Development of a Palliative Care Toolkit for the COVID-19 Pandemic

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40 Abstract

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42 The COVID-19 pandemic has led to high numbers of critically ill and dying patients in need of 43 expert management of dyspnea, delirium, and serious illness communication. The rapid spread 44 of SARS-CoV-2 creates surges of infected patients requiring hospitalization and puts palliative 45 care programs at risk of being overwhelmed by patients, families, and clinicians seeking help. In 46 response to this unprecedented need for palliative care, our program sought to create a collection of palliative care resources for non-palliative care clinicians. A workgroup of 47 interdisciplinary palliative care clinicians developed the Palliative Care Toolkit, consisting of a 48 detailed chapter in a COVID-19 online resource, a mobile and desktop web application, one-49 page guides, pocket cards, and communication skills training videos. The suite of resources 50 51 provides expert and evidence-based guidance on symptom management including dyspnea, 52 pain, and delirium, and also on serious illness communication, including conversations about 53 goals of care, code status, and end-of-life. We also created a nurse resource hotline staffed by 54 palliative care nurse practitioners and virtual office hours staffed by a palliative care attending 55 physician. Since its development, the Toolkit has helped us disseminate best practices to nonpalliative care clinicians delivering primary palliative care, allowing our team to focus on the 56 57 highest-need consults, and increasing acceptance of palliative care across hospital settings.

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61 62	Introduction	
62 63	Palliative care can play a central role in a healthcare institution's response to the COVID-	
64	19 pandemic. ¹ The high numbers of critically ill and dying patients create a sharp increase in the	
65	need for expert management of dyspnea, delirium, and serious illness conversations, in	
66	particular. With the rapid spread of COVID-19 driving surges of infected patients requiring	
67	hospitalization, the demand for palliative care consultation can accelerate quickly, putting	
68	programs at risk of becoming overwhelmed by the volume of patients, families, and referring	
69	teams in need of help. ²	
70	Aware of this possibility, our palliative care program at Dana-Farber Cancer Institute	
71	(DFCI) and Brigham and Women's Hospital (BWH) created a compendium of palliative care	
72	educational materials over six weeks that could serve as a resource to non-palliative care	
73	clinicians caring for these patients. To build the primary palliative care skillset of these	
74	clinicians and to expand our reach, we organized these resources into a Palliative Care Toolkit	
75	that we made available to frontline clinicians caring for patients with palliative care needs	
76	during the pandemic.	
77 78 79	Methods	
80	First, we put together an interdisciplinary workgroup comprised of attendings, fellows,	
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nurse practitioners, educators, and informaticians to create the Toolkit. Team members were
assigned to work on particular sub-projects, with ongoing collaboration and exchange of
resources across the larger group. The workgroup met several times a week for several weeks
and then weekly thereafter to monitor the progress of projects and strategize about next steps.

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We identified and followed several principles: 1) tools should focus on the care of patients with			
COVID-19, although they may have wider applicability, 2) tools should be clear, concise, and			
reflect palliative care best practices, 3) tools should be accessible to a wide variety of clinicians			
in a wide variety of settings, and 4) although tools may take different forms and formats, they			
should have internal consistency in content. As we created the Toolkit, we referenced materials			
at our institutions ³⁻⁵ as well as outside institutions, including materials from Massachusetts			
General Hospital and VitalTalk. ^{6,7}			
We started by writing a detailed palliative care chapter for covidprotocols.org, a			
comprehensive online resource created by the BWH Division of Pulmonary and Critical Care			
Medicine to disseminate best practices in treating patients with COVID-19. A subgroup of us			
subsequently distilled information from that chapter to create one-page palliative care			
summaries and pocket cards. We gave these to clinicians working in the Emergency			
Department, COVID ICU's, and COVID Hospital Medicine services and also adapted them for use			

98 by bedside nurses. Simultaneously, a separate subgroup built a web application (Pallicovid.app)

to host these resources online and to make them universally accessible by any mobile or

100 desktop device. An additional subgroup scripted and filmed six short communication skills

101 videos modeling techniques to use in goals of care conversations in the Emergency

