

Exploring Experiences of Bereaved Caregivers of Older Adult Patients With Acute Myeloid Leukemia

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Caregivers of older adults with acute myeloid leukemia (AML) are requiring more support now that novel, nonintensive therapies, such as hypomethylating agents and venetoclax, are shifting the burden of care to the outpatient setting. Early findings from a larger study describe supportive care needs from the perspective of bereaved caregivers that align with existing research, informing the development of best practices for oncology nurses who support caregivers of older adults with AML.

AT A GLANCE

- Caregivers of older adults with AML experience significant distress, unique challenges, and heavy care burden compounded by lower utilization of palliative care services.
- Oncology nurses play a pivotal role in addressing caregivers' individualized needs for information and coping during treatment for AML.
- Oncology nurses are well positioned to provide continuous support to caregivers during survivorship that promotes meaning, condolence, and closure in bereavement.

KEYWORDS

acute myeloid leukemia; palliative care; bereavement; caregivers; end of life

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diagnosis of acute myeloid leukemia (AML) is often unexpected, life-threatening, and associated with high levels of distress, confusion, and upheaval in the lives of patients and caregivers (Albrecht & Bryant, 2019; Leak Bryant et al., 2015; Rodin et al., 2018). Older adults with AML are living longer because of more effective novel regimens using hypomethylating agents and venetoclax, but these survival benefits may extend and escalate patient and caregiver needs for palliative care at home and in other outpatient settings (Jonas & Pollyea, 2019; Kent et al., 2016). Caregiving spouses of older adults may be additionally challenged by their own health concerns or other age-related limitations (Kehoe et al., 2019). During survivorship, caregivers struggling to balance their own needs with their many responsibilities may benefit from access to supportive care through the survivor's healthcare team. However, these supports may no longer be available to caregivers in bereavement because of the natural end of contact with the cancer care team after the patient's death (Holtslander et al., 2017). These factors can correlate to a complicated adjustment for caregivers after death (Holtslander et al., 2017) and can lead to complicated grief, defined as a prolonged period of profound difficulty accepting and adjusting to loss (Toftagen et al., 2017).

The caregiving experience for AML is not well documented, particularly from the perspective of bereavement (Grover et al., 2019). This article will describe findings from an oncology nurse-led qualitative interview study exploring the experience of bereaved caregivers for older adults with AML and identify clinical implications for oncology nurses who support these caregivers in survivorship and bereavement.

Methods

This study was part of the control arm of a nurse-led palliative and supportive care intervention study for patients with AML aged 60 years or older receiving hypomethylating agents and venetoclax treatment and their caregivers. Since the study began in September 2020 and ended in September 2021, a total of 20 patients and 14 caregivers were enrolled. Three patients who received hypomethylating agents and venetoclax therapy died during study follow-up; all were survived by their caregiver. Of these three caregivers, two (one wife and one daughter) consented to be interviewed three to six months into their