | Website (COVID-19–Specific Address) |
|-------------------|-------------------------------------|
| American Academy of Hospice and Palliative Medicine | http://aahpm.org/education/covid-19-resources |
| Center to Advance Palliative Care | https://www.capc.org/covid-19/ |
| End-of-Life Nursing Education Consortium | http://aacn nursing. org/ELNEC/COVID-19 |
| Get Palliative Care | https://getpalliativecare. org/whatis/disease-types/covid-19-and-palliative-care/covid-19-tips/ |
| Hospice and Palliative Nurses Association | https://advancingexpertcare.org/covid-19-resources |
| International Association of Hospice and Palliative Care | http://globalpalliativecare.org/covid-19/ |
| International Children’s Palliative Care Network | http://www.icpcn.org/coronavirus-and-childrens-palliative-care/ |
| National Association for Home Care & Hospice | https://www.nahc.org/resources-services/coronavirus-resources/ |
| National Coalition for Hospice and Palliative Care | https://www.nationalcoalitionhpc.org/covid19/ |
| National Hospice and Palliative Care Organization | https://www.nhpco.org/coronavirus/ |
| National POLST | https://polst.org/covid/ |
| Physician Assistants in Hospice and Palliative Medicine | https://www.pahpm.org/page-18492 |
| Respecting Choices | https://respectingchoices.org/covid-19-resources/ |
| Supportive Care Coalition | https://supportivecarecoalition.org/resources-blog/2020/3/19/covid-19-resources |
| VitalTalk | https://www.vitaltalk.org/covid-resources/ |

Abbreviation: POLST, Physician Orders for Life-Sustaining Treatments.
Target Care Settings and Audiences
For this objective, we ascertained from organization websites their target care settings (e.g., inpatient, outpatient, assisted living, homecare) and audience (clinician, patient, family). Authors specifically looked for the “care-specific tab” on each COVID-19 resource Web page to make it easier for end users to sift through information pertaining to the question that the end user is trying to answer and to reduce overextrapolation of the intended audience and care setting on behalf of the organization. By being explicit in this manner, the authors were able to create an easy-to-use visual map that aids in identifying where pertinent resources can be found for end users (see Table 2).

Most of the included Web pages (n = 12, 80%) specified their intended audience as well as care settings. Two organizations, Center to Advance Palliative Care and Respecting Choices, offered comprehensive COVID-19 resources that were intended for all audiences and applicable to any care setting. The End-of-Life Nursing Education Consortium and HPNA offered clinician-focused information that could be used in all care settings. For instance, HPNA offered direct links to printable PDF files, which included nursing assessment, pharmacological and nonpharmacological management, and discussion points for patient/family education. Similarly, the American Academy of Hospice and Palliative Medicine offered resources pertinent to inpatient/outpatient, NH, and long-term care settings. COVID-19–related information offered on the American Academy of Hospice and Palliative Medicine Web page was applicable to a broader audience including clinicians, physicians, educators, and even clinical researchers.

Family members and informal caregivers of patients receiving PC services in a homecare setting and/or inpatient hospice setting can locate additional resources through the National Association for Home Care and Hospice website. Families of pediatric patients receiving PC services in an inpatient and/or homecare setting can access COVID-19 resources through the International Children’s Palliative Care Network.

Identification of Specific Contents Available on Each Resource Page
Table 3 provides a visual map of resources presented in each organizational Web page that clinicians, patients, and families can access. Information extracted during this process was classified into 4 key user-friendly domains: (1) care discussion and planning, (2) communication, (3) symptom management, and (4) access to care. When a clinician needs guidance, or a family caregiver is seeking further information on ACP and making choices on goals of care, they can easily find the necessary resources through the visual map.