102 Department, ICU, and Hospital Medicine settings.

103 Once our resources were developed, we worked with the leadership of each 104 collaborating clinical service to disseminate our tools by email communication and by posting to 105 their online platforms for clinical resources. Additionally, we realized that some clinicians would 106 have questions not covered by the tools, no matter how comprehensive. To meet this need, we

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107	created two additional resources: 1) a 24/7 palliative care COVID nurse resource line covered b
108	our nurse practitioners to advise bedside nurses, and 2) daily videoconference office hours
109	staffed by one of our attending physicians available to hospital teams with palliative care
110	management questions.
111 112 113	Results
114	The Toolkit, available at pallicovid.app, includes a collection of resources described in
115	Table 1. Users can access links to the one-page summaries, pocket cards, covidprotocols.org,
116	and the communication skills videos.
117	The combination of physical tools (pocket cards and one-page summaries), online tools
118	(the palliative care section of covidprotocols.org and communications skills videos), real-time
119	support tools (the 24/7 nurse resource line, daily palliative care office hours), and the Pallicovic
120	app has been well received by referring teams. We are able to direct clinicians to these
121	resources to answer straightforward questions and as a result we have been better able to
122	focus on more complex consultations that require higher-level palliative care expertise.
123	In response to the pandemic, we have also built new clinical programs aligned with the
124	Emergency Department, ICU, and Hospital Medicine teams. As we connected with attendings,
125	trainees, nursing leaders, and bedside nurses in those settings, we distributed information
126	about the Toolkit and made the resources available to all. Doing so has strengthened our
127	credibility as helpful partners in the crisis, even if we were not able to perform a consultation
128	for every patient we were called to see.

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129	We plan to continue to enhance the Toolkit, including adding a coaching option for		
130	referring teams needing more robust help with a particular case, but not a full consult.		
131	Meanwhile, we are finding that the current resources are being met with great enthusiasm.		
132	Covidprotocols.org had more than 660,000 page views between March 31, when the palliative		
133	care chapter went live, and May 4. Similarly, the pockets cards have been positively received;		
134	we ran out of the first order of 300 cards within two weeks. In addition, the Pallicovid app was		
135	accessed by over 2000 users between April 7 (its launch date) and May 4th.		
136 137 138	Discussion		
139	The COVID-19 pandemic is providing surprising opportunities for creativity in the midst		
140	of chaos and hardship. Our group's experience creating the Palliative Care Toolkit is one such		
141	example, allowing us to pull our varied skills and interests together in order to rapidly create a		
142	suite of helpful resources in anticipation of a surge of seriously ill patients at our hospital. We		
143	will continue to track the use of the various resources over time and ask for feedback from		
144	referring clinicians to determine which ones are proving especially useful. We will also adapt		
145	different parts of the Toolkit for different clinical settings where appropriate; the		
146	communication skills videos are one example of this kind of specialization.		
147	We anticipate that many clinical and educational strategies developed during the		
148	pandemic will continue to be useful long afterward. In creating the Toolkit, our group is		
149	discovering new opportunities to expand our program's reach and help referring teams without		
150	the need to perform a full consultation in response to every request. We are still experimenting		
151	with which requests for consults can be adequately addressed by pointing to the resources in		

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the Toolkit and which requests should result in full consults, and we are in the process of creating algorithms to standardize our triage practice. But we are embracing the possibilities afforded by having an array of specific, useful tools to put in the hands of our colleagues to help them care for their patients, especially with real-time back up from the nursing resource line and daily office hours. Our early experience demonstrates that we can provide a high level of support and availability while using our human resources far more efficiently than we have in the past.

159 A more ambitious hope is that the Toolkit will help strengthen the integration of our 160 palliative care program within our hospital. While our team is well supported by the hospital, in 161 the minds of some of our colleagues our specialty still remains inextricably linked to end of life 162 care. As we now help teams care for patients with COVID-19 who sometimes recover from 163 critical illness, it seems possible that the pandemic is creating an opening for real culture 164 change in how palliative care is viewed at our institution. The Palliative Care Toolkit is one tangible demonstration of our intention to be available to teams caring for seriously ill patients 165 166 regardless of life expectancy or code status.

