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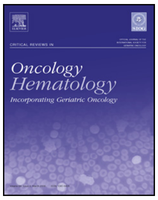

Quality end-of-Life cancer care: An overdue imperative

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ABSTRACT

This review assesses the current status of end-of-life care based on large-scale, multiyear nationwide surveys of treatment modality, setting, and cost of care during terminal patients' last months of life. It shows that end-of-life care goals often remain suboptimal. Contributing factors include prioritized life preservation, uneven commitment to palliative care, few palliative care specialists, and perverse financial incentives that encourage costly interventions. Although not determinant per se, these factors coupled to doubts about what constitutes end-of-life can lead to overextended disease treatment and a late implementation of palliative care. In order to bridge the existing gap between care received and care expected and achieve quality end-of-life and promote death with dignity, we propose both to view the person rather than the disease as the unit of care and a pragmatic definition of end-of-life. Such a strategy should facilitate selecting an optimal time to transition from disease-targeted treatment to palliative care.

1. Introduction

In recent decades, enormous progress has been achieved in our knowledge of cancer at all levels. In the area of therapeutics, for instance, our armamentarium now ranges from chemotherapy drugs, to targeted agents, to immunotherapeutic approaches, to vaccines. Since 2005, FDA has approved over 60 new anti-cancer agents and expanded the indications for many others, greatly widening the range of tools to treat most cancers. Thanks to this wide choice at our disposal, patients with advanced-stage cancer of the types known to be curable are vigorously treated with specific regimens likely to achieve that goal (Faguet, 2005). Patients with advanced-stage cancer of the types known to be incurable but responsive to treatment are offered regimens with the best risk-benefit ratio and tolerable side effects, in hopes of controlling disease progression and prolonging survival. Patients, whose tumors fail to respond to such first-line regimens, progress during treatment, or relapse after an initial tumor response, are usually treated with second-line regimens often followed by salvage-therapy without meaningfully altering the course of the disease in most cases. Such emphasis on disease control stems from both a desire to optimize each patient's prospects of achieving the best possible outcome and a reluctance to give up despite setbacks hoping the next treatment regimen might succeed where the previous one failed. However, while curative in some cases and prolonging survival of many others, extending this approach to the end-of-life (EOL) seldom achieves EOL care goals (Foley and Gelband, 2001). Factors that contribute to an over-extended focus on the disease include prioritizing life prolongation or preservation, caregivers' inadequate palliative care skills, insufficient number of palliative

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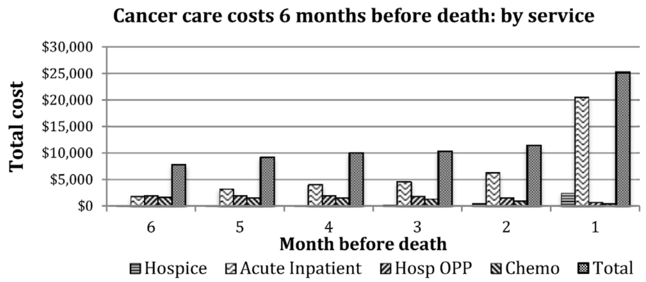

Fig. 1. Cancer care costs during the last 6 months of life: by category.

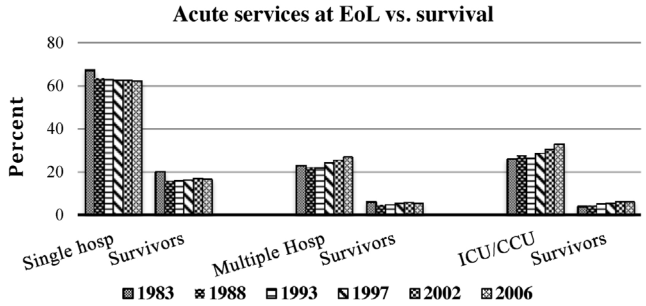

Fig. 2. Acute EOL care vs. Survival: 1983–2006.
Derived from Ref. Teno et al., 2013a.

