

Palliative care for the terminally ill in America: the consideration of QALYs, costs, and ethical issues

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Abstract The drive for cost-effective use of medical interventions has advantages, but can also be challenging in the context of end-of-life palliative treatments. A quality-adjusted life-year (QALY) provides a common currency to assess the extent of the benefits gained from a variety of interventions in terms of health-related quality of life and survival for the patient. However, since it is in the nature of end-of-life palliative care that the benefits it brings to its patients are of short duration, it fares poorly under a policy of QALY-maximization. Nevertheless, we argue that the goals of palliative care and QALY are not incompatible, and optimal integration of palliative care into the calculation of QALY may reveal a mechanism to modify considerations of how optimal quality of life can be achieved, even in the face of terminal illness. The use of QALYs in resource allocation means that palliative care will always compete with alternative uses of the same money. More research should be conducted to evaluate choices between palliative care and more aggressive therapies for the terminally ill. However, current limited data show that investing in palliative care makes more sense not only ethically, but also financially.

Keywords Palliative care · End-of-life care · Health policy · QALY · Costs · Ethics

Introduction

Health care expenditures on in the United States exceeded \$2.3 trillion in 2008, more than three times the \$714 billion spent in 1990, and they are expected to continue growing rapidly over the next decade (Centers for Medicare and Medicaid Services 2010). A disproportionate share is spent at the end of life (Zhang et al. 2009). Thirty percent of Medicare's annual expenditures cover the health care costs of the 6% of people who die each year (Barnato et al. 2004). About one-third of expenditures accrue in the last 30 days of life (Emanuel et al. 2002). Acute care for veteran patients with advanced cancer in the final month of life account for 78% of costs incurred in the final year of life (Yu 2006). Most of these costs are due to the application of highly technological interventions.

While researchers are able to show the costs are driven by technologies at the end of life, the critical question remains how much of those aggressive treatments, additional hospitalizations, tests and physician visits resulted in better care or better quality of life. Finding answers to that question is difficult and controversial, but is becoming increasingly important as the United States is coming under growing pressure to curb rising costs and to optimize the use of scarce resources among competing demands, while confronting unrelenting challenges to improve outcomes. With a finite budget, the government, insurers, and health care systems cannot afford to cover all the treatments available. They must prioritize their expenditures against an incessant flow of new technologies and therapies each of which is claimed to enhance the health status of particular patient groups.

The drive for cost-effective use of medical interventions has advantages, but can also be challenging in the context of end-of-life palliative care. A quality-adjusted life-year

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(QALY) provides a tool to evaluate the extent of the benefits gained from a variety of interventions in terms of each intervention's effect on health-related quality of life and survival for the patient. Conventional wisdom is that end-of-life palliative care expenditures fare poorly under a policy of QALY-maximization because the benefits they bring to patients are typically of short duration. Nevertheless, we argue that the goals of palliative care and QALY maximizing are compatible. Symphonizing palliative care and QALYs may prompt us to adjust considerations of how quality of life can be optimized, even in the face of terminal illness. Moreover, investing in palliative care for the terminally ill makes sense not only financially, but also ethically.

Palliative care for the terminally ill

End of life is a period of time during which a person's condition is actively deteriorating and when death is expected. End of Life Care can help those with advanced, progressive, incurable conditions to live as well as possible until they die. Clinical prognostic indicators provide a mechanism to identify when end of life care is appropriate. This point will be different for each individual and will often depend on the assessment of health care professionals and/or the patient themselves. Recognizing the point at which illness becomes advanced or reaches the end of life phase allows health care providers to plan best care for their patients to meet their needs and those of their families and caretakers throughout the last phase of life and into bereavement (Orszag and Ellis 2007).

Though often equated with end of life care, palliative care is much broader. Palliative care also encompasses symptom management and supported decision making (Mahon and Sorrell 2008). The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies (National Consensus Project for Quality Palliative Care 2009).

Palliative care is distinguished from other medical specialties in that it does not focus on disease management. Instead, given the current state of a patient's disease, palliative care integrates symptom management and guided decision making to allow the patient to live well, to optimize quality of life (Kelley and Meier 2010). Palliative care can benefit patients with all potentially serious diseases, such as Alzheimer's disease, heart failure, chronic obstructive pulmonary disease, HIV, and cancer (Goldstein and Lynn 2006; Lorenz et al. 2008; McCrone 2009; Qaseem et al. 2008).

