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The Price of Palliative Care: Toward a Complete Accounting of Costs and Benefits

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The costs and benefits of hospice and palliative care have recently received attention for many compelling reasons. First, the cost of medical care over a lifetime is largely expended near the end-of-life [1]. The impending demographic bulge of aging baby boomers will only heighten concerns about costs. Second, hospice and palliative care have been offered as potential vehicles for reducing late-in-life spending [2]. Third, palliative care has gained legitimacy as a distinct medical specialty, having as it does a characteristic philosophy, specialized skill sets, and specific service delivery needs [3]. This philosophy of care is consistent with and, to some degree, builds on the philosophy of care that geriatrics also promotes (see the article by Cox Hayley and Sachs elsewhere in this issue for more information).

In this article, currently accepted standards for cost-benefit analysis of health care interventions are outlined, and a framework to evaluate palliative care within these standards is provided. Recent publications on the economic implications of palliative care are reviewed, which are only the “tip of the iceberg” of the potential costs and benefits. Using this framework, the authors

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offer guidelines for performing comprehensive cost-benefit analyses of palliative care and conclude that many of the issues beneath the surface may be substantial and deserving of closer scrutiny. Methods for gathering relevant cost-benefit information are detailed, along with potential obstacles to implementation. This approach is applicable to palliative care in general, including palliative care for elders.

The gold standard for cost-benefit research

The United States Panel on Cost-Effectiveness convened in the mid-1990s to establish guidelines for health care cost-benefit and cost-effectiveness research [4]. The panel concluded that cost-benefit analyses of health care interventions should consider medical and nonmedical costs and benefits, and many economic analyses of health care interventions follow these guidelines [5–8]. According to the guidelines, a comprehensive study should measure the following elements:

1. Changes in use of health care resources. Health care resources include personnel, materials, and equipment used during the course of treatment. These expenditures may be offset by reductions in spending for other medical care services. For example, if hospice use is associated with a decline in hospitalization, the savings from the latter should be deducted from the cost of the former. Researchers may apply standard accounting techniques to measure these resource costs. However, there are considerable issues associated with the allocation of overhead for health care providers, and research and development costs for suppliers of drugs, devices, and diagnostic technologies [9]. It may be difficult for researchers to resolve these issues with available data.
2. Changes in the use of non-health care resources. Health care is time-consuming. The cost of the time of professional health care providers is accounted for in the costs of health care resources. Others also invest time in the medical process. Patients spend time undergoing treatment and family members divert time from other activities. This detracts from workplace productivity and leisure. For patients and family members, it is customary to value time at the individual's hourly wage because economic theory suggests the hourly wage corresponds to marginal workplace productivity and the marginal value of leisure time. The value of time for individuals who are not in the labor force, especially retirees, is harder to pin down. It may be convenient to ignore the benefits of their leisure time. Nonetheless, ignoring this value would bias cost-benefit estimates in favor of time-consuming interventions (eg, interventions that require considerable travel time or lengthy therapeutic treatments.) Other non-health care resources may include child care costs for parents who must tend to an elderly relative and the costs of renovating or remodeling a home to accommodate the care of a patient with special needs.

3. Quality and quantity of life. The ultimate goal of most health care interventions is to improve the quality and quantity of life. Quantity can be measured in various ways, such as life expectancy and infant mortality. Cost-effectiveness studies increasingly use quality-adjusted life years (QALY) to account simultaneously for quantity and quality.

There is an imperfect overlap between what is measured in QALY scores and what is measured under the category “non–health care resources.” For example, an improvement in health that enables one to work may receive a high QALY score, precisely because of the ability to work. This creates the potential for double counting in any study that directly measures non–health care resources and QALY improvements. This remains an unresolved issue in the broader literature on cost-effectiveness analysis, but may be especially important in palliative care, where patients may experience large, temporary changes in quality of life and workplace productivity.

Quality measures need not be restricted to the patient. Interventions may affect the quality of life of family members as well, independent of the effects on time and productivity. The panel’s recommendations stress the importance of measuring the full costs and benefits that accrue to society.

Cost-benefit analysis and palliative care

Palliative care impacts patients, caregivers, family members, and the community in varied ways. Understanding these differences serves as a foundation for the cost-benefit analysis methodology.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Palliative care also “offers a support system to help patients live as actively as possible until death,” enhances and prolongs their life, and can aid in family coping [10].