### TABLE 2
Target Audience/Care Setting–Specific Tab for COVID-19 Resource Provided by Organization

| Care Setting–Specific Tab | Inpatient | Outpatient | Nursing Home/LTC | Homecare |
|---------------------------|-----------|------------|------------------|----------|
| Clinician, patient, family| VitalTalk |            | CAPC             |          |
|                           |           |            | Respecting Choices| IAHPC    |
|                           |           |            | NHPCO            | NAHC     |
| Clinician only            | AAHPM     |            |                  |          |
| Clinician, family         |           |            | HPNA             |          |
| Clinician, patient        |           |            | National POLST   |          |
| Patient, family           | Get Palliative Care |  | IPCPN            | ICPCN    |

Abbreviation: AAHPM, American Academy of Hospice and Palliative Medicine; CAPC, Center to Advance Palliative Care; ELNEC, End-of-Life Nursing Education Consortium; HPNA, Hospice and Palliative Nurses Association; IAHPC, International Association of Hospice and Palliative Care; ICPCN, International Children’s Palliative Care Network; LTC, long-term care; NAHC, National Association for Home Care & Hospice; POLST, Physician Orders for Life-Sustaining Treatments.
| Table 3 | COVID-19 Resources Available per Domain and Organization |
|---------|---------------------------------------------------------|
|         | Care Discussion and Planning Domain | Communication Domain | Symptom Management Domain | Access to Care Domain |
|         | ACP | Goals of Care | Treatment Preferences | Medical Care Priorities | Care Team Meetings | Family Meetings | Sharing Last Words/Legacies | Breathlessness/Dyspnea | Pain/Other Symptoms | Telehealth | Virtual Office Hours | Webinars/Podcasts |
| AAHPM   | —   | —           | Yes<sup>a</sup> | —               | —         | Yes<sup>a</sup> | —         | —         | Yes<sup>a</sup> | —         | —         | —         |
| CAPC    | Yes<sup>b</sup> | Yes<sup>b</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>a</sup> | Yes<sup>b</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | —         | Yes<sup>b</sup> | Yes<sup>b</sup> |
| ELNEC   | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | —         | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | —         | Yes<sup>c</sup> | —         | Yes<sup>a</sup> | —         |
| Get Palliative Care | — | — | — | — | Yes<sup>a</sup> | — | — | Yes<sup>a</sup> | Yes<sup>c</sup> | — | — | — |
| HPNA    | Yes<sup>a</sup> | — | Yes<sup>b</sup> | — | Yes<sup>b</sup> | Yes<sup>a</sup> | — | Yes<sup>c</sup> | Yes<sup>d</sup> | Yes<sup>a</sup> | Yes<sup>b</sup> | Yes<sup>b</sup> |
| IAHPC   | — | Yes<sup>a</sup> | Yes<sup>b</sup> | — | — | Yes<sup>a</sup> | — | Yes<sup>b</sup> | Yes<sup>b</sup> | Yes<sup>a</sup> | — | Yes<sup>b</sup> |
| ICPCN   | — | — | — | — | — | — | — | Yes<sup>c</sup> | Yes<sup>b</sup> | Yes<sup>b</sup> | — | Yes<sup>b</sup> |
| NAHC    | — | — | — | — | — | — | — | — | — | Yes<sup>a</sup> | — | Yes<sup>b</sup> |
| NCHPC   | — | — | Yes<sup>a</sup> | — | — | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | — |
| NHPCO   | Yes<sup>a</sup> | Yes<sup>a</sup> | — | Yes<sup>a</sup> | — | — | — | — | — | Yes<sup>a</sup> | — | Yes<sup>a</sup> |
| National POLST | Yes<sup>c</sup> | Yes<sup>a</sup> | Yes<sup>b</sup> | — | — | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>a</sup> | — |
| PAHPM   | Yes<sup>a</sup> | — | Yes<sup>a</sup> | — | Yes<sup>a</sup> | Yes<sup>a</sup> | — | Yes<sup>a</sup> | — | Yes<sup>a</sup> | — | Yes<sup>c</sup> |
| Respecting Choices | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>b</sup> | Yes<sup>a</sup> | — | Yes<sup>a</sup> | Yes<sup>a</sup> | — | Yes<sup>a</sup> |
| Supportive Care Coalition | Yes<sup>c</sup> | Yes<sup>b</sup> | — | — | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | Yes<sup>c</sup> | — | Yes<sup>a</sup> | — |
| VitalTalk | Yes<sup>c</sup> | Yes<sup>c</sup> | — | — | — | Yes<sup>a</sup> | Yes<sup>a</sup> | Yes<sup>c</sup> | Yes<sup>a</sup> | Yes<sup>c</sup> | — | Yes<sup>c</sup> |

