
Abstract

Adapting an Advance Care Planning Intervention Delivered via Telehealth for Older Patients With Acute Myeloid Leukemia and Myelodysplastic Syndromes

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Abstract

Background: Older patients with acute myeloid leukemia (AML) and myelodysplastic syndromes (MDS) experience high-intensity care (eg, chemotherapy, hospitalization, and life-sustaining treatments) during the end of life. Early advance care planning (ACP) may promote end-of-life care that is more consistent with patients' values and goals. As the COVID-19 pandemic has resulted in a rapid shift to telehealth, the use of such methods may improve access to ACP among this vulnerable population.

Objective: In this qualitative study, we aimed to adapt an evidence-based ACP intervention, the Serious Illness Care Program (SICP), to be delivered via telehealth for older adults with AML and MDS.

Methods: We conducted semistructured interviews with 14 oncology clinicians and 10 palliative care clinicians (physicians, advanced practitioners, and nurses), as well as 15 patients and 4 caregivers. Oncology and palliative care clinicians were recruited if they had cared for at least one patient with AML or MDS in the past year. Eligible patients were aged ≥ 60 years and had a diagnosis of AML or MDS, and their caregivers, if available, were recruited. Interviews were transcribed and qualitatively coded by 2 independent coders using MAXQDA (VERBI GmbH). We used directed content analyses focused on the content and delivery (telehealth vs in-person ACP) of the SICP.

Results: The mean ages of clinicians, patients, and caregivers were 48, 71, and 66 years, respectively. Health literacy, which was measured using the 6-item Cancer Health Literacy Test, was high in both patients (score: mean 6; range 0-6) and caregivers (score: mean 6). The majority of participants liked the intent and content of the SICP, with suggestions mainly on wording changes. One patient stated, "I wish I'd had a little of this back in the beginning, it would've eased my way through...." Oncologists expressed positive feedback for the SICP language "planting the seeds" of the ACP conversation, emphasizing that "it doesn't mean that it's going to happen." Oncology and palliative care clinicians were comfortable with conducting ACP discussions via telehealth. Providers felt that the use of telehealth in ACP conversations would allow them to "deliver care with less burden." Most patients and caregivers however were comfortable with conducting ACP conversations via telehealth "after the first couple of appointments [being] in-person" to first establish care. Lastly, providers felt that including a geriatric assessment summary prior to ACP conversations "helps to ground and anchor the discussion," as it provides a "sense of baseline functionality...[and] quality of life."

Conclusions: Overall, the SICP was well received by clinicians, patients, and caregivers. This stakeholder feedback will help us to better understand current barriers to ACP conversations and gauge whether telehealth may be utilized to help improve access to ACP. This feedback will be used to further refine the SICP intervention for a future single-arm pilot study.

Trial Registration: ClinicalTrials.gov NCT04745676; <https://clinicaltrials.gov/ct2/show/NCT04745676>

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Conflicts of Interest: None declared.

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KEYWORDS

advance care planning; telehealth; acute myeloid leukemia; myelodysplastic syndromes

Multimedia Appendix 1

UConn quotes table.

[\[PNG File , 68 KB-Multimedia Appendix 1\]](#)

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