Table 1
A classification of palliative care costs and benefits

Category	Potential costs and benefits
Patient medical	Improve quality and quantity of life for the patient Costs of medical care services
Patient nonmedical	Changes in workplace productivity of the patient Accommodations by employers
Family medical	Changes in quality of life of family members Changes in health care use of family members (eg, mental health expenditures)
Family nonmedical	Changes in workplace productivity and school performance of family members

This definition identifies many potential costs and benefits of palliative care that are consistent with the United States Panel of Cost-Effectiveness guidelines. [Table 1](#) offers a framework for categorizing these costs and benefits in a manner that is consistent with the guidelines while capturing the essence of the goals of palliative care. This table distinguishes between patient costs and benefits and the costs and benefits that accrue to the family. Family is used broadly here to represent those close to or providing informal care to the patient. Potential costs and benefits to a broader unit of the community are discussed later in this article. Medical costs and benefits associated with delivery of health care services and health outcomes are distinguished from nonmedical costs and benefits associated primarily with workplace productivity.

To give an idea of how these costs and benefits can manifest themselves in a real end-of-life situation, consider the case of a woman who had a 2-year trajectory with adenocarcinoma of unknown origin whose treatment integrated curative therapy with palliative care [11]. The integrated team of caregivers allowed for support in the workplace and home, enabling the woman to stay in the workplace until 2 months before her death (effects: patient nonmedical and possibly patient medical). Care continued through to the completion of 1 year of bereavement care for her husband (effect: family medical). This patient's husband took some time off work but maintained his job and continued to work after his wife's death (effect: family nonmedical). Her children experienced a normal bereavement and did not suffer declines in workplace or schoolwork quality. This is probably not an isolated case, as research suggests that palliative care may help families adjust to the death of a loved one [12]. As a result, families may remain effective in essential roles in the household and in the workforce (effects: family medical and family nonmedical).

What has been measured and what remains to be measured

Several studies have examined the effects of palliative care on patient medical costs. Two recent studies reached similar conclusions. As one report stated, "There are few solid data that show hospice reduces costs" [13,14]. A review of earlier studies identified three randomized trials of hospice and advanced directives and also found no demonstrated reductions in medical costs [15]. Based on the latter review of the literature, the authors question congressional funding of hospice care and conclude, "We should await further study before cashing the check." The most recent studies suggest that palliative care may reduce hospitalizations and intrusive interventions, although these studies do not directly measure costs [16,17]. No known studies assess the impact of palliative care on medical costs specifically for elders. Differences in medical need and symptom prevalence suggest that the calculus may be different.

In focusing on patient medical costs, the research literature to date has ignored the other important elements of cost-benefit analysis identified by the United States Panel on Cost-Effectiveness. As a result, claims that we should not "cash

the check” may be premature. The failure to fully consider all costs and benefits of palliative care would be acceptable if medical costs dominated all other effects. Given that palliative care appears to have roughly zero net effect on patient medical costs, it is imperative to measure other effects. If these nonmedical and family effects are amplified by the demographic bulge of elders, this will be of importance in the coming decades; the final conclusion about the cost-benefit ratio of palliative care depends on it.

The importance of measuring everything

Current studies of palliative care fall short of the goal of measuring all relevant costs and benefits and instead focus on patient medical costs. This would be acceptable if two conditions were met: (a) patient medical costs were measured accurately and (b) the unmeasured components were expected to be of trivial importance. Unfortunately, one or both conditions are unlikely to be met.

Measuring patient medical costs and benefits

To date, the research literature on palliative care has focused largely on patient medical costs. Typical methods examine gross charges or, at best, apply “cost-to-charge” ratios to estimate costs. It is a gross error to use charges to measure costs. Because of various idiosyncrasies in health care reimbursements, charges often bear little relation to costs. In hospitals, charges may exceed costs by a factor of 2 or more. By the same token, actual reimbursements are, at best, a good approximation to costs.

