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Outcomes.

1. Determine whether the COVID-19 pandemic changed patients' perceived willingness to talk about advance care planning and preferences for care in the event of severe COVID-19 illness

2. Determine whether the preferences for care changed during COVID-19 for Black and White patients

Importance. Rates of advance care planning (ACP) are lower and preferences for life-prolong therapies are higher among Black patients than White patients.

Objective. To examine whether the COVID-19 pandemic, which has disproportionately affected Black patients, has changed racial differences in beliefs about ACP or preferences for end-of-life (EOL) care.

Methods. We used data from EQUAL ACP, a comparative effectiveness trial of 2 ACP interventions in seriously ill patients ≥ 65 years old seen in 10 primary care clinics in the South. We asked about COVID-19-related ACP and preferences for care. We used chi-square tests to examine racial differences in responses.

Results. The sample included 164 Black and 109 White patients. The mean age was 75 years; 63% were female. Similar proportions of Black and White patients (15.9% and 16.8%) reported being "more willing to talk to family/friends/doctors" about wishes for medical care as a result of the pandemic, although most (81.7% and 82.6%) reported "no change in willingness" ($p = 0.85$). A greater proportion of White than Black patients (26.6% vs. 20.7%) reported talking to family or friends about their wishes for COVID-19-related medical care. There were significant racial differences ($p < .001$) in EOL care preferences in the event of severe COVID illness. Black patients (36% vs. 12%) were more likely to want all treatments to keep them alive as long as possible, and White patients (75% vs. 55%) were more likely to only want a time-limited trial of life-prolonging measures.

Conclusion. In this sample, most patients reported that the COVID-19 pandemic has not changed their willingness to participate in ACP discussions. Black patients were more likely than White patients to want life-prolonging measures in the event of severe COVID illness.

Impact. Further studies should identify disparities in the quality of palliative care for patients with COVID-19 and determine potential drivers.

"Huffing and Puffing" vs. "Shortness of Breath": Including Colloquial Expressions in a Keyword Library for Detecting Symptoms (RP313)

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Outcomes.

1. Contrast examples of symptom expressions and examine the implications of not understanding certain expressions

2. Describe the importance of capturing patient-centered language in developing algorithms to detect symptoms

Importance. Among seriously ill patients, symptom burden is often unrecognized. Computational methods can be used for attending to this burden; these tools can assist with symptom identification for patient monitoring and quality improvement. A natural language processing keyword library can be used as a rudimentary tool to detect "symptom talk" and assist the development of more advanced algorithms.

Objective(s). To build a PRO-CTCAE symptom keyword library inclusive of the various verbal expressions by which patients and their physicians describe symptoms.

Method(s). A keyword library was drafted using transcription data from the Communication in Oncologist-Patient Encounters (COPE) trial, which includes audio-recorded outpatient oncology encounters between patient-oncologist dyads. In 93 conversations, three human annotators determined whether symptoms were discussed in each speaker turn, on a scale of 0 (not relevant) to 3 (relevant). For a subset of 48 conversations, words in all turns coded as 3 were extracted and relevant terms added to the developing library. This library was supplemented with language from a prior study extracting symptoms from clinical notes and with a priori additions. The library was tested on 45 additional conversations.

Results. The current library comprises 738 terms, including 137 symptom-related medications and 46 colloquialisms. In the test sample of 45 conversations coded as 3, keywords captured PRO-CTCAE symptom-containing turns with a sensitivity of 78.2%, a specificity of 95.3%, and an accuracy of 83.8%. Preliminary qualitative observations suggest that clinicians more often

refer to symptoms via medications (e.g., “Pulmicort”), whereas patients used colloquial verbiage to describe symptoms (e.g., “huffing and puffing”).

Conclusion(s). This rudimentary keyword library manages to capture most “symptom talk.”

Impact. Patients may verbalize symptoms using different language than clinicians, which clinicians should take care to recognize. In algorithms to recognize symptom talk, supplementing standardized clinical terms with patient-centered terms may better capture symptom burden in cancer and work toward the mitigation of symptom-related suffering in this seriously ill population.

An Evidence-Informed Cancer Care Communication Tool to Support Patients, Family, and Cancer and Palliative Care Clinicians During the COVID-19 Pandemic (RP314)

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Outcomes.

1. Understand the challenges of cancer care communication during the pandemic

2. Learn about a new tool for improving cancer care communication during the pandemic

Importance. The COVID-19 pandemic transformed the landscape of cancer care. Changes were not always communicated to cancer patients, and it is unknown how it impacted patient decision making.

Objective(s). Develop an evidence-informed communication tool to support patients, family, and cancer and palliative care clinicians navigating cancer care during a pandemic.

Method(s). Interviews with 71 participants (48 patients, 4 caregivers, 19 clinicians) between August 2020 and July 2021 at four U.S. academic cancer centers. Four focus groups with five professionals representing oncology and palliative care advisory organizations. A 3-hour virtual Stakeholder Summit with 25 attendees representing patients and family, cancer and palliative care clinicians, researchers, and advocacy organizations.

Results. The initial tool had five domains based on focus group and interview data, reduced to three domains during iterative discussion at the stakeholder summit: COVID-19-related changes and concerns, coping with cancer during the pandemic, and telehealth preferences. Conversations about COVID-19 between patients, caregivers, and clinicians can be emotionally

stressful or even taboo in some locales. Stakeholders advised building a tool to facilitate deeper discussions about COVID-19 while allowing patients to opt out and, if preferred, defer pandemic decision making to clinicians. Stakeholders noted that the tool should list only content and preferences that can actually be accommodated by cancer clinicians. Telehealth has different limitations and benefits, which created different preferences for clinicians, patients, and caregivers. Stakeholders agreed that a domain that captured patients’ preferences for its use should be kept.

Conclusion(s). A stakeholder-developed and evidence-informed communication tool that outlines pandemic-related changes and existing options for care may help patients and caregivers be more knowledgeable and active in decision making related to their care during the pandemic.

Impact. A communication tool can illuminate and potentiate patient, family, and clinician discussion about care preferences, even during a pandemic.

Nephrology and Palliative Care Providers’ Experiences and Beliefs in Engaging American Indian Patients in Palliative Care Conversations (RP315)

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Outcomes.

1. Describe nephrology and palliative care providers’ beliefs and experiences in engaging in palliative care conversations with American Indians

2. Examine the role of provider stereotypes in cultivating American Indian trust, engaging with family members, evaluating end-of-life preferences, and negotiating community resources

Importance. American Indians with chronic kidney disease are twice as likely to develop end-stage renal disease. Palliative care is underused by American Indian patients, although studies show that it is not due to an unwillingness to engage in conversations about the end of life.

Objective(s). The aim of our study was to explore the experiences and beliefs of nephrology and palliative care providers of one tribal community with respect to engaging patients and family members in palliative care.

Method(s). Using an interview guide, individual, in-depth interviews were conducted between March and August 2019 with eligible participants. We used constant comparative analysis of interview transcripts.