care specialists, and perverse financial incentives that encourage costly interventions (Institute of Medicine, 2014). In the absence of a clear understanding of when a patient reaches EOL, these dynamics can lead to the protracted aggressive management of terminal cancer patients using invasive procedures with palliative care being relegated to the last few days of life. Such an EOL care strategy is ineffective, costly, detrimental to QOL, and often in conflict with patients' needs and preferences. Although adoption of palliative and hospice care has progressed in recent years, its outcome remains controversies. After identifying driving forces underlying the wanting status of EOL care we propose means to deliver quality EOL to the half million US cancer patients and nearly 10 million worldwide who reach EOL and die each year (National Vital Statistics Reports, 2016; World Heath Organization, 2015).

2. Data sources, review of the literature, and discussion

We analyzed large-scale, multiyear nationwide surveys of treatment modality, setting, intensity, and cost of care during terminal patients' last months of life (Chastek et al., 2012; Morden et al., 2012; Obermeyer et al., 2014; Clark, 2007; Barnato et al., 2007). Our analysis covering over 1 million terminal cancer and non-cancer patients who died between 2000 and 2009, demonstrate that on the average end-of-life care goals remained unmet. For instance, in a recent study of 28,530 privately insured oncology patients conducted between July 2002 and December 2009 the mean health care cost incurred in the last six months before death was $74,212 of which 55% ($40,702) was for inpatient care and only 4% ($3,256) for hospice care (Chastek et al., 2012). Acute inpatient care costs increased progressively each month, from $1,785 on the sixth month before death to $20,559 during the last month, or 81% of that month's total care cost ($25,256). In contrast, hospice care costs increased from a negligible $28 on the sixth month before death to $2,464 in the last month of life (a paltry 9.8% of that month's total care cost). Other disease-targeted treatment costs decreased somewhat each month but persisted to the end, including chemotherapy (Fig. 1)

Likewise, a survey of EOL care delivered to 215,311 Medicare beneficiaries with cancer dying between 2003 and 2007 revealed that 10 or more physicians were involved during patients' last 6 months of life in 48.1% of cases, 64.9% were hospitalized during the last month of life, including 24.7% to ICU facilities, and 30.2% died while hospitalized (Morden et al., 2012). And, although 53.8% were enrolled in hospice care during the last month of life, the average stay was only 8.4 days. Similarly, in a more recent study involving 86,851 Medicare fee-for-service beneficiaries with poor-prognosis cancer, 60% were transferred eventually to a hospice program but the median stay was only 11 days (Obermeyer et al., 2014). Revealingly, a subset of 18,165 patients enrolled in hospice care experienced lower rates of hospitalization, ICU admissions, invasive procedures, lower total costs, and fewer (14% vs. 74%) died in hospital or nursing facilities than 18,165 matched non-hospice patients. Survival and other benefits of instituting early palliative care have been amply confirmed in several prospective studies including one of patients with newly diagnosed metastatic non–small-cell lung cancer randomized to receive either early palliative care along with standard oncologic care or standard oncologic care alone (Temel et al., 2010). Patients assigned to early palliative care had a better quality of life, fewer hospitalizations, were less likely to die in the hospital, fewer received aggressive EOL treatment, and on the average survived longer than those in the group that received standard oncologic care alone. Hence, the type and setting of EOL care rendered to over a third of a million terminal cancer patients from both the private and public sectors between 2002 and 2009 demonstrate that physicians utilize acute inpatient services through the EOL and call on consultants in vain efforts to prolong patients' survival while making only a token and late use of palliative care and hospice support.

