Understanding Referrals to Outpatient Palliative Care and Goals of Care Discussions With Individuals Diagnosed with Stage IV Advanced Cancer

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Background

For individuals diagnosed with a stage IV cancer, earlier referral to palliative care may improve patient outcomes. We know little about when, if, and how patients and their providers discuss palliative care.

Methods

At a multi-specialty practice with an established outpatient palliative care program, we identified stage IV cancer patients diagnosed 1/1/2012-12/31/2017. We analyzed electronic health record data of patients who had died regarding formal referrals to and encounters with palliative care. We also conducted interviews with 16 oncology and palliative care team members regarding their experiences.

Results

Of the patients diagnosed with stage IV cancer, 695 were deceased, of these 347 (50%) were referred to palliative care, and 286 (41%) had at least one palliative care visit. Providers made 384 unique referrals for these deceased patients, 279 (73%) by oncologists, 41 (11%) by primary care physicians and 64 by other specialties. Median time between diagnosis and referral was 64 days (mean 204, max 1780). A quarter of patients died within 108 days, a quarter lived over 529 days. Among the first group, 137 (85%) survived at least 30 days; among these, 45% were referred and 45% of these referrals were within 14 days of diagnosis. Among patients in the top quartile for survival, 59% had a referral, but only 4% of those occurred within 14 days of diagnosis.

Among 19 oncologists, focusing on those with 10+ patients, referral rates ranged from 5-6% (3 physicians) to one physician who referred 72%. Interviews suggest widely varying perceptions across the oncologists. Some reported discussing palliative care at the first visit, while others described taking their cues from patients. Many physicians described patients with worsening symptoms as the best palliative care candidates, but noted that once initiated, many patients and families benefit from other services provided by the palliative care team such as goals of care conversations and more emotional support.

Conclusion

These data indicates wide variation in referrals to palliative care by oncologists. Interviews suggest patient preferences play a role, but the variability across oncologists presents a challenge to ensuring patients' needs and preferences are elicited and honored.