A common approach for measuring costs is to begin with charges and then apply a cost-to-charge ratio, such as that found in Medicare cost reports. This is problematic as well because the computation of cost-to-charge ratios is highly sensitive to the methods chosen for allocating overhead. This is, unfortunately, common in the medical cost-benefit literature and is not easily addressed. For example, a study of care for ventilator-assisted children found that the resulting bias could be substantial, exceeding \$10,000 per patient, because the hospitalized children received minimal medical attention despite that they were housed in seemingly high-cost intensive care units [18]. Studies of palliative care should consider whether hospitalized end-of-life patients receive a level of care that is commensurate with the allocation of costs.

Studies show that palliative care can improve the quality of life for patients, but these results have not been integrated into cost-benefit studies. Quantifying the benefits in dollar terms is a challenge. Currently, the most popular approach for quantifying the value of life uses tools such as the quality-adjusted life year. Combining quantity and quality of life, QALYs are built using life expectancy estimates and health-related quality of life weights that are associated with particular health states. Descriptive health status measures, such as the Quality of Well-Being scale [19], the EQ-5D [20], and Health Utilities Index [21] are used

to elicit these values from a given population. Individuals rank symptoms such as physical function, social function, emotional well-being, and pain. In all such scales, the ultimate product is a range of health utilities from 0 (death) to 1 (full health). These health utilities are then multiplied by an appropriate life expectancy to arrive at many QALYs. Different interventions will ideally increase either the quantity or quality of life, thus increasing the number of QALYs gained.

There are four key elements to QALYs that take on challenging new dimensions when used to quantify the health benefits of palliative care. The first is to establish what to measure. Health is a multidimensional concept and the dimensions of interest are different for the end-of-life. Qualitative research into patients' experiences at the end-of-life indicates that other domains of health-related quality of life, such as the spiritual and familial, become important or even prominent [22,23]. The results of a recently published survey indicate nearly 40% of respondents stated that "achieving a sense of control" and "strengthening relationships with loved ones" were important domains of end-of-life care [24]. Evaluating how to construct or adapt current quality of life measures so that they will be relevant to the end-of-life and also usable to derive health utilities is necessary.

The second challenge revives the traditional debate over whose health state preferences are the proper ones to use in QALY analysis. The United States Panel on Cost-Effectiveness has determined that population ratings of health states should be used to obtain health utilities. However, the preferences of palliative care patients may not coincide with the preferences of specific patient groups or the population as a whole. QALYs were developed with the idea that a patient's goal is the improvement of their health state. Though short-term improvements in health are an important goal of palliative care, long-term improvements are, by definition, unattainable. Traditionally, the population as a whole places lower weights on the health states of patients than do patients themselves for numerous potential reasons [25,26]. However, querying end-of-life patients on their preferences would present many challenges, including nonresponse and attrition biases and the need for proxy respondents.

A third challenge is to establish how to measure quality of life in a way that accounts for the duration of the condition and the ultimate outcome. It is not sufficient to ask individuals to place a score on a given condition because it must be understood that the condition will only last 6 months, and the ultimate outcome of the condition is death. In the aforementioned study, over 60% of respondents stated that "avoiding inappropriate prolongation of dying" was an important aspect of end-of-life care. Realistic measurement scales and techniques for palliative care must reflect the reality that many patients believe prolonging life is undesirable.

The final challenge is to place an acceptable dollar value on QALYs. Though these scales were developed for cost-effectiveness analysis (ie, to provide a uniform metric with which to evaluate the differential costs of achieving a quality adjusted year of life), they are not sufficient for cost-benefit analysis [27]. The

latter requires putting a dollar value on a QALY. Research from the willingness-to-pay literature shows wide variation in the value placed on a QALY, most likely due to the various methods one can employ to arrive at a figure [28]. The most popular approach is to use economic evaluations, such as those described by Viscusi and Aldy, who place a dollar value of a QALY at about \$100,000 to \$200,000 [29]. This approach is not universally accepted and many government agencies, including those in Australia, Canada, and the United Kingdom, routinely place a lower dollar value on QALYs when evaluating new technologies for government reimbursement [30].

To see how sensitive cost-benefit analyses may be to the dollar value placed on a QALY, consider the following example. One study reports that a patient whose condition was “in hospital; limited walking; back pain; needs help for self-care; loss of consciousness” would receive a QALY score of .30 [31]. This valuation excludes domains of relevance to end-of-life patients, so it is likely that researchers will have to construct well-being scores *de novo*. Even so, it is possible to conjecture about the potential magnitude of quality-of-life effects.

