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Invited commentary on Factors Important to Patients' Quality-of-Life at the End-of-Life for the Archives of Internal Medicine

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In this issue Zhang, Nilsson, and Prigerson¹ seek to discover the best predictors of quality of life for cancer patients in the last week of their lives. This investigation is one aspect of the Coping with Cancer study, a multi-site prospective longitudinal study of advanced cancer patients who were followed for several months until death.

Patients and their caregivers provided various demographic, medical, and psychosocial data at entry to the study and a caregiver rated quality of life just before death retrospectively several weeks postmortem. This assessment consisted of ratings by the informant for the patient's last week of life in three areas, physical distress, psychological distress, and overall quality of life, which were summed to create the primary outcome measure of quality of life.

After applying sophisticated random effects modeling and cross-validation techniques, Zhang et al identified several key predictors of informant-rated quality of life just before death. Among these predictors, dying in the hospital and intensive care unit admissions in the last week of life accounted for the greatest variance in poor quality of life; patients' worries were also associated with worse quality of life. Factors that contributed to greater quality of life included patients' self-reported participation in prayer and in-hospital pastoral care, and self-reported therapeutic alliances with their physicians. Zhang et al conclude that these data suggest a significant role for physicians even when cures are unavailable by cultivating therapeutic alliances, promoting introspection perhaps through pastoral services, reducing worrying, and avoiding unnecessary hospitalizations.

Health-related QOL is a complex and multifaceted construct that can refer to physical, social, or psychological factors, but defies exact definition.² As an overall measure of well-being, functional health, and life satisfaction, QOL has been used in a variety of ways from measuring personal appraisals of one's overall circumstances to progress in eliminating health disparities and success in addressing public health goals in epidemiologic studies. Its use has found various applications, including guides to care for other terminal diseases such as dementia.³

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In their comments on Gill and Feinstein's seminal paper on QOL, Guyatt and Cook⁴ set forth criteria for judging whether it was assessed adequately. Among their criteria, drawn from Gill and Feinstein, they suggest the key question is whether "patients were asked to place a value on their lives" (p 631). None of these authors suggest how we might assess the paradox of life quality when time to expected death is measured in hours or days. Nevertheless, the concept persists, even though it seems contrary to quality of life. It speaks to the absence of unnecessary pain and discomfort near the end of life, and an acceptance for the inevitable short time left to live. Although Zhang's three items are surely related to self-assessed value of life, there is ample room for more work in this area to characterize what quality of life means for patients with terminal illnesses.

The concept of QOL at EOL in cancer patients has been under-examined in cancer medicine in the quest to develop newer, more advanced, and effective modalities of interventional, cytotoxic therapies. This study highlights the paucity of research in an area that is vital to give us important tools in further refining coherent treatment strategies for patients throughout the timeline of cancer treatment and disease trajectory. This study examines issues fundamental to providing high quality state-of-the art cancer care. It is surprising at this stage in the development and implementation of complex multi-modality cancer treatment strategies that the factors most critical in influencing QOL at EOL are not clearly defined and considered along the entire timeline beginning with cancer diagnosis.

Zhang and colleagues have provided important insights by identifying the 9 factors that account for ~20% of the variance in EOL QOL. It is likely that several patient-centered and provider-centered factors account for the unexplained variance. Although they measured several characteristics while patients were alive, none of the measures were assessed before the patients became ill or before they began treatment. This is important because dispositions and personality characteristics are related to self-rated QOL, particularly optimism,⁵ one facet of extraversion in the five-factor model of personality.⁶ There is an accumulating literature suggesting that personality attributes are at least as important for predicting QOL as clinical factors, for example in major colorectal surgery.⁷ Other attributes worth considering include science and health literacy levels among patients and their caregivers; race, ethnicity, language, cultural competence among care providers; and, consistency of longitudinal care planning as well as quality of physician-patient bi-directional communication and their overall relationships.

The American Society of Clinical Oncology (ASCO) statement on individualized care for advanced cancer patients⁸ argues that paradigm of care must change and that this change must include the very areas that Zhang highlights as factors that are associated with QOL at EOL. Cancer care providers must not only answer the question whether we can treat advanced cancer but also must simultaneously address the ways that QOL can be maximized throughout interventional treatments and the time course of the disease in individual patients. Physicians are urged to recognize the need for individualized care that will facilitate setting of appropriate treatment goals and endpoints that focus on QOL, not solely survival at any cost.

The challenge of providing care in advanced cancer lies not in knowing which modalities may offer the best chance for disease response and prolonged survival. The challenge is in providers' abilities to develop and maintain effective integrated relationships with their patients that are strong enough to provide the communication channel to convey the emotionally difficult messages relevant to prognosis, true efficacy of therapy, the futility of care and when active palliation is the best treatment modality available. Physician-patient communication is a cornerstone of high quality medical care in all facets of medicine; however, in the high emotion setting often present when caring for advanced cancer patients these channels of communication are stressed. In a study by Mohan and colleagues⁹ physicians on average demonstrated low skill at handling emotions and only moderate skill at discussing end-of-life goals. Failure of these channels of communication and undefined incompletely developed partnerships between patient and care provider likely frequently result in provision of care that ultimately negatively affects QOL at EOL (e.g., ICU stay and chemotherapy in the final week of life).

This work as well as the ASCO statement supports early introduction of palliative care for advanced cancer patients. In some cases active palliative care in conjunction with standard oncologic care extends survival in advanced non-small cell lung cancer metastatic as well as decreases the level of aggressive care at the end of life.¹⁰ This study is worth highlighting also because it inherently understood the need to include patients who were racially and ethnically diverse since racial and ethnic differences are important influences on many facets of health status and health care access especially in physician patient interaction and communication and delivery of care.¹¹

Selecting predictors from a large set of measures is fraught with difficulties, not the least of which is whether results capitalize on chance and the low likelihood for replications in independent samples. Future work should be broadly inclusive of the diversity of this country as well as those whose first language is not English.

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