Provider-patient communication over time also is crucial in palliative care. Overall costs for patients who have a

palliative care consult are significantly lower than for patients who do not (Morrison et al. 2008). These savings are accrued primarily by ensuring that the treatments being provided to the patient are consonant with the patients' preferences, values, and needs. Such discussions have been found to lead to agreements that certain high tech, aggressive interventions will not be used. Treatments that no longer benefit the patient are discontinued. When the costs of care for the final 5 days of hospitalized patients' lives were compared among those who did and did not receive palliative care, Smith et al., found that non-palliative care cancer patients' costs were \$12,319 (in 2002 dollars), while palliative care patients' costs were \$5,313. Group differences in the use of chemotherapy and other medications (\$2,267 vs. \$511), medical supplies (\$1,821 vs. \$731), and diagnostic imaging (\$615 vs. \$29) accounted for variations in costs (Naik 2004). Researchers also have shown that patients who have undergone more technological interventions have had a more burdensome death (Zhang et al. 2009).

Providing the most appropriate treatments involves expertise in the three dimensions of palliative care: symptom management, supported decision making, and end of life care. Each of these is grounded in expert knowledge and a precise understanding of the patient's condition, so that treatments that cannot benefit the patient are not offered. The symptom management dimension of palliative care is crucial for allowing patients to die well. Dying well generally means a diminished symptom burden, such as less pain, less difficulty breathing, better capacity to interact with those around the patient, and the avoidance of burdensome treatments that lack benefit.

In one of the most important palliative care studies to date, Temel et al. (2010) studied the effects of providing palliative care from the time of a patient's lung cancer diagnosis. "Specific attention was paid to assessing physical and psychosocial symptoms, establishing goals of care, assisting with decision making regarding treatments, and coordinating care on the bases of the individual needs of the patient" (p. 734). Patients in the palliative care group had less aggressive end of life care, more documented resuscitation preferences, and improved care by several measures. Patients in the palliative care group also lived significantly longer than patients in the traditional care group (11.6 vs. 8.9 months).

These study results are similar to the findings of Schneiderman et al. (2003), who, in a prospective, randomized controlled, multi-site trial found that intensive care unit (ICU) patients who were offered an ethics consultation lived the end of their lives differently than those who did not. The experimental group (ethics consult offered) had significantly fewer hospital days (−2.95 days), ICU days (−1.44 days), and days of ventilator support (−1.7 days).

In both cases better decision making meant utilizing treatments that were more likely to benefit the patients and eschewing non-beneficial therapies.

Both the Temel et al. (2010) and Schneiderman et al. (2003) studies reinforce the importance of skilled communication for end of life decision making. In addition, both demonstrated that value is accrued by cost savings. It should be noted that in both studies, patients in the palliative care group did not die any sooner, and in the Temel study, patients actually lived significantly longer. This is significant because too often, people equate ethics or palliative care with “pulling the plug.”

Nearly 30% of US hospitals, including 70% of teaching hospitals, had palliative care services in 2007. Morrison (2010) and colleagues estimated that if 50% of US hospitals had palliative care services, approximately 1.5% of hospitalized patients would benefit, and Medicare direct cost savings would be \$1.2 billion per year. If 7.5% of hospitalized Medicare patients, (meaning not only more hospitals but also more patients at each hospital) received palliative care services, estimated savings would potentially reach \$6 billion per year.

QALYs and palliative care

The application of QALYs in resource allocation decisions is increasingly common and widely accepted as decision makers are faced with persistent and recurring resource constraints (National Health Service 2010). A QALY essentially is a measure of a person’s length of life weighted by a valuation of their health-related quality of life (Loomes and McKenzie 1989). This instrument can be employed, along with information on costs of interventions, in decision-making about health service resource allocation. Basically, it allows us to compare how many extra QALYs the new treatment provides compared to the existing treatment, and also how much those QALYs cost to provide. In other words, the cost per QALY for these treatments are compared to provide valuable information for decision-makers as they address the healthcare dilemma of resource allocation.