Suppose that the aforementioned patient received palliative care and experienced a QALY gain from .30 to .40 due to an increased sense of coming to peace with death, facilitated by palliative care personnel. If this gain lasted for the final 6 months of this patient’s life, and a conservative estimate of the dollar value of a QALY of \$50,000 is used, there is an implied benefit of \$2500. This does not mean that palliative care would generate benefits of such a magnitude, but merely points out that, given the substantial dollar value placed on QALYs, even modest changes in QALY scores can have a considerable impact on benefits.

Patient nonmedical costs and benefits

End-of-life patients incur many nonmedical costs, including costs for transportation, homemaking, and personal care [32]. End-of-life patients also lose time from work, although this cost is not well documented. The impact of palliative care on these nonmedical costs can be great. If the overall cost-benefit literature is a guide, the effect of palliative care on workplace productivity alone may be great enough to justify the effort to document these effects. The National Institutes of Health report that the costs associated with workplace productivity losses exceed the direct costs of medical care for many diseases, including Alzheimer’s disease, cancer, and Parkinson’s disease [33].

If initiated early in the disease, individuals who receive palliative care may experience declines in productivity because they take time off from work to visit providers. As the disease progresses, however, palliative care may enable workers to remain on the job longer. Careful studies should document the net effect of palliative care on time in the workplace, valuing changes in workplace productivity at market wages. Because elders in the workforce will be an important component of economic viability during the era of aging baby boomers, specific attention to these effects for elders is also needed. Because palliative care treatment has the potential to shorten or extend workplace productivity by weeks or

months, the dollar value of the effect will likely be measured, at a minimum, in the thousands of dollars.

Palliative care will also affect the time available to patients who are not in the labor force. The issues associated with valuing this time for cost-benefit analysis can be complex and are beyond the scope of this essay. The value of leisure time is implicitly accounted for in QALY scores and should not be double-counted.

Employers of patients who receive palliative care may need to make special workplace accommodations, perhaps to stay in compliance with the Americans with Disabilities Act. Examples may range from reconfiguring an employee's workspace to purchasing specialized machines and materials. Though the cost of many accommodations is negligible or low, they can at times be expensive and must be included in the analysis [34].

Family medical costs and benefits

Illness and death affect not only the patient but family members who endure the caregiving and bereavement processes. In the same way, palliative care is a health intervention that will affect the family as well as the patient. The effects of illness and death care on paid, formal caregivers are not discussed here as these costs are presumably factored into their wages and need not be considered separately. The health effects on informal caregivers are, however, of concern to palliative care researchers. In several studies, caregiver burden has been associated with various negative health effects [35,36]. Caregiving has also been cited as an independent risk factor for mortality [37]. The literature on caregiving burden has tended to oversample those caregivers who are most at risk for developing health problems, such as dementia caregivers. Indeed, a recent study indicated that noncaregivers who reported severe parental disability were significantly more likely to experience symptoms of depression, and that caregivers were not found to experience depressive symptoms [38]. A recent meta-analysis, however, showed that negative health effects, such as increased stress, depression, subjective well-being, and physical health, still exist for more representative samples of caregivers [39].

The palliative care paradigm, with its potential to improve the quality of death for the patient and family, may directly address these medical costs of illness for the family. The aforementioned case studies describe the positive benefits of palliative care for the patient, and more quantitative studies have shown family benefits [40]. One study found that hospice use is associated with a statistically significant decreased rate of death among surviving spouses [41]. (The authors of the study suggest this is due to reduced stress.) Thus, it is important to measure the benefits of palliative care in this domain.

These findings suggest the need for costing the health care use of key third parties, such as caregivers, who are often family members. In addition, a QALY analysis must be conducted for caregivers during the period of illness and, ideally, up to 1 year after death, because this is the standard recommended length of palliative care team support and interventions. Measuring the quality of life

of caregivers raises questions similar to those that arise in attempting to measure the quality of life of end-of-life patients. There are several instruments that measure the quality-of-life of caregivers, often created for specific diseases [42]. In addition, a quality-of-life instrument for caregivers at the end-of-life is also in development [43]. Whether these instruments should be adapted to an economic analysis or whether it is sufficient to use existing health measurement scales for a QALY analysis is a point that should be considered.

