QALYs or quackery? The quagmire of quantifying the cost of breathing

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Lung transplantation has become an accepted therapy to palliate end-stage lung disease. Broader application is currently limited by a scarcity of suitable donors. Because it is an expensive undertaking, lung transplantation must be regularly evaluated to ensure that it provides value to society and to the patients who may benefit, because “not even the richest countries can now afford to undertake every health care activity that might conceivably do someone some good somewhere sometime.”¹

In this issue of the *Journal*, Anyanwu and associates² present an analysis of the economic impact of lung transplantation in the United Kingdom. The study compared the costs of 677 thoracic transplantation procedures with the costs accrued by patients on the waiting list during a 4-year period. From these data Anyanwu and associates estimated the incremental cost per life-year gained and the cost per quality-adjusted life-year (QALY) gained. Studies like this often form the basis for resource allocation decisions. Caution must be exercised in extrapolating these results to different health care systems in different countries, however, and also in using this kind of information to allocate resources.

Anyanwu and associates compared the cost of transplantation with the cost of care for listed patients who had not yet undergone transplantation. However, the opportunity to transplant a given patient depends on the organ distribution algorithm in place. In the United States, lungs are distributed within geographic regions primarily according to waiting time. In the United Kingdom, thoracic organs are distributed to centers on a “rotational” system, with centers possessing considerable latitude concerning allocation to individuals on their list. It is therefore likely that as patients become more ill in the United Kingdom, they are more likely to receive transplants and thus be removed from the list. Patients on the waiting list are therefore not an ideal group to compare costs with transplant recipients. The distribution algorithm could result in an underestimation of the costs of care for patients with end-stage lung disease; in turn, this would result in underestimation of the incremental cost of lung transplantation and undervaluing of the transplant procedure. A fundamental problem of any analysis of incremental costs of a particular therapy such as lung transplantation is the inescapable fact that death is relatively cheap. The cost of caring for patients who need a transplant but do not get one is limited by survival probability without transplantation; as an alternative to transplantation, death becomes an economic bargain.

Anyanwu and associates assumed that all listed patients were similar in health-related quality of life (QOL), which was estimated by a separate analysis of 87 patients awaiting lung transplantation who voluntarily answered a questionnaire.³ However, patients awaiting lung transplantation comprise a spectrum, ranging from those with minimally symptomatic pulmonary hypertension to those in an intensive care unit with an exacerbation of cystic fibrosis or chronic obstructive pulmonary disease. In our experience⁴ patients with cystic fibrosis awaiting lung transplantation had lower levels of anxiety and used more functional coping strategies than did

patients with other end-stage lung disease. Similarly, transplant recipients are not a homogeneous group. Nevertheless, this study obtained utility data directly from patients who had end-stage lung disease or who had undergone lung transplantation, a method considered superior to assignment by unaffected individuals or health care providers.^{5,6} In fairness, there was no other suitable group to use as a control, but the additional costs that might have been incurred by patients with end-stage disease becoming more ill cannot be taken into account if they are removed from the list for transplantation.

Anwanyu and associates correctly pointed out that there is a paucity of studies addressing the cost-utility of lung transplantation. Some studies have questioned a survival benefit of lung transplantation, whereas others have shown clear survival benefit of lung transplantation for US patients with cystic fibrosis and idiopathic pulmonary fibrosis, which became apparent after 1 month for patients with cystic fibrosis and 3 months for patients with idiopathic pulmonary fibrosis.⁷

The implicit assumption that lung transplantation must increase life expectancy to be valuable may be flawed. If transplantation can relieve incapacitating and intolerable dyspnea, then it may be a reasonable (albeit expensive) therapy that increases QOL among survivors. With the growing disparity between donor availability and demand among lung transplant recipients, however, it may be reasonable to preferentially direct organs toward those judged more likely to die without lung transplantation. Such an algorithm for lung distribution is currently under development in the United States, and will probably be circulated for public comment by the United Network for Organ Sharing (UNOS) soon. This approach attempts to address the problem of increasing numbers of deaths among patients on the UNOS lung transplantation waiting list.