Such an extended aggressive disease-focused stance, to the detriment of palliative care, also applies to terminal cancers in the young and to other terminal diseases as shown in two recent studies (Mack et al., 2015a; Teno et al., 2013a). The latter compared sites of death and types of care delivered to nearly 850,000 Medicare beneficiaries who died in 2000, 2005, and 2009 (Teno et al., 2013b). Although more Medicare beneficiaries died at home, and more received hospice care as the decade progressed, the frequency of hospitalizations and ICU stay increased over time leading an accompanying editorial to observe "the focus appears to be on providing curative care in the acute hospital regardless of the likelihood of benefit or preferences of patients. . . [suggesting] the increased availability of palliative and hospice care services does not appear to have changed the focus on aggressive, curative care. Hospice services appeared to be tagged on to the last days of life (Jenq and Tinetti, 2013)."

Indeed, if intensive acute care at he EOL is intended to prolong survival, results achieved thus far have not being encouraging. For instance, a retrospective survey of in-hospital care and ICU/CCU usage among Medicare beneficiaries during the last months of life ranked by survival status between 1978 and 2006 revealed that of approximately 2/3 of patients hospitalized during a typical month only 16.0% to 20.1% survived their first hospitalization. Out of the 20.3% to 27.0% hospitalized multiple times and out of the 26.1% to 33.1% treated in ICU/CCU settings, only 4.0% to 6.3% survived, respectively (Riley and Lubitz, 2010) (Fig. 2). Although the authors noted a statistically significant trend in the latter two categories, it lacks clinical relevance given the negligible survival rates reported and the inconsequential rise over a three decades-long observation period (Faguet and Davis, 1984).

3. An evidence-based EOL care strategy

While there is no one-size-fits-all approach to EOL care, prioritizing the individual rather than the disease at each stage of the process and recognizing when EOL begins are essential starting points. Hence, we propose a person-centered, family-oriented management approach that includes a much-needed pragmatic and practicable definition of EOL to guide a timely switch from disease-focused treatment to palliative care designed to meet the needs of cancer patients at all stages. It consists of an evolving and seamlessly integrated approach to care beginning with an aggressive disease control stance initially, coupled with supportive and palliative care as an essential component of the overall management plan, becoming the main focus near the EOL when the chances of disease control have receded.

EOL can be defined as the phase entered by terminal patients when further disease-targeted treatment cannot reasonably be expected to be successful and/or is likely to further degrade QOL. However, identifying when a patient enters EOL and further treatment is futile are perhaps the most difficult decisions advanced cancer caregivers face. Indeed, few care decisions have more profound implications for patients and their loved ones than those made near the EOL, especially when to discontinue disease-targeted treatment in favor of palliative care. Facing such decisions is no easy task. Indeed, the caregiver must decide when and whether further treatment is futile or could potentially impair QOL and even shorten survival. The concept of medical futility is controversial with advocates arguing that as stewards of scarce resources and repositories of the necessary knowledge, physicians are not required to offer useless or harmful treatments. Critics mainly contend that physicians have no grounds to impose their personal values on how and when to treat especially because unexpected responders do occur within a majority of non-responders (Caplan, 1996; Schneiderman et al., 1996). Yet, while the atypical responder and the rare outlier must be part of every treatment decision equation, the ethical issue is whether the burden of further treatment to the majority of patients who inevitably will not respond justifies the benefit to a few that might. This predicament is further compounded by the uncertainty of what is EOL and when it begins. Indeed, there is no consensus on when a patient enters the EOL stage and the concept has yet to be quantifiably defined, rendering the transition point imprecise, subjective, and compliant. A Google search for “what is EOL”, “EOL duration”, and “EOL definition” yielded unhelpful results ranging from “the time surrounding death” (National Institute of Aging Helping with comfort and care, 2016) to the more time-linked but still imprecise “when patients are likely to die within the next 12 months (General Medical Council, 2010).” Remarkably, even otherwise well-designed EOL care guidelines developed by panels of experts do not include a definition of EOL (Quality standard for end of life care for adults, 2013; Emanuel et al., 1999; Institute of Medicine, 2014).