To see how a QALY analysis would represent the benefits of palliative care for the family, recall the aforementioned example where a patient in the last 6 months of life increased her health-related quality of life from .30 to .40 on a scale from 0 (death) to 1 (full health), resulting in benefits of \$2500. Suppose that palliative care resulted in a “good death” that provided less stress and fewer physical and mental health problems for a spouse caregiver. Assume this increased health state is represented by a modest increase in health utility of .02 for the caregiver, from .78 to .80. Though this may seem like a small increase, one should also consider that the health effect will most likely last longer, past the death of the spouse. If the effect were to last for 1 year (6 months before the end-of-life of the spouse plus 6 months after the death of the spouse), then again using the conservative estimate of \$50,000 per QALY, palliative care would achieve benefits of \$1000 in addition to those accrued to the patient. Though this is a theoretical example, it is easy to see how neglect of these third-party benefits would lead to an undervaluing of palliative care.

Family nonmedical costs and benefits

There is evidence that when individuals are chronically or seriously ill, family caregivers trade off time in other activities to devote more time to the affected individual [44–46]. They may take on fewer responsibilities at work or leave the labor force entirely [47–49]. Palliative care might substitute for family caregiver time and enable family members to return to work. On the other hand, it may facilitate home care for patients who might otherwise be institutionalized and, as a result, a family member may withdraw from the labor force to remain at home with the patient.

In either event, the value of the associated change in family productivity must be considered. Although there are no known studies of the effects of palliative care on family productivity, some related studies suggest that it could be large. For example, one study of informal care of frail elderly estimated the lost wages associated with caregiving at nearly \$10,000 per frailty episode [50]. A study of home care for ventilator-assisted children found that 39% of family members had lost income from work [51]. Though this time lost might be hard to evaluate in dollars, palliative care may also affect the academic performance of school children.

In most communities, and most nations, the cumulative economic effects of palliative care can be approximated by adding up the individual effects. This is because only a small minority of individuals are dying at any time and may

potentially benefit from palliative care. Thus, there is no “community wide” effect of palliative care apart from the effects on individuals. In some communities in developing nations, for example those most heavily affected by HIV, a nontrivial percentage of the population may require palliative care. In these situations, the effects of palliative care must also account for its impact on the community and nation as a whole.

It is well understood in economics that when one examines the output of an economy, “the whole is greater than the sum of the parts.” That is, one cannot approximate total economic output by taking the marginal contribution of one worker and multiplying by the number of workers. In the same way, the aggregate effects of palliative care in some communities may exceed the sum of the individual effects described above. In countries with a heavy burden of HIV/AIDS in which large portions of the workforce are taken out by the epidemic, these superadditive effects may be profound. In Botswana, for instance, 38.8% of the adult population is estimated to be living with HIV/AIDS, and in Zimbabwe the figure is 33.7% [52]. The proportion of caregivers must be similarly large in both countries, and the number of those who are living with HIV/AIDS and providing informal care is also likely to be high. The costs and benefits of palliative care in these situations are not established. It is also not known how much the nonlinear economic impact of palliative care might be in these situations. The potentially profound economic impact makes a reliable cost-benefit analysis an urgent matter.

Cost-benefit studies of palliative care: how to collect the measures

The current CBA literature on palliative care focuses exclusively on patient medical costs, with mixed results. It seems that the effect of palliative care on aggregate medical costs is small. This suggests that patient nonmedical costs and benefits as well as costs and benefits for the family can be decisive factors in cost-benefit analysis. A complete economic study must take these into account. This necessarily entails collecting far more information than is typical.

Patient medical costs

Current studies of patient medical costs rely on data from Medicare. Medicare Part A reports charges for all inpatient services and Part B reports ancillary charges, including physician services. Charges are based on provider fee schedules and represent what would be paid by a patient with generous indemnity insurance. For most patients, the actual payments to providers are determined by either government fiat (Medicare and Medicaid) or through negotiations between payers and providers (managed care insurers). It is notoriously difficult to obtain actual reimbursement data. Actual costs are also difficult to estimate. Many researchers apply cost-to-charge ratios (obtained from Medicare cost reports) to actual charges. This is an approximation at best because

of the vagaries of overhead allocation. In recent years, many hospitals have implemented activity-based cost accounting (ABC) systems that improve (but do not perfect) overhead allocation. ABC hospitals may be able to provide reasonably accurate cost estimates, even if their Medicare cost reports remain problematic. Other providers, including physicians and extended care facilities, do a much poorer job of allocating fixed costs. However, they also have fewer fixed costs to allocate. The extent of errors in cost measurement among non-hospital providers is unknown.

