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COVID-19 Content

How COVID-19 Changed Advance Care Planning: Insights From the West Virginia Center for End-of-Life Care



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Abstract

Context. Coronavirus disease 2019 (COVID-19) led to increased attention nationally on advance care planning.

Objectives. To describe the impact COVID-19 had on advance care planning based on changes in the calls to the West Virginia Center for End-of-Life Care (center) and in the volume and types of documents requested from and submitted to the center and its e-Directive Registry (registry).

Methods. A retrospective and observational analysis between January 1, 2020 and June 30, 2020 of calls to the center; advance directives downloaded from the center's Web site as well as mailed to the public and medical orders mailed to health care professionals on request to the center; and advance directives and medical orders submitted to the registry.

Results. The nature of calls changed to COVID-19-related topics, including confirmation of forms on the registry, urgent desire to initiate advance care planning, temporary rescindment of treatment-limiting forms, and questions on how to honor patients' wishes in advance directives and medical orders in light of their COVID-19 status. Also in the first six months of 2020, the center distributed more advance directives than it had during the same months in the last five years and more medical orders than it had in the preceding four years when there were no revisions to the medical order forms required by changes to the state law.

Conclusion. COVID-19 resulted in a new sense of urgency regarding advance care planning by West Virginians with increased attention to document their wishes and ensure that they were in the registry. *J Pain Symptom Manage* 2020;60:e5–e9. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words

COVID-19, advance care planning, medical orders, advance directives

Key Message

During the coronavirus disease 2019 pandemic, there was a new sense of urgency and interest in advance care planning in West Virginia resulting in calls and requests to the Center for End-of-Life Care to ensure that patients' wishes were accurately documented in its statewide registry so that they would be respected.

Introduction

In 2010, the West Virginia (WV) Center for End-of-Life Care (the center) created the WV e-Directive

Registry (the registry), and in 2012, the registry became available online on the state's health information exchange portal, the West Virginia Health Information Network. This enabled Health Insurance Portability and Accountability Act-compliant and password-protected 24/7 access for treating health care providers to their patients' advance directives and medical orders in emergencies.

The subsequent coronavirus disease 2019 (COVID-19) pandemic heightened the awareness of health care providers and the public on end-of-life issues and prompted patients to engage in advance care planning.^{1–5} The purpose of this brief report is to describe the impact that COVID-19 had on advance

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care planning in WV during the first six months of 2020 including the peak of the pandemic shutdown. The impact is reflected by changes in the calls to the center and in the volume and types of documents requested from and submitted to the center and registry compared with data from the same months in the preceding six years.

Methods

Design and Setting

This is a retrospective and an observational analysis between January 1, 2020 and June 30, 2020 of advance directives and medical orders (do-not-resuscitate [DNR] and physician orders for scope of treatment [POST] forms) submitted to the registry and of advance directives and medical orders distributed by the center on request. The function of the registry and submission of forms to it have been previously described.^{6,7}

Measurements

The following variables were analyzed: POST and DNR mailed to health care providers, advance directives mailed and downloaded from the center Web site, phone calls to the center, and forms submitted to the registry. The West Virginia University Institutional Review Board granted approval for registry-based research (#1208000278).

Results

The Center

Beginning January 2020, many WV residents and health care professionals began contacting the center with topics related to COVID-19. In the order of frequency with the most common first, calls to the center related to four main topics: confirmation of documents in the registry, urgent desire to initiate advance care planning, request for temporary rescindment of treatment-limiting forms, and patient-specific questions about how to honor patients' wishes in advance directives and medical orders in light of their COVID-19 status. [Table 1](#) shows the frequency of consecutive voice mails per topic for 141 voice mails received during the 20-day period between March 20, 2020 and April 8, 2020. The 141 voice mails account for 26.4% of the total 534 voice mails received or calls placed by the center during March and April 2020. It is noteworthy that there were a disproportionate number of calls and voice mails to the center during these two months because the calls and voice mails represented 51% (534 of 1046) of the calls and voice mails for the six month period of the study. The 141 voice mails in [Table 1](#) were selected based on

available data at the time of the study (i.e., the voice mails from March 20, 2020 to April 8, 2020 were still available for retrospective data analysis) and are representative of the total calls received. Twenty-three of the voice mails were classified as other/irrelevant in [Table 1](#) as they did not directly pertain to any of the topics (i.e., a death notice, wrong number, or wrong department) or could not be classified based on the caller not leaving a voice mail message.

COVID-19-related concerns also resulted in a spike in advance care planning medical order form requests. Excluding the years of 2016 and 2017 when the center distributed revised DNR and POST forms because of changes in state law regarding signatory authority on medical orders of advanced practice registered nurses (2016) and physician assistants (2017),⁸ the center distributed more of these medical order forms in the first six months of 2020 than in the same months in 2014, 2015, 2018, and 2019 ([Fig. 1](#)). During March–June 2020, the center limited distribution of POST forms and DNR cards to 100 per mailing to conserve the center's supply during the pandemic when there might be delays in form production.