Cost-utility analysis seeks to use cost per QALY gained to guide resource allocation decisions.⁸ Although this is a valuable tool to understand relative costs of various therapies, it suffers from some limitations. QALY-based comparisons tend to discriminate against elderly persons, those with reduced life expectancies, and disabled persons.^{6,9} Because older people have a lower life expectancy than do younger people, any life-saving therapy will understandably result in potentially higher QALY gains for younger individuals. Is there a useful concept of “age-achievable QALY?”¹⁰ Is a QALY the same value for a 20-year-old as for a 50-year-old or an 80-year-old? When asked what is was like to be 90 years old, the late comedian George Burns reportedly quipped, “It’s better than the alternative!” Nord¹¹ argues that people’s interest in and entitlement to continued life may be independent of their health. Nord and colleagues wrote, “A life year gained should count as one and no less than one as long as the year is considered preferable to being dead by the person concerned.”¹⁶

In performing cost-utility analyses, economists assume that society and individuals value current utility higher than future utility. Thus, future benefits and costs are “discounted,” which represents a value judgment on preference for current to future consumption. However, it is not clear that people value future health any less than current health. A higher discount rate results in less weight to future benefits. Thus, a high discount rate will favor an intervention that substantially enhances health-related QOL but has little effect on survival over one that enhances survival but has little effect on QOL, even if the QALY gains for the two interventions are identical.⁹ In the analysis of Anyanwu and associates, discounting at 6% per year resulted in an increase in cost per QALY of over 40% (see Table 5 in the article).²

There are substantial differences among countries in cost of medical care. Ramsey and coworkers’ pilot study¹² early in the experience of the lung transplantation program in Seattle determined that the incremental cost per QALY gained through lung transplantation was \$176,817, compared with a range from \$29,285 to \$48,241 in the UK study and \$71,000 in a Dutch study.¹³ There are several reasons for cost differences among countries and health care systems, and there is clearly a difference in various nations’ ability to pay for expensive technologies and, thus, to be able to afford “expensive” QALYs.

QALYs are *not* a form of quackery, but any plan to distribute health care services must take into account the fact that most people cannot stand idly by when an identified individual person’s life is threatened if effective rescue measures are available.¹⁴ This “rule of rescue” poses a serious problem for resource allocation planners because of the human imperative to rescue life¹⁵ and the ethical construct of distributive justice (what we owe each other).¹⁴

By focusing on costs per QALY, we may overlook the intrinsic value of lung transplantation to our patients and society as a whole. Thus the quagmire: The fundamental problem is the assumption that there is a mathematical continuum between death and excellent health. The tool used by the investigators to measure QOL in the current study was the EuroQol EQ5D questionnaire, which allows 243 permutations of health states. A regression equation defines a utility value for these health states and, when used correctly, produces an aggregate numeric value for QOL.³ In our zeal to be objective, have we lost touch with what is important? How do we put a value on watching another sunset, hearing another song, sharing time with a loved one, or pursuing (and attaining) a lifetime dream? What is the value of a QALY? There is no consensus regarding the appropriate dollar value per QALY gained on which to base resource allocation decisions. Estimates of the value of a QALY differ widely, depending on the approach used to calculate this value, from \$24,777 to \$428,286 (median \$265,345).¹⁶

What value should we attach to being able to breathe comfortably? The quality of well-being scale has been used to measure life quality in patients with cystic fibrosis who have undergone lung transplantation. If a young adult who has never enjoyed good health enjoys 9 of the best months he or she has had in the past decade after a lung transplantation and then dies of a viral illness, what is this worth to the patient?¹⁷ To the family? To society?

We must continue to evaluate the cost-benefit and utility of our interventions, as Anyanwu and colleagues have attempted,² because we may identify strategies to save money and make expensive therapies more economically sound. However, we must also be skeptical of efforts to make cost per QALY the *sole* determinant of resource allocation in health care. Life is too short, and for some breathing is too difficult.

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