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Cutting Through the Noise

How Social Media Can Provide Insight Into Advance Care Planning in the COVID-19 Pandemic



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Editor's Note: The following editorial was intended to accompany an article in the June 2022 issue. We are publishing it this month to provide full access to our readers.

Advance care planning (ACP) strategies to improve patient-aligned end-of-life care remain a significant challenge. Even most patients with serious illness do not complete written advance directives (ADs), despite options to complete one online, in the doctor's office, or with a lawyer.^{1,2} Nor is it clear that ADs, or ACP more generally, improve the end-of-life experiences for patients and their families; rates of burdensome, goal-discordant care at end-of-life remain high.³ As a result, there have been calls to focus instead on designating health care agents; however, surrogate decision-makers often fail to understand patient preferences accurately, which contributes to goal-discordant end-of-life care.^{4,5}

The COVID-19 pandemic stressed an already imperfect system for end-of-life decision-making and magnified many of its problems. It disproportionately afflicted vulnerable and underserved patient populations who are most affected by legal and other barriers to ACP

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and AD completion.⁶ It worsened the end-of-life experience by isolating patients from loved ones, and it made surrogate decision-making even more challenging. Understanding how perspectives of ACP changed during the pandemic offers useful insight into opportunities to improve ACP.

In *CHEST* (June 2022), Patel et al⁷ use a novel big data approach to measure patient perceptions of ACP through machine learning (ML). By applying natural language processing (NLP) to Twitter metadata, they found that public discussion of ACP and life-sustaining interventions (LSIs) both increased during the early days of the pandemic in spring of 2020 but that ACP messages were viewed less frequently and more negatively than discussions of LSIs. Their approach offers a novel complement to most ACP studies, which have focused on self-reported data and smaller samples in health care settings.³

Patel et al⁷ were able to exploit Twitter metadata to apply ML techniques to Twitter. Historic data on the social media platform retains information about the short-form 280-character messages ("tweets"), including who viewed them, whether the messages were "re-tweeted" by followers, and user demographic characteristics such as geolocation. With this amount of data readily available, medical researchers have used it to analyze sentiments around topics such as the COVID-19 vaccine.⁸

Patel et al⁷ analyzed ACP and LSI messaging through a stepwise approach. First, tweets were categorized into the categories of ACP or LSIs based on the content of the tweet. Tweets discussing do not resuscitate/do not intubate (DNR/DNI) status or ADs were classified as ACP and those about extracorporeal membrane oxygenation, CPR, ventilation, and high flow oxygen as LSIs. Twitter users were also categorized as either clinicians, individuals, influencers, or organizations through analysis of user display names and profile biographies. Second, the group used unsupervised ML (in which the ML model finds patterns without being trained on prelabeled data) to categorize English-language tweets by topic (eg, personal experiences, discrimination, legal advice) in the year leading up to and after the start of the COVID-19 pandemic. Finally, they used an established NLP technique (Valence Aware

Dictionary and sEntiment Reasoner) to measure the intensity of sentiment on an axis from extremely positive to extreme negatively.

Using these techniques, Patel et al⁷ identified 67,162 tweets about ACP and 202,585 tweets about LSIs. Tweets from both categories increased significantly after the beginning of the COVID-19 pandemic. ML determined the ACP topics of personal experiences and concerns about DNR/DNI-related discrimination against elderly people and people with disabilities were tweeted most frequently. Sentiment analysis found that most individual topics were not strongly positive or negative; however, tweets about LSIs were significantly more positive than tweets about ACP. This was primarily driven by tweets about DNR/DNI-related discrimination, which contained the most negative sentiment of any individual topic. Retweet-to-tweet ratio was highest for tweets that shared personal experiences about death and ACP, which suggests that the use of storytelling may have increased user engagement. In general, their findings were consistent with earlier small-data work that found increased attention to ADs and ACP during the pandemic.⁹

Their study has some limitations. One limitation is generalizability to patient populations of interest in ACP. The demographics of Twitter skew younger, wealthier, and less racially diverse than seriously ill populations. The use of only English language tweets may further bias representation of perceptions in non-native English language countries and cultures. Second, their ML measures may fail to measure engagement and sentiment accurately. Measuring tweet views and retweet-to-tweet ratios may not provide a picture of ACP engagement as it has been previously measured.¹⁰ Furthermore, NLP classification of a message's positive or negative valence may miss important information about the complexity of the message's emotional content. Finally, separating LSIs and ACP into two separate categories may not replicate how decisions about specific LSIs are incorporated into ACP.

But those limitations aside, the study offers a promising new direction in research on ACP through the application of ML. It suggests potential new pathways to understand ACP perceptions outside of health care settings and design interventions to promote better ACP. One new direction would be to apply ML techniques to different social media communities, teasing out how cultural differences influence ACP perceptions and effective approaches to the promotion of ACP. A second option would be to combine lessons

from this study with new digital modalities for documenting ACP, which have shown potential to increase ACP engagement.^{11,12} It may be possible to design social media-based interventions that promote the use of these digital platforms through the use of the study's most engaging ACP topic: personal experiences. These interventions might increase ACP engagement and the proportion of patients with serious illness with completed ADs and ACP documentation.

The more challenging question, of whether increased or better executed ACP could improve end-of-life care significantly for patients and families, is a separate one. But the use of novel approaches, such as ML when applied to social media and other big data sources, may be needed to help answer that question.

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