In the first six months of 2020, the center distributed 10,093 advance directives, which were second only in number in the first six months in a seven-year period to 2015 when the center distributed 10,722 advance directives ([Fig. 1](#)) and the highest in the last five years.

[Fig. 1](#) shows the comparison of distribution rates by form type (advance directives, POST forms, and DNR cards) for the first six months (June 1–June 30 per year) of the last seven years (2014–2020). The previous six years are shown to establish the average and range of distribution rates for typical years for comparison to 2020. The years of 2016 and 2017 were atypically high because new versions of the DNR and POST forms were released in those years. In past years, the center staff noted that form distribution rates were significantly higher in years when revised versions of the medical orders were released because of changes in state code.

The Registry

In the first six months of 2019, the registry received 5934 forms, including 2048 combined living will and Medical Power of Attorney forms, 1091 DNR cards, 1171 Medical Power of Attorney forms, 897 POST forms, and 378 living will forms.

During the first six months of 2020, the registry received 6471 forms, including 1582 combined living will and Medical Power of Attorney forms, 1933 DNR cards, 1158 Medical Power of Attorney forms, 961 POST forms, and 331 living will forms. [Fig. 2](#) shows the comparison of submission rates by form type to the registry for the first six months of 2019 and

Table 1
Proposed Title Classification of Phone Calls to the Center During the COVID-19 Pandemic

Topic	Number of Voice Mails Received	Representative Comment
Confirmation of documents in the registry	97	<ul style="list-style-type: none"> ... I wanted to make sure you got them (forms) so that everything can be in the Registry if I, God forbid, end up going to the hospital <i>Topic summary:</i> Updating demographic information on the registry; confirming that the most current forms are on the registry
Urgent desire to initiate advance care planning	12	<ul style="list-style-type: none"> I want to get (an advance directive) filled out for my (spouse), because (spouse) needs one too. I have a (advance directive or medical order) with you. It was created back in 2014, and I would like to update that. I would also like to register my (spouse's) name. <i>Topic summary:</i> Requesting new blank forms to be mailed for completion; phone discussions on how to complete advance directives; questions about advance directive and/or medical order reciprocity across states
Request for temporary rescindment of treatment-limiting forms	6	<ul style="list-style-type: none"> If I should be hospitalized because of this virus (COVID-19), I understand ... they might refuse me care for resuscitation. If this is true, then I would like to cancel my (DNR) until this epidemic gets over I (would) want to be put on a vent [sic] (for COVID-19) <i>Topic summary:</i> Desire to temporarily cancel forms to ensure full treatment options are available for COVID-19
Patient-specific questions about how to honor a patient's wishes in advance directives and medical orders in light of their COVID-19 status	3	<ul style="list-style-type: none"> <i>Case summary:</i> The MPOA representative for a patient in a long-term care facility is the patient's only living child by blood. The patient's family, including 5 of the 7 grandchildren, were concerned that the MPOA representative may no longer have decision-making capacity due to neurological issues following a stroke. The patient had previously requested to be DNR status, which was documented. The MPOA representative changed the DNR status and indicated that the patient should receive CPR. The majority of the family believes this change is inconsistent with the patient's wishes and that the change was made or influenced by the MPOA representative's spouse instead of the MPOA representative. The MPOA representative's spouse has been acting as the MPOA representative during this time, which is not in accordance with the patient's MPOA form. Due to COVID-19, none of the concerned family members are able to visit the MPOA representative to determine decision-making capacity. No one is able to visit the patient, whom has rapidly declining health, due to COVID-19 as well.
Other/irrelevant	23	<ul style="list-style-type: none"> <i>Topic summary:</i> No message; wrong number; death notice

COVID-19 = coronavirus disease 2019; DNR = do not resuscitate; MPOA = Medical Power of Attorney.

2020. Most remarkable is the 77.18% increase in DNR cards (1933 vs. 1091) received in the first six months of 2020.

Discussion

COVID-19 resulted in a new sense of urgency of patients receiving care in WV regarding advance care planning with increased attention to documenting their current wishes for medical care accurately and to ensuring that they were recorded in the registry. The center's toll-free phone line enabled callers to ask pandemic-related questions about advance care planning, advance directives, and medical orders and to confirm that their treatment wishes were documented in the registry. These calls may serve as a snapshot of the attitudes of patients in WV, and possibly in the U.S., with regard to advance care planning prompted by pandemic-related concerns.

Most significant is the increase in medical order and advance directive distribution by the center during the

first six months of 2020 as compared with the preceding six years. Health care providers requested an additional 1600 more POST forms and 450 more DNR cards than were actually distributed during the study period because of pandemic-related distribution limits per request. They are not included in Fig. 1.

