

The value of life near its end and terminal care

by

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Abstract

Medical care at the end of life, estimated to contribute up to a quarter of US health care spending, often encounters skepticism from payers and policy makers who question its high cost and often minimal health benefits. It seems generally agreed upon that medical resources are being wasted on excessive care for end-of-life treatments that often only prolong minimally an already frail life. However, though many observers have claimed that such spending is often irrational and wasteful, little explicit and systematic analysis exists on the incentives that determine end of life health care spending. There exists no positive theory that attempts to explain the high degree of end-of life spending and why differences across individuals, populations, or time occur in such spending. This paper attempts to provide the first rational and systematic analysis of the incentives behind end of life care. The main argument we make is that existing theoretical and empirical analysis of the value of life do not apply, and often under-values, the value of life near its end and terminal care. We argue that several factors drive up the value of life near its end including the low opportunity cost of medical spending near ones death, the value of hope including living into new innovations, and potential positive effect of on the value of life from being frail. We calibrate the ex-post value of hope associated with treatments for HIV patients to be as much as five times as high as standard estimates of treatment value.

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Section 1: Introduction

Medical care at the end of life often encounters skepticism from payers and policy makers who question its high cost and often minimal health benefits. Indeed, many studies have found that a large share of overall life-time spending on medical care, about a quarter, occurs at an individual's last year of life, regardless of whether that care is privately or publicly financed (Hogan et al. 2000; Lubitz and Riley 1993). It therefore seems generally agreed upon that medical resources are being wasted on excessive care for end-of-life treatments that often only prolong minimally an already frail life. This excessive care at the end of life partially affects the overall distribution of health care spending as it is highly skewed, average spending levels driven many times by extreme spending levels on dying individuals. For example, it has estimated that about close to half of the overall spending on old individuals in the US stems from the top 5 % of the spending distribution (Garber et al (1998)).

From an economic standpoint, it seems obvious that much of this extreme end of life-spending is irrational in the sense that the value of a life year is often estimated to be in the range of 100 thousand dollars², but overall spending in extending life a few months near death can sometimes be in the millions. Indeed, it can be argued that this vast misallocation of resources induced by excessive end of life health care has important consequences for the overall economy as end of life care makes up a substantial share of the 16% or so of the economy spent on health care. This over-spending on terminal care also has important implications for the public programs, such as Medicare and Medicaid in the US, that pay for much of this excessive end of life care, as well as Social Security, which ends up financing the longer but lower quality lives it induces.

However, though many observers have claimed that such spending is often futile and wasteful, it persists and is growing both in the private and public sector presumably indicating there are some less understood benefits to these activities. Indeed, little explicit and systematic analysis exists on the incentives that determine end of life health care spending. We argue that a positive analysis of why and when high levels of terminal care spending occurs is the prerequisite before any normative claims can be made and before any policy proposals aimed at limiting such care can be justified on an efficiency basis.

In this paper, we attempt to provide a rational choice analysis of the incentives behind end of life care. The main argument we make is that existing theoretical and empirical analysis of the value of a life do not apply to the valuation of life near its end, and as a consequence to the demand for terminal care. In particular, several forces operate in

² It is interesting to note that this estimate of the value of a life year is in the range of a simple valuation of the time of a year in the US using wages as the lower bound on the value of leisure time. More precisely, if average labor earnings are in the range of \$30-40 thousand per year and working time makes up about a third of total time awake (8 hour work day during weekdays and 7 hours of daily sleep) then the range for a lower bound on the value of a life year is \$90-120 thousand. Also, see Hirth et al (2000) for a survey indicating larger values.

allocating resources towards extending life at its end that implies that the value of extending life in those situations appear larger than previous analysis suggests.

First, if resources have no value when dead, a self-interested individual would be willing to forego his entire wealth to extend his life when dying, even if only for a few months. A substantial amount of spending on futile care is rational when there is no or less value of leaving wealth behind. The desire to spend ones wealth on terminal care is highly related to existing evidence suggesting that about of half of personal bankruptcies are associated with unforeseen health care spending, often taking place when faced with life-threatening diseases (Himmelstein (2005)). We argue, similar to other goods, that there is a declining willingness to pay for additional year as a function of how many years one has to live. This is related to how the value of a statistical life year is taught and explained as it is often prefaced with claiming that it is not about how much people are willing to pay to avoid the choice of having a gun put to their head, presumably ones wealth. However, terminal care decisions are often of exactly that nature.

Second, we argue that an important ignored component of spending on end-of-life care concerns preserving the hope of living, and that preserving hope raises valuation. We define the value of hope explicitly as the *current* consumption of *future* survival. If a patient is given a death sentence in 6 months, he values those 6 months less than if he knew he would live after that. The fear of knowing that the end is near is a bad. We derive how this value of hope raises the willingness to pay for what appears as otherwise futile treatments. Related to such a value of hope is the option value of seeing a new treatment being discovered before one's death. Indeed, many celebrities, e.g. Michael J Fox and the late Christopher Reed, have invested a large share of their wealth in speeding up the arrival of a cure for themselves.