Although QALYs and palliative care are different concepts, there is a distinct similarity between the application of QALYs and palliative care: namely, the goal of choosing the most appropriate treatments in a specific clinical situation. The differences, however, may seem glaring. A QALY is a “one size fits all” macro level analysis. The conclusion of a QALY calculation and cost-utility analysis is not prescriptive. Instead, it provides a scientific foundation for decision-makers to select the most appropriate treatments in the presence of a certain condition. The driving force behind QALYs is the optimal utilization of

finite resources. Like QALYs and cost-utility calculations, palliative care involves a benefit-burden analysis for optimal treatment recommendations, but the level of analysis in palliative care is for the individual. The conclusions of QALYs and cost-utility analyses can be generalized to a population group. Palliative care, however, is customized and involves identifying which treatments can benefit a specific patient, considering the disease, the likelihood of cure, and how comfortable the individual patient can be made. Palliative care may vary considerably among patients, even those with the same illness.

In this technology-driven health care system, we frequently face a bias toward providing maximum high tech interventions, whether machines or pharmaceuticals. When a young man with an advanced cancer comes in, there is often an aggressive plan for him to participate in a clinical trial, involving perhaps months of treatments, even though under objective clinical prognosis his death is likely within days. Oftentimes, the oncology team is eager to get the intravenous access started to provide experimental treatments, without the young man’s impending death ever being acknowledged or discussed. This young patient’s family, unaware of his approaching death, may also push for the experimental therapy, believing the experimental treatment could help. If his family had realized that his death was imminent, the time might have been spent quite differently, and his care would have been structured differently. There is often such an emphasis on providing aggressive therapies, on “fighting,” that the provision of objective medical information is eschewed. That causes harm.

Death is too often viewed as a failure. Efforts to save a life often continue long after it is no longer possible. Not uncommonly, providers chose to administer a specific treatment so that the family would believe they “did everything,” rather than because the treatment would benefit the patient. The overwhelming reality is that many decisions for terminally ill patients are not made well. Empirical research shows that patients do not prefer hospital-based acute medical care at the end of life, but the actual patterns of medical care observed before death are most patients dying in acute-care hospitals while receiving invasive therapies (Lamont 2005). To do better, providers must consider QALYs and cost-utility analysis, and incorporate family centered palliative care.

Comparing like with like

The celebrated strength of the QALY approach is comparability: health gains can be compared across a wide range of diseases and settings. The strength, however, has limitations. It is rather unsuitable to allow comparison between

palliative care for the terminally ill and non-end-of-life treatments. At the end of a patient's life, there is a shift of goals to focus primarily on the patient's comfort. High-quality end-of-life care is not intended to extend lifespan, but rather is aimed at improving the quality of a brief span of life. Yet the brevity of lifespan affected results in palliative care yielding a fraction of a QALY unit.

The use of QALYs in resource allocation means that palliative care will always compete with alternative uses of the same money. Decision makers who utilize QALYs and cost-utility analysis to allocate resources, however, should not compare like (end-of-life treatments) with unlike (non end-of-life treatments). Care at the end of life is qualitatively different from much of the rest of one's health care. End of life care is distinguished by differences in the goals of patient care. For most of one's life, the goal of medical care is to help the patient to live as long and as well as possible. At the end of life, however, there is a shift of goals away from the cure and prolongation of life. Instead, the care focuses on the relief of pain and other symptoms, the alleviation of psychological and spiritual suffering, and the enhancement of the meaning and quality of the patient's remaining life. In addition, researchers have shown that there is a broad consensus that the end of life is a period during which medical care should be different from that in other periods in patients' lives (Lamont 2005). More specifically, patients, families, and health care providers believe that medical care during this unique period should be home-based and focused on ameliorating patient symptoms through minimally invasive means rather than hospital-based acute care, and focused on extending life through invasive approaches (Lamont 2005). Thus, different dimensions of objectives and outcomes from those distinct services do not justify comparison between end-of-life treatments and non end-of-life treatments. End of life care is distinctive enough to necessitate a different calculus. Researchers have proposed modification of QALYs to allow such comparison (Hughes 2005). But that is unnecessary. Palliative care for the terminally ill should only be compared to other end-of-life services, including relevant oncology and other disease focused interventions. When compared to other end-of-life treatments, end-of-life palliative care is enormously cost-effective demonstrated by aforementioned empirical evident (Temel et al. 2010).