Although there was only a 9.05% increase in forms submitted to the registry (6471 vs. 5934), it is important to note there was a 77.18% increase in DNR cards submitted to the registry (1933 vs. 1091). This increase may reflect the concerns of patients who did not want heroic measures at the end of life if they were sick with COVID-19. Also portrayed in Fig. 2 is the increase in e-Directive Registry sign-up forms from 2019 to 2020. The registry uses an opt-in based system; this allows patients the option to choose whether their forms are included in the registry. For forms to be made available to treating health care providers through the registry, patients must either submit an e-Directive Registry sign-up form along with their form, which authorizes the registry to enter it into the database, or patients must submit forms that already include an

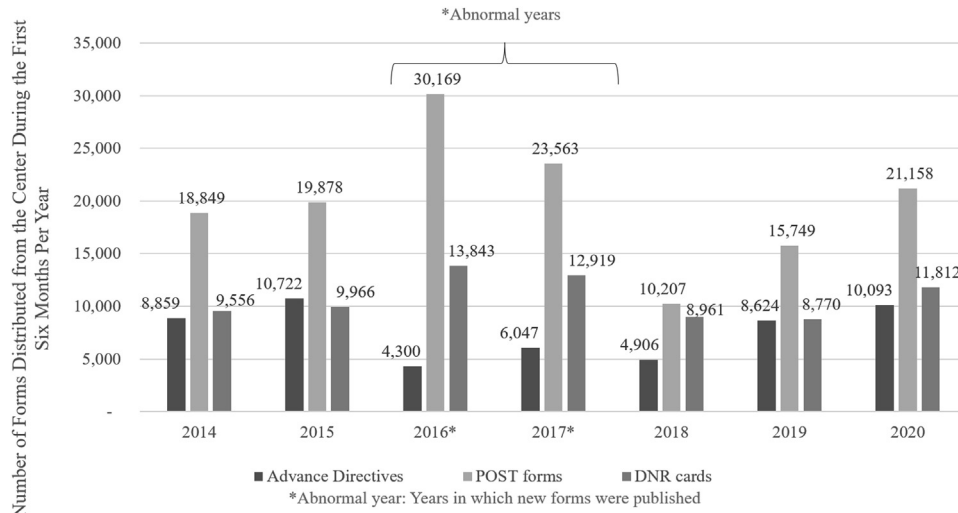


Fig. 1. Distribution comparison by form type for the first six months of 2014–2020. POST = physician orders for scope of treatment; DNR = do not resuscitate.

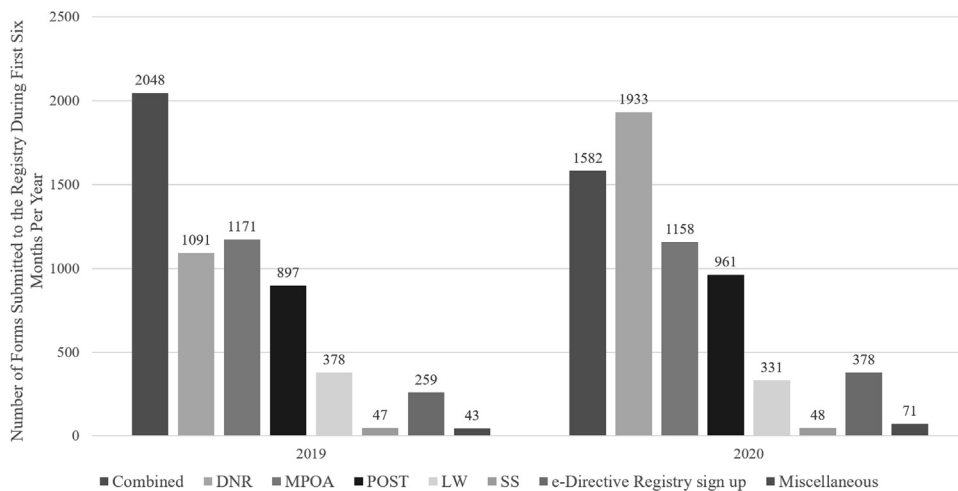


Fig. 2. Submission comparison by form type for the first six months of 2019 and 2020. DNR = do not resuscitate; MPOA = Medical Power of Attorney; POST = physician orders for scope of treatment; LW = living will; SS = surrogate selection.

initialed registry opt-in box on the form. During this study, there was a 45.95% increase in e-Directive Registry sign-up forms submitted to the registry (378 vs. 259). This increase resulted from patients who had previously completed forms without an opt-in box or chosen in the past not to opt in deciding that they wanted their forms in the registry.

The COVID-19 pandemic has resulted in dramatic changes in health care. An area in which it has had a major effect—advance care planning—is one in which patients frequently procrastinate or avoid altogether. Prompted by the pandemic and the heightened concerns about widespread illness, patients seeking health care in WV contacted the West Virginia Center for End-of-Life Care to ensure that their wishes were recorded in the registry and available to treating health care providers in an emergency. Even as the

crisis of the pandemic appears to be subsiding, clinicians have noted a new openness of patients to engage in advance care planning to maintain control over their health care. The changes seen in WV may represent a glimpse into what may be a greater receptivity to advance care planning in this country in the future.

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