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EHR-Integrated Patient-Reported Outcomes in Ambulatory Oncology: A Critical Opportunity for Timely and Targeted Palliative Care

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The aim of systematic symptom screening and monitoring using patient-reported outcomes (PROs) is to collect actionable data and provide responsive care that is centered around patients' needs. Recent evidence demonstrates that routine assessment of PROs in ambulatory oncology improves patient–provider communication, satisfaction with care, health-related quality of life (HRQoL), symptom burden, and clinical outcomes.[1–4] As a result, there has been a significant interest in both incorporating these assessments as standard of care and integrating them in the electronic health record (EHR) so that results populate in real-time and facilitate care coordination. A recent study by our team demonstrates initial feasibility of EHR-integrated PROs among diverse Spanish and English speakers and provides a framework for implementation using the Exploration, Preparation, Implementation, Sustainment (EPIS) model.[5] However, despite the growing movement to implement routine EHR-integrated assessments of PROs in oncology, there has been little consideration of how these assessments should interface with palliative care and how they can be leveraged to deploy timely referrals for the patients who need them most during cancer treatment and across the survivorship continuum.[6]

Although outdated models of care only incorporated palliative care at end of life after disease-modifying treatment was no longer available, newer evidence-based models emphasize its integration earlier in the disease course in the ambulatory setting to proactively prevent unnecessary suffering.[6] Robust evidence from randomized controlled trials (RCTs) demonstrates that early integration of specialty palliative care (ie, interdisciplinary teams led by board-certified palliative medicine physicians) for patients with advanced cancer improves outcomes throughout the disease course by reducing symptom burden, improving HRQoL and satisfaction with care, and increasing advance care planning.[7–9] Furthermore, guidelines from NCCN and ASCO state that palliative care needs should be continuously assessed in *all patients with cancer*, regardless of disease stage, to ensure prompt referrals to specialty palliative care for patients with palliative care needs, such as high symptom burden and/or unmet physical, psychosocial, and existential care needs.

Current State of Palliative Care Research and Practice

Despite the benefits of early integration of palliative care, many patients still only receive palliative care late in the disease continuum, at or near end of life, or not at all. Furthermore, RCTs examining the efficacy of palliative care have typically tested a model of care that uniformly integrates palliative care within 3 months of diagnosis for individuals with advanced cancer and has a prescriptive follow-up schedule (eg, at least one outpatient palliative care appointment per month). Importantly, an approach based solely on diagnosis fails to account for heterogeneity across patients and the need to deploy care that is responsive to their unique symptom profiles and supportive care needs. The well-documented growing shortage of palliative care

providers also makes it highly unlikely that this approach is broadly scalable across oncology settings. Therefore, the alternative model set forth by Hui et al[6] of timely and targeted palliative care ("selecting the *right* patient for the *right* level of intervention at the *right* time") is a much-preferred alternative. This needs-based approach ensures that patients who are most likely to benefit from palliative care are systematically identified through screening and receive care in response to their symptoms and supportive care needs to proactively avoid symptom crises and improve HRQoL. We posit that the implementation of routine EHR-integrated PROs is a critical opportunity to guide timely and targeted palliative care.

Recommendations

EHR-integrated assessments can be used as a vehicle to systematically screen patients' symptoms and care needs to (1) identify those who would most benefit from palliative care, and (2) guide the integration of palliative care to be more patient-centered and considerate of structural limitations, such as the capacity of the specialty palliative care workforce. We propose that a comprehensive assessment of PROs that includes multiple domains of symptoms and HRQoL should be used to screen for the potential need for a palliative care referral. An ongoing noninferiority trial by Post et al[10] is currently testing whether using PROs to track symptoms and HRQoL to inform the integration of palliative care among patients with advanced lung cancer is as effective as the previously described standard model of early integration for all at diagnosis. While we await these results and the results of future studies, we outline a set of practical recommendations that can be considered by providers and stakeholders who are interested in implementing EHR-integrated assessments of PROs as part of routine care in ambulatory oncology so that they can be leveraged to facilitate timely and targeted palliative care.

Involve Palliative Care Stakeholders

It is imperative to involve the palliative care team, including specialty palliative medicine physicians, in the implementation of systematic EHR-integrated PROs screening and monitoring and the design of an outpatient palliative care–specific referral pathway. This should be done as early as possible to increase interdisciplinary collaboration and buy-in from both referring clinicians and the palliative care team. Stakeholders, including patients, oncology providers, and the palliative care team, should also collaborate to inform user-centered design of the EHR-integrated assessments to optimize PRO completion rates and clinician responses to alerts.

Define PROs Relevant to Palliative Care

PROs that will be assessed should be reviewed to identify those that are relevant to palliative care needs. Needs that warrant palliative care referral may exist across different domains, including physical symptoms (eg, cancer-related or treatment-related pain, peripheral neuropathy, dyspnea, gastrointestinal complaints, fatigue, insomnia), psychosocial concerns (eg, cancer-related or treatment-related depression or anxiety, difficulty coping, distress about medical decision-making, family and/or caregiver burnout, poor social support), and decline in functional status.