167 The resources included in the DFCI/BWH Palliative Care Toolkit can serve as a useful 168 example for other programs facing challenges similar to our own. These tools can be adapted 169 to a wide variety of clinical settings that are anticipating or experiencing higher than usual 170 palliative care needs during the pandemic. We hope other programs find – as we have found – 171 that the Toolkit helps disseminate best practices in communication and symptom management, 172 allowing palliative care specialists to focus on the highest-need consults, and increasing 173 acceptance of palliative care across hospital settings.

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175 Disclosure/Conflict of Interest

- 176 Dr. Abrahm reports personal fees from UpToDate, personal fees from Johns Hopkins
- 177 University Press, personal fees from Pfizer, other from Manipal University and Tata Memorial
- 178 Hospital, and personal fees from Living Beyond Breast Cancer during the conduct of the study.

179 All other authors have nothing to disclose.

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180 References

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181				
182	1.	Etkind SN, Bone AE, Lovell N, et al. The Role and Response of Palliative Care and Hospice		
183		Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the		
184		COVID-19 Pandemic [published online ahead of print, 2020 Apr 8]. J Pain Symptom		
185		Manage. 2020;S0885-3924(20)30182-2. doi:10.1016/j.jpainsymman.2020.03.029		
186	2.	Powell VD, Silveira MJ. What Should Palliative Care's Response Be to the COVID-19		
187		Pandemic? [published online ahead of print, 2020 Mar 27]. J Pain Symptom Manage.		
188		2020;S0885-3924(20)30164-0. doi:10.1016/j.jpainsymman.2020.03.013		
189	3.	Abrahm JL. A Physician's Guide to Pain and Symptom Management in Cancer Patients,		
190		3rd ed. Baltimore: Johns Hopkins University Press, 2014.		
191	4.	Kematick BS, Phantumvanit V, Lynch M, et al. Pain Management Tables & Guidelines.		
192		Dana-Farber Cancer Institute & Brigham and Women's Hospital, 2017. Available from:		
193		pinkbook.dfci.org. Accessed May 4, 2020.		
194	5.	Suliman I, Xiang E, McBride P, et al. Adult Guidelines for Assessment and Management		
195		of Nausea and Vomiting. Dana-Farber Cancer Institute & Brigham and Women's		
196		Hospital, 2018. Available from: pinkbook.dfci.org. Accessed May 4, 2020.		
197	6.	Back AL. COVID-Ready Communication Skills: A Playbook of VitalTalk Tips. Seattle:		
198		VitalTalk, 2020. Available from: <u>https://www.vitaltalk.org/covid-resources/</u> . Accessed		
199		May 5, 2020.		
200	7.	Childers JW, Back AL, Tulsky JA, Arnold RM. REMAP: A Framework for Goals of Care		
201		Conversations. J Oncol Pract. 2017;13(10):e844-e850.		
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Table 1. The DFCI/BWH Palliative Care Toolkit for the COVID-19 Pandemic

TOOL	DESCRIPTION	HOW TO ACCESS
Pallicovid.app	Online progressive web application that can be downloaded to a smartphone or desktop with links to the one-page summaries, pocket cards, covidprotocols.org, communication videos, and links to institution-specific resources	Online at pallicovid.app, also available as mobile phone or desktop applications
Palliative Care section of CovidProtocols.org	Online resource with guidelines for managing anxiety, dyspnea, pain, nausea/vomiting, constipation, care of the imminently dying patient, and communication skills, also with links to institution-specific resources	Online at Covidprotocols.org, link from pallicovid.app
One-page summaries	2 one-page guides for managing dyspnea, pain, delirium, constipation, and goals of care conversations	Posted in clinician workrooms; online at covidprotocols.org and pallicovid.app
Pocket cards	Concise guidelines from one-page summaries	Distributed by hand, covidprotocols.org, pallicovid.app
Communication skills videos	Six short videos specific to different clinical settings (3 for the ICU, 2 for Hospital Medicine, 1 for the ED) with guidelines on how to discuss serious news, goals of care, and code status.	Links from covidprotocols.org, pallicovid.app
COVID Nurse resource line	Pager covered 24/7 by palliative care nurse practitioners for nursing advice on communication and symptom management for patients with COVID-19 and their families	BWH pager
Palliative Care office hours	One-hour availability offered daily by a palliative care attending for informal consultation, curbsides	Zoom line