Third, the *social* value of terminal care is often greater than the *private* value of the same treatments. However, existing analysis of the value of a life year may sometimes only concern private valuation³. If the extension of a given persons life has positive external effects on others (family members, altruistic tax-payers, or interest groups benefiting from public provision of care), larger spending than what is privately optimal, and estimated, would be observed, whether efficient or not. Indeed, as the willingness to pay for life extension is limited privately by ones wealth, the mere existence of the Medicaid program for the poor in the US seems inconsistent with a private valuation approach being relevant, as it would be infeasible for those patients to pay the end of life care they receive. Rich countries many times don't tolerate poor people dying when existing technologies can save them.

Fourth, we argue that rational terminal care often is larger for frail patients than commonly argued. In particular, we show when the value of terminal care may be the same regardless of the "quality" of life of the patient whose life is extended. Therefore, even though a person may be frail and in very ill health, it may nevertheless be rational for him to value terminal care as much as a perfectly healthy person. There is a vast

³ See Becker, Philipson, and Soares (2003) who discusses the general R&D implications of a wedge in the social and private value of health care.

health economic literature arguing that there is less value in prolonging a life of lower quality, as is the driving assumption of so called “quality-of-life-year” (QUALY) analysis.

Because of these factors, the value of terminal care may exceed the levels currently attributed to such care. To empirically assess the importance of one of these factors, the value of hope, we calibrate the option value of new innovation associated with terminal care for HIV patients in the 1990s . We find that the ex-post value of hope associated with treatments for HIV patients to be as much as five times as high as standard estimates of the value of treatments extending life marginally.

The paper may be briefly outlined as follows. Section 2 discusses the non-linearity of the value of life. Section 3 discusses how the value of hope raises spending. Section 4 discusses altruism within and across families affects terminal care. Section 5 discusses the impact of quality of life on rational terminal care. Section 6 discusses terminal care insurance and Section 7 R&D for new terminal care technologies. Section 8 provides our calibrations for HIV. Lastly, section 9 concludes.

Section 2: Rational Terminal Care and the Non-Linearity of The Value of Life

Consider the indirect utility function $V(Y,S)$ of an individual with lifetime wealth Y and survival function S . For example, this indirect utility function may be the one resulting from a canonical consumption problem of the type

$$V(Y, S) = \max \int_0^{\infty} \exp(-\rho t) S(t) u(c(t)) dt \quad (1)$$

subject to

$$Y = \int_0^{\infty} \exp(-rt) S(t) y(t) dt = \int_0^{\infty} \exp(-rt) S(t) c(t) dt, \quad (2)$$

where $y(t)$ is income at age t , $c(t)$ consumption at t , r and ρ is the interest rate and time-preference.

For any such indirect utility function V , consider how much an individual would be willing to pay for a product that changed his survival function from S to S' . If we denote this amount by $v(S', S)$, it satisfies⁴:

$$V(Y - v(S', S), S') = V(Y, S). \quad (3)$$

This *infra-marginal* valuation formula⁵ differs from the existing value-of-life methodology used in the empirical literature which considers *marginal* changes in life-

⁴ An analogous argument occurs if the individual is asked to value a probability distribution over a set of feasible survival functions induced by treatment.

gains. This basic definition has remarkably strong implications for the economic value of raising survival for people who are near their end of their life. In particular, consider the value of a gain in survival to S' for an individual who is near his end of life, approximated by his existing survival function satisfying $S = 0$. The value of this survival gain satisfies:

$$v(S', 0) = Y \text{ for all } S' \quad (4)$$

This extreme implication states that an individual is willing to pay his entire wealth for any gain in survival. In particular, the individual is willing to give up all his wealth *no matter how small the gain in survival is*. Put differently, if the opportunity cost of spending is zero when there is no value of leaving resources behind when dead, an individual is willing to spend all of his wealth to prolong life, though perhaps just briefly. This is an extreme implication induced by the complementarity between consumption and longevity (see Dow et al (1999)); as consumption is worthless without life, all of it will be sacrificed to gain more life.

More generally, there may be inherent *non-linearity* in the valuation of life in the sense that the marginal value of an additional life year will likely fall with the more life one has. This implies that the value of big changes in survival cannot be as easily inferred from the value of small changes in survival. There is an implicit linearity assumption when aggregating up the value of life-improvements from the marginal valuations estimated in the existing literature. Consider the common practice of infra-marginal valuation through multiplying life years gained with a constant marginal value of a life year of, say, \$100 thousand.