It is generally agreed that age and performance status, type and stage of disease, concurrent conditions, socioeconomic and other factors are risk factors influence survival and must be taken into account for planning cancer treatment at the onset but also subsequently in response to evolving disease and patient circumstances (Barry et al., 2013). Although there is no consensus on how to best manage patients beyond first-line therapy, recent studies suggest that efficacy of prior treatment significantly affect the outcome of subsequent treatments with failure to respond to second-line therapy being a harbinger of poor outcome (Park et al., 2015; Well et al., 2016; Younes et al., 2011). At that stage, survival can range from a few weeks to one year or longer. Indeed, a subset of patients with unresponsive but slowly progressive cancer can survive many months with or without treatment. Such frequently asymptomatic cases represent a patient population subset requiring little intervention until a new transition point is reached. Hence, failure to respond to or progression during second-line treatment, or relapse soon thereafter suggest EOL might be near prompting a reassessment of management priorities. At that juncture, physician and patient can decide, jointly, whether to proceed with third-line therapy or to realign focus towards supportive and palliative care. This approach is widely applicable as it is flexible in its application, respects physicians’ prerogatives and patients’ autonomy, and promotes both shared decisions and a timely switch to palliative care. First, it acknowledges limitations in the science and art of medicine in predicting a terminal patient’s remaining life expectancy (Gripp et al., 2007). Second, it allows flexibility for caregivers and patients to decide together the most appropriate time to transition from disease-targeted treatment to palliative care as the primary focus, based on disease characteristics and on patient circumstances, goals, and preferences. Third, delaying the transition point respects the autonomy of patients who choose to continue disease-targeted treatment despite understanding the remote chances of success, as was the case of 30% of terminal cancer patients in a recent study (Mack et al., 2015b). In such cases, supportive and palliative care can take an escalating role in order to comply with a patient’s wishes while preserving QOL. Fourth, a timely adoption of palliative care will qualify more patients to benefit from Medicare and other insurers’ hospice programs. It does not constitute a disguised form of active or passive euthanasia but allowing a natural process to take place following ethical principles focused on finding a timely balance between disease-targeted treatment and palliative care envisaged in an advance care planning formulated at the outset but revisited at disease- and patient-prompted intervals. The latter is necessary as patients’ preferences and goals often evolve in either direction when facing death (Fried et al., 2002). While the trusted primary-care physician often begins such discussions, as the disease progresses planning of care requires the participation of Oncologists and of Palliative Care Specialists who are best qualified to assist and guide patients make objective EOL decisions. They must be good listeners, encourage patients express their inner fears, anxieties, and final wishes, and provide guidance for dying patients to fulfill their final short-term goals, free of pain and suffering, surrounded by loved ones (Gawande A The Reith Lectures, 2014).

Widespread adoption of both the proposed definition of EOL and person approach to EOL care will require effective policies to educate current and future healthcare professionals and an open public discussion of the modern experience of dying leading to embracing the notion that death is an inevitable part of life that must be assisted in order to ensure a more humane EOL. It also will require a reorientation of payment systems away from fee-for-service and other financial incentives and towards a greater use of palliative and hospice support better suited to meet the needs of patients at the EOL (Institute of Medicine, 2014). In the meantime, the proposed EOL care guidelines could serve as a springboard to move the conversation forward.

4. Summary and recommendations

Several large-scale, multiyear, nationwide surveys have shown that while many terminal cancer patients receive appropriate supportive and palliative EOL care, most are subjected to needlessly intensive disease-focused management through the EOL. Such a strategy is ineffective, costly, detrimental to QOL, and fails to prolong survival as intended. Out of many factors at play, not knowing when a patient enters the EOL phase is pivotal as it renders the transition from disease-targeted treatment to palliative care imprecise, subjective, and compliant. We propose an integrated patient-centered management approach that includes a much-needed pragmatic definition of EOL designed to guide caregivers and patients identify, together, the most suitable point of transition to ensure QOL, death with dignity, and help relatives achieve closure.

Conflict of interest

None.

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