Ethical considerations

Is our approach ethical? In most specific bioethical quandaries in health care, the focus is on a particular patient. In contemplating how to optimize finite health care resources, however, the core of the determination shifts from the individual patient to the population. The ethical theory of

utilitarianism accommodates population level analyses. From this perspective, the morally appropriate choices are those that will bring about the greatest good for the population.

Therefore, in making decisions about health care, this ethical approach necessitates consideration of the benefit to be gained from the various competing alternatives in terms of the improvement in health for an individual, as well as considering the number of individuals who could benefit. In the context of the allocation of limited healthcare resources, a vital issue is the cost of the benefit required by the healthcare intervention. This ethical position favors resources being allocated to less expensive medical care that provides the greatest benefit. This may be an intervention that generates a large benefit for a small number of people or a small benefit for a large group of patients. The operationalization of utilitarianism in the allocation of resources is evident in the application of QALYs as a mechanism to measure the net benefit of health care interventions, allowing comparison across treatments.

A powerful critique of utilitarianism in resource allocation, from the viewpoint of equalitarianism, is that it overlooks the individual health care needs, and therefore does not provide an equitable method of allocating resources. Aristotle, explaining his view of distributive justice, wrote, in effect, that equals should be treated equally, and unequals treated unequally in proportion to the relevant inequalities (Daniels 2000). This is known as Aristotle's "formal principle of equality". Part of its value lies in the implicit demand that we explicate the criteria used to determine what constitutes "equal". The utilitarian or QALY based approach could be said to treat unequals equally, in that it does not take account of differences in individuals' needs for health care but focuses entirely on the benefit gained from an intervention. Some individuals or groups of patients will have poorer health than others, or more serious diseases, and will have a greater need for health care. If degree of need is a main criterion, a just distribution of health care resources may require that these individuals or groups with greater needs have more resources, even if the benefit gained by a treatment is small compared to that achieved by a different treatment in patients who are less sick.

In sum, utilitarianism fails to consider differences in need for—and goals of—patient care. Equalitarianism, on the contrary, does not maximize net social utility. To reconcile these two different philosophical positions, the QALY based approach should not treat unequals (end of life and non-end of life) equally. In considering more equitable distribution of health care resources while maximizing utility, QALY based calculation, coupled with the idea equals being treated equally, may be the best approach to allocation of scarce resources in health care. On this

premise, more investment in palliative care for the terminally ill is justified ethically.

Conclusions and policy implications

There is a need to identify end of life specifically as a unique and ultimate period within a person's pathway of care. Acknowledgement of this period provides an opportunity to deliver high standards of care, grounded in choice and responsiveness to needs for both the patient and their family. It is essential to develop more valid and reliable predictive algorithms to help health care providers, patients, and families to identify the beginning of the end of life.

"In the end, it's not the years in your life that count. It's the life in your years". (Abraham Lincoln, quote). This quote may forever hold true, though Lincoln may not have foreseen how much the "life in your years", especially at the end of life, would actually cost nowadays. Increasingly, it is expensive to die (Zhang et al. 2009). But, the critical issue is whether dying expensive means dying better. In the era of skyrocketing costs in healthcare and a world of limited resources, a QALY provides a common currency to value the extent of the benefits gained from various interventions in terms of quality and quantity of life. Overarching themes of optimizing quality of life are mutual to both QALYs application and palliative care. Harmonizing the two may lead us to modify considerations of how optimal quality of life can be achieved. The government should aid more comparative effectiveness research on end-of-life palliative care, and encourage health care providers to advise patients on the cost-effectiveness of the options for end-of-life care, which may include advance directives to forgo aggressive life-sustaining treatment.

End of life care is an increasingly important health care issue, and represents a significant burden of costs to the society. Palliative care provides a counterintuitive approach to the high-tech American model of health care. Nevertheless, current limited data show that investing in palliative care makes more sense both ethically and financially. What is surprising, unfortunately, is the lack of public understanding and emphasis on palliative care, the gaps in implementing what is cost-effective in end of life care, and in training palliative care professionals, and the vast deficits in palliative care research support to find effective solutions.

What is urgently needed now is a concerted effort by health care systems, palliative care providers, and the government, to make comprehensive palliative care accessible to terminally ill patients and their families, and to make every effort to explore, understand, and address pain and suffering that persist despite their best efforts.

More research should also be conducted to evaluate how supported decision making can guide choices between palliative care and more aggressive therapies for the terminally ill.

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