Abbreviations: AAHPM, American Academy of Hospice and Palliative Medicine; ACP, advance care planning; CAPC, Center to Advance Palliative Care; CPR, cardiopulmonary resuscitation; EoL, end of life; GoL, goals of care; ELNEC, End-of-Life Nursing Education Consortium; HPNA, Hospice and Palliative Nurses Association; IAHPC, International Association of Hospice and Palliative Care; ICPCN, International Children’s Palliative Care Network; NAHC, National Association for Home Care & Hospice; NHPCO, National Hospice and Palliative Care Organization; NCHPC, National Coalition for Hospice and Palliative Care; POLST, Physician Orders for Life-Sustaining Treatment.

<sup>a</sup>Information accessible through outside link or via other websites.

<sup>b</sup>Information is offered through own website and offers outside link/resource page.

<sup>c</sup>Information offered via own website.
care, they can look under the Care Discussion and Planning domain. Similarly, when caring for patient(s) exhibiting breathlessness, resources can be found under the Symptom Management domain. It is noteworthy that guidance for telehealth was made available on all Web pages. In addition, if a clinician wishes to seek further information that may have not been covered by organizational Web page(s), they can look under the Access to Care domain, specifically at virtual office hours, and participate in virtual live sessions to ask questions and obtain much needed information.

CONCLUSION

This article provides, to our knowledge, the first summary of content on COVID-19–related Web pages created by PC/EoL organizations that are readily accessible to clinicians, PC recipients, and their families. Although previous articles have examined web-based resources that are useful in health care delivery, many were limited to a specific population (by disease type) and not specific to the PC field.44–46 Two findings from this project bear further discussion.

First, only 1 website was pediatric-specific. Although a large number of pediatric PC programs exist that offer up-to-date COVID-19–related resources and virtual visits (eg, Boston Children’s Hospital; www.childrenshospital.org/conditions-and-treatments/conditions/c/coronavirus), they are often institution-specific, geared toward individuals who receive care at the institution, and/or vary greatly in terms of contents that they contain. Recently, this gap was recognized by the National Coalition for Hospice and Palliative Care (NCHPC).47 With the increased demands and need for a pediatric-specific national task force, NCHPC announced a newly formed Task Force (group of PC experts from different disciplines). The NCHPC shared the vision to create a platform where all patients, families, and caregivers who need it will have access to quality hospice care and PC.47

Second, it was observed that several Web pages linked external PC/EoL resources to their Web pages. For example, several Web pages provided a link to VitalTalk, a platform that provides communication aids designed to provide training on how to navigate conversations when caring for seriously ill patients. Similarly, several websites provided links to Center to Advance Palliative Care’s COVID toolkit, allowing for more rapid identification of COVID-19 resources. This approach of sharing resources among partner organizations prevents the duplication of efforts and allows for consistency in the dissemination of research and evidence-based clinical practice.

LIMITATION

This project is a cross-sectional study, which provides a snapshot of resources at the time of data collection. However, given the dynamic and rapidly evolving situation coupled with the unprecedented rate of publishing, resources can change quickly, making it impractical to provide a comprehensive guide of available resources in real time. By compiling a list of Web pages of both national and international PC/EoL organizations, we hope that the process of rapidly locating the appropriate web resources can be facilitated. It is also noteworthy that no non–PC-focused resources were identified in this study. This may limit the audience of this article to those who are already familiar with PC.

RECOMMENDATIONS

We recommend the use of this guide to all frontline clinicians who need guidance in clinically managing PC patients and clinicians integrating primary/basic PC into care of their patients. We also suggest that the resources included in this guide can help patients receiving PC and their caregivers as well; however, the availability of these resources must be communicated clearly by a clinician on how to access a particular resource. We recommend that, as resources are rapidly being introduced into the worldwide web by PC/EoL organizations, resources that are sparsely covered across organizations be targeted such as health care priorities, care team meetings, sharing last words/legacies, and virtual office hours.

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