Patient medical benefits

The end of life is a sufficiently distinct life stage with its own health-related domains that it is necessary to either supplement existing quality-of-life scales developed for economic analysis or adapt existing psychometric scales of quality of life at the end-of-life. Current health measurement scales will not suffice. Dowie [53] suggests the use of a generic health measure instead of a condition-specific measure whenever possible. It is unclear if using a generic measure with added end-of-life domains would be a practical approach. Although it is essential that such domains to be included when measuring quality-of-life at the end-of-life, they may not be suited to evaluating health conditions in other life stages. Thus, the end-of-life may be a situation unique enough to warrant the use of a condition-specific measure and may fit with Dowie's strict criteria for using a condition-specific measure instead of a generic measure. The drawback to this approach is that it may not be valid to compare end-of-life interventions with other interventions because using different sets of scales will yield different sets of health utilities for health states across the life course. Comparisons between various types of palliative care and usual hospital care can, however, still be performed.

Over the past 30 years several instruments have been proposed to measure quality of care at the end of life or quality of death and dying [54,55]. A new generation of instruments that incorporate the domains that are unique to the end of life is being created to measure quality of life at the end of life [56,57]. However, these instruments have their roots in psychometrics rather than economic theory. They were not designed to elicit health utilities but rather to measure human characteristics. Thus, it will be necessary to take one of two paths. New measures that are more in line with economic theory can be devised, or health utilities can be extracted from current psychometric scales. Researchers have used various statistical techniques to extract health utilities from the visual analog scales (VAS) used in the SF-36 general health measure with some success [58–60]. Even though the health utilities of the EQ-5D and SF-36 purport to measure the same thing, in a population of liver transplant patients, they were found to be more sensitive to lower and higher health states respectively [61]. Although they may be one way to obtain the health utilities necessary for a QALY analysis in the future, methods for extracting health utilities from VAS instruments cannot currently be used with confidence [62]. Constructing new quality-of-life scales consistent with economic theory may be the more fruitful path.

The health preferences of a community sample should be used to elicit health utilities and to guide social policy decisions rather than individual treatment decisions. However, once a certain amount of resources has been allocated to a population subgroup, there is a strong argument for using the preferences of that subgroup to determine which interventions should be funded and at what levels. Daniels [63] makes a similar case with respect to Medicaid recipients. There are, however, many practical barriers to obtaining preferences from palliative care patients. Nonresponse bias due to the severity of illness ensures that a palliative care population will be representative of only the least ill patients. The use of caregiver proxies is a potential solution to this problem because there appears to be a degree of agreement between patients and their caregiver proxies on health-related quality-of-life questions [64]. Nonresponse due to the threatening nature of standard gamble (SG) and time trade-off (TTO) questions may also bias results, although the use of a chained SG and TTO method could somewhat alleviate these problems [65]. Instead of using a patient population, the authors suggest the modification of the methods of eliciting preferences from the general population to make salient the issues unique to the end of life.

The two issues of importance in eliciting health preferences are time and perspective. Palliative care patients who are, by definition, hospice eligible have a prognosis of only 6 months or less. The TTO and SG methods assume that all conditions are chronic until death. Death is, however, usually a distant consideration or is used as part of a gamble to elicit preferences. To incorporate death as an imminent consideration, the researcher should state this contextual fact before the description of the health state domains and their severities. The researcher should also insert it directly into the TTO or SG by making the health state that is to be evaluated last only a few months instead of “for the rest of your life” or a large number of years, as they are usually structured to do. The wording of the question can also have an effect on the perspective frame used by the respondent, be it personal, social, or socially inclusive personal [66]. Because most people will experience a terminal state for a nontrivial amount of time, the third perspective should be incorporated into the question as well.

Temporary health states within those last months of life can also be important because terminal illness can progress through multiple varied stages, and the temporary side effects of treatments can vary as well. For this reason, the researcher should use a chained TTO or SG as described by Torrance [67] that compares health states to an anchor state that must be carefully selected. The chained TTO in particular has been shown to be particularly sensitive to small changes in health states [68].

Patient nonmedical costs and benefits

Methods for collecting data associated with many relevant patient and family nonmedical costs are well established. The approach used by Aday et al [51] in their study of ventilator-dependent children is instructive. Children in this study

were discharged from hospitals to receive care in their homes, and family members were trained to assist skilled home nurses in providing care. Through semistructured interviews with the parents of the affected children, researchers documented a wide range of costs and benefits of hospital and home care. Researchers began the interviews with open-ended questions, such as “Now that [name of child] is home, what are your and your family’s greatest problems and concerns?” Once they had identified a range of issues, interviewers asked for details about specific areas of nonmedical costs, including “Did the family member stop work at any time due to the child’s illness? Did the family member spend time and money for transportation related to care for the child? Was there lost vacation time? Were there any disruptions of education of family members?” All questions pertained to the period of time when the child was hospitalized and the time when the child was home, reflecting the fact that these disruptions can occur in either setting.

The Aday et al study [51] also considered family medical costs. Interviewers inquired about family medical costs associated with mental health issues, such as stress, feelings of abandonment, and loss of privacy. The researchers did not, however, apply mental health QALY scores to their findings.

Family medical costs and benefits

To take into account the health effects on the informal caregiver or family members, a certain number of third parties (if they exist) must be the target of a separate costing and QALY analysis. While the situations of end-of-life caregivers are distinct from the general population, they are unlikely to adopt whole new domains of health-related quality of life. Their health risks are well covered by the more mainstream physical, emotional, and social domains of existing quality-of-life instruments. Thus, the researcher should use these instead of a more condition-specific measure. The authors propose the inclusion of only the primary caregiver or spouse in the analysis initially. The health effects beyond the spouse or primary caregiver have not been adequately demonstrated. However, future studies on health effects may warrant the extension of economic analysis of family medical costs and benefits to other parties, such as non-caregiving adult children. Analyses should extend to 1 year after the death of the patient because that is benchmark for bereavement and the theoretical length of palliative care interventions.

Measuring societal costs above and beyond the costs to individuals requires measures of aggregate economic output at the community level. Obtaining such measures in developing nations is unusual but not unprecedented [69].

Family nonmedical costs and benefits

Previous work that studied the impact of parental frailty (described above) has typically made use of secondary data sources, such as the Health and Retirement Study and the Study of Assets and Health Dynamics among the Oldest Old, or

similar national surveys. These large national surveys provide a useful guide to what palliative care researchers need to be mindful of in crafting future surveys that will better address palliative care costs and benefits. It is important to elicit information on assistance (all types, including time and financial) as well as information work status for all adult children.

The largest nonmedical factor that is affected by a dying loved one, and thus potentially impacted by palliative care, is work hours. In surveying family members, longitudinal measures are preferred to cross-sectional measures, but are often much more difficult and costly to acquire. A survey should first ascertain whether each child is currently working for pay and the number of hours they typically work per week. Because other factors beyond the health status of their loved one will likely affect hours of work, it is important to get information on wages, educational attainment, marital status and work status of spouse, number and ages of their own children, age, and their own health status. With this information it is possible to construct a basic multivariate model to measure the impact of palliative care on hours of work by family members and still control for other confounding factors.

Summary

The previous literature evaluating the economic impact of palliative care has reached a threshold. In particular, the focus on patient medical costs alone has indicated that the advantages of palliative care are, at best, marginal. The effects of palliative care on the family and on nonmedical costs may be significant but have thus far been ignored, despite the fact that a central claim of the palliative care movement is that the family is an important unit of concern. Palliative care for elders may have some unique effects during the impending demographic bulge, and studies on the economics of palliative care for elders are needed. Thus, it is essential that future research measure the other economic components.

The authors have identified many components of palliative care that require attention. The methods for collecting much of this information, including nonmedical costs, are well established and merely need application to palliative care. Methods for measuring quality-of-life for end-of-life patients are still being developed. All future studies should include nonmedical costs and, eventually, should add quantified measures of medical benefits. The magnitudes of these effects may be great enough to profoundly change the way the cost/benefit ratio of palliative care is perceived.

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