Establish Parameters for Referral Suggestions

Target patient populations for completion of the EHR-integrated assessments should be identified and thresholds for symptom severities that will trigger best practice alert in EHRs suggesting palliative care referral should be defined. Thresholds can be based on existing clinical cutoffs or by scores determined to

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be clinically-meaningful by oncology and palliative care providers. Thresholds can also be combined with other relevant data mined from the EHR that are relevant for palliative care, such as missing advance directives or multiple hospitalizations or emergency department visits in a defined period of time. EHR-integrated PROs may also allow for automated identification of symptom and event clusters or phenotypes that indicate palliative care needs. Criteria for triggering a suggestion for palliative care referral will need to be refined in accordance with the current scope, size, and role of the palliative care team at each institution. For example, a well-staffed palliative care team with multiple interdisciplinary members, including a social worker and psychologist, may encourage referrals for depression in the context of advanced cancer; however, other teams may not be resourced to see these patients or may have a different service line that is more appropriate.

Multi-Pronged Approach to Palliative Care Referrals

EHR-integrated assessment of PROs should be conceptualized as a supplemental tool for earlier identification of palliative care needs. This referral pathway is neither sensitive nor specific enough to identify all patients who may benefit from palliative care. Therefore, it is crucial to implement and fortify complementary referral pathways in each institution, because EHR-integrated assessments are not intended to substitute clinician judgment. Institutions may consider expansion of privileges for placement of referrals to palliative care beyond physicians and advance practice providers to other clinical staff who can be trained to identify palliative care needs and place referrals, such as social workers, nurses, and patient navigators. Institutions can also create a pathway for self-referral by providing patients with brief educational introductions to palliative care when palliative care needs are identified in the EHR-integrated assessment.

Ongoing Programmatic Evaluation

Ongoing EHR-integrated assessments should be used to (1) continuously track patient care needs from time of initial palliative care referral through resolution of symptoms or end of life, (2) perform early and frequent evaluations of the appropriateness of palliative care referrals generated by EHR-integrated assessments and adjust process as needed, and (3) assess the impact of EHR-integrated assessments on timing and volume of palliative care referrals at institution. Well-controlled dissemination and implementation studies are also needed to evaluate the effects of palliative care referrals guided by EHR-integrated PROs on systems-level outcomes, such as provider satisfaction and healthcare utilization and cost. Future research should consider the role of EHR-integrated PROs in serious illnesses beyond cancer. Routine assessments in lower-resource settings, such as those with no EHR or a very limited palliative care workforce, may require more robust adaptation using an implementation science framework.

Conclusions

According to the WHO, the "impeccable assessment" of physical symptoms and psychosocial concerns is a defining component of palliative care. However, best practices to screen and identify patients with cancer with complex needs who would benefit from palliative care have not been established. Furthermore, there has been little crosstalk between the movement in oncology to implement EHR-integrated PROs and efforts to optimize the integration of palliative care among individuals with cancer. More research is needed to leverage the implementation of routine EHR-integrated PROs in ambulatory cancer care as a critical opportunity to guide timely and targeted palliative care using a patient-centered, needs-based approach.

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References

1. Basch E, Deal AM, Kris MG, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. J Clin Oncol 2016;34:557–565.
2. Basch E, Deal AM, Dueck AC, et al. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. JAMA 2017;318:197–198.
3. Basch E, Schrag D, Henson S, et al. Effect of electronic symptom monitoring on patient-reported outcomes among patients with metastatic cancer: a randomized clinical trial. JAMA 2022;327:2413–2422.
4. Kotronoulas G, Kearney N, Maguire R, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. J Clin Oncol 2014;32:1480–1501.
5. Penedo FJ, Medina HN, Moreno PI, et al. Implementation and feasibility of an electronic health record–integrated patient-reported outcomes symptom and needs monitoring pilot in ambulatory oncology. J Clin Oncol. Published online March 15, 2022. doi:10.1200/OP.21.00706
6. Hui D, Hannon BL, Zimmermann C, et al. Improving patient and caregiver outcomes in oncology: team-based, timely, and targeted palliative care. CA Cancer J Clin 2018;68:356–376.
7. Gaertner J, Siemens W, Meerpohl JJ, et al. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. BMJ 2017;357:j2925.
8. Kavalieratos D, Corbelli J, Zhang D, et al. Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. JAMA 2016;316:2104–2114.
9. Hui D, Bruera E. Integrating palliative care into the trajectory of cancer care. Nat Rev Clin Oncol 2016;13:159–171.
10. Post KE, Heuer LB, Kamal AH, et al. Study protocol for a randomised trial evaluating the non-inferiority of stepped palliative care versus early integrated palliative care for patients with advanced lung cancer. BMJ Open 2022;12:e057591.