To illustrate simply, consider the canonical consumption problem above in the case of no discounting and a deterministic lifetime. In this case, the indirect utility function is made of T years of consumption of the overall wealth Y split up over the T years as in

$$V(Y, T) = Tu(Y / T) \quad (5)$$

This implies the marginal value of life

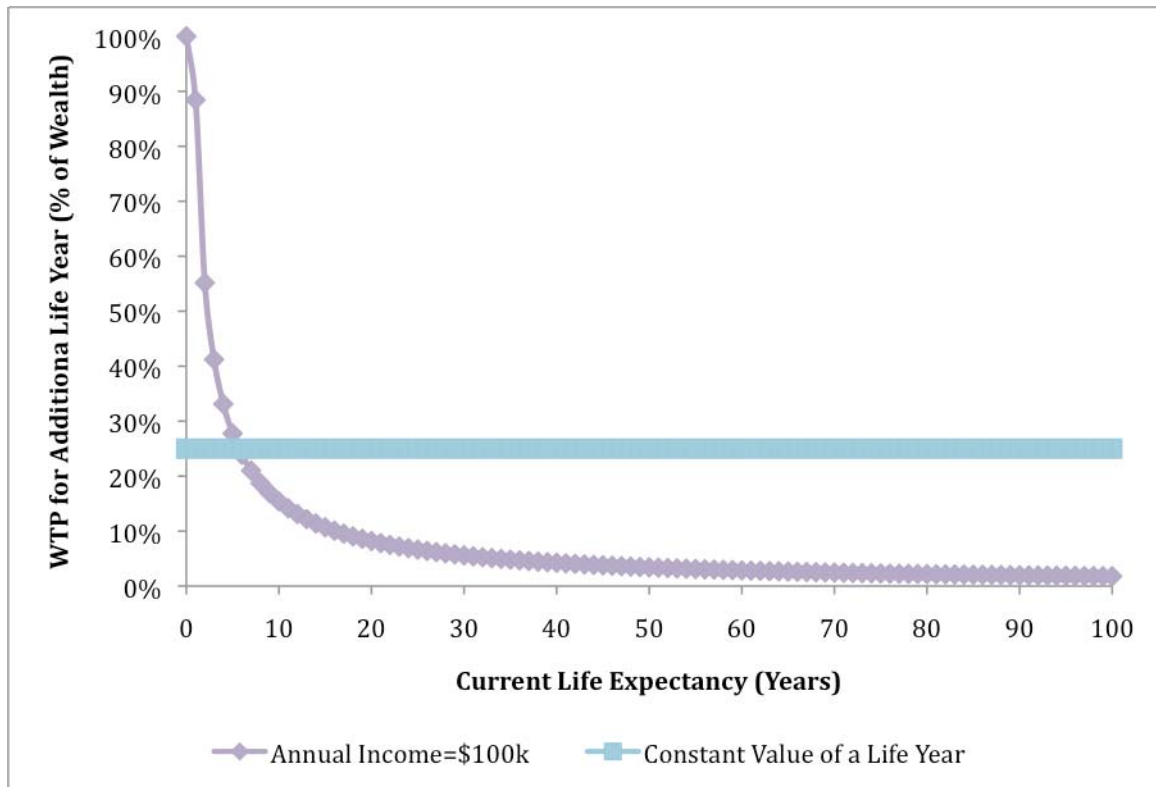
$$dY/dT = -V_T/V_Y = c - u/u' \quad (6)$$

This says that if the elasticity of the utility function with respect to consumption is one, then there is no value of life. This is the case when utility is proportional to consumption $u = ac$ so that the indirect utility only depends on wealth $V = aY$. In this case, the loss in quality of life due to a longer life equals gain due to the rise in the quantity of life.

As illustrated in Figure 1, the typical pattern of willingness to pay for a life year will fall with the life expectancy. The value of a life year equals the level of wealth when the alternative is death and falls from there.

⁵ See Becker et al (2005) for a more elaborate discussion of infra-marginal valuation in a different context.

Figure 1: Declining marginal value of a life-year as a function of life-expectancy



In the example above, it can be shown⁶ that when u is concave then this marginal value of life falls with longevity then the marginal value falls in longevity as in $d/dT [dY/dT] \leq 0$.

This is similar to diminishing marginal utility in consumption of other goods⁷. The important point is that if the marginal value of life declines with life in this way, the marginal value of life from those who have a lot of it, e.g. workers healthy enough to participate in labor markets, may not reflect the value of terminal care for those who have less of it.

Section 3: The Value of Hope in Terminal Care

⁶ Differentiating $c-u'$ with respect to T yields $[-u''u/(u')^2](dc/dT)$ which is negative.

⁷ For example, when the utility function takes the constant elasticity form, $u(c) = c^a$, then the indirect utility function takes the Cobb-Douglas form $V(Y, T) = T^{1-a}Y^a$ which displays the traditional declining marginal rate of substitution with the levels of the two “goods”.

Many observers of end of life care claim that some notion of “hope” is important for patients to invest time and money into staying alive⁸. We formalize the value of hope as stemming from the current consumption of future survival; the person values knowing today that there is chance of living tomorrow. If certain death was known to prevail tomorrow the person would be without hope and thereby enjoy living less today. This is incorporated into the previous analysis by letting current utility become an increasing function of survival. Consider the case when this takes the linear form

$$U(S, c) = Hu(S) + U(c) \quad (7)$$

Here, the parameter H is the marginal value of hope and $u(S)$ is the current utility of future survival which rises in first-degree dominance. For example, $u(s) = \int S(t)dt$ may be the life-expectancy induced by the survival function. For the canonical consumption problem above the present value of expected utility now satisfies

$$V(Y, S; H) = AHu(s) + V(S, Y) \quad (8)$$

where A is the value of a life-long annuity and $V(Y, S)$ is the value function without hope from before. If we denote by $v(H)$ the infra-marginal value of life as a function of the value of hope this satisfies

$$V(Y - v(H), S') - V(Y, S) = H[Au(S) - A'u(S')] \quad (9)$$

The left hand side is simply the implicit definition of the standard infra-marginal value of life. The right hand side falls with the value of hope and the infra-marginal change in survival. Consequently the value of life as a function of hope, $v(H)$, is an increasing function. Whenever future survival is valued in terms of current consumption then future survival gains are ‘double counted’ in their value; they affect the value of future consumption in a standard manner but in addition also raises the value of current consumption. This double counting due to hope may take place more so in end of life care decisions than in the labor- or product market setting where marginal valuations of life are estimated.

We argued before that a declining marginal value of life with the level of longevity implied that empirical estimates of the value of life for healthy people would differ from the valuation relevant to terminal care. The analog argument can be made for a declining marginal value of hope with longevity. If the marginal value today of living in the future goes down with future longevity, then empirical estimates of the value of life are biased when applied to terminal care for two reasons; the first because the traditional value of life declines with longevity and the second that the value of hope does too.

3.1: Hope and the Option Value of New Innovation

⁸ See Rasiel et al (2005) for a prospect-theory interpretation of terminal care with highly uncertain outcomes.

Future survival may not have consumption value in itself but may be valued in non-standard ways through its effect on being able to take advantage of future technologies. In other words, there is an option value of terminal care due to that it may enable the person to live to see future cures.

Consider an uncertain time of arrival A of a new discovery and let G denotes its cdf. If $C(t)$ denotes the higher survival curve associated with the cure and S the survival in absence of a cure, the individual faces the expected survival function denoted S_C defined by

$$S_C(t) = \int_0^{\infty} S_a(t) dG(a)$$

where S_a the survival that takes place in case the cure arrives at time a , defined by $S_a=S(t)$ for $t \leq a$ and $S_a(t)=C(t) - [C(a)-S(a)]$ if $t \geq a$.

Now consider the value v_C of taking on a given treatment that yields a higher survival S' rather than S . In presence of the possibility of a future cure this value is defined by

$$V(Y-v_C, S'_C) = V(Y, S_C)$$

This value reduces to the value v discussed in previous sections before when there is no possibility of a cure, that is, if G was degenerate. The difference in value between the traditional willingness to pay for a treatment v and the nonstandard value v_C is the larger possibility of living to see a cure under the treatment.

This simple analysis has several direct implications. We would generally predict that factors that raise the rate of future innovation will also raise the demand for terminal care holding the effectiveness ($S'-S$) of current treatments constant. One such factor would be a larger and more promising pipeline of treatments being investigated for future market approval. Another may be the size or prevalence of the disease as market size raises R&D incentives. Also, it seems reasonable to assume that lack of discovery in the past would lower expectations of immediate discoveries now. If 40 years without any huge breakthroughs have taken place, it seems less likely that a break-through will take place than if the disease is new. This would lead to the prediction that, the demand for terminal care treatments would rise in the novelty of the disease, holding the effectiveness of current treatments constant.

The option a value of future cures also may lead one to predict a risk-loving nature of taking on treatments if there is mass at the end tail of living into new innovations. Having a 10 percent chance of living 10 years may be more valuable than living 1 year for certain. Treatments with the same mean survival or treatment effect may differ in value due to that larger variance raises the chance of seeing a cure.

Moreover, the option value implies that randomized clinical trials where future treatments are not incorporated yield biased estimates of the full treatment effect taking into account the larger chance to live to see new innovations for a superior treatments, that is, $S'_C - S_C$ differs from $S'-S$.

Section 4: The Social vs Private Value of Life

The previous section considered a self-interested individual in isolation, which is the concern of existing empirical work on the statistical value of a life through labor-, product-, or regulatory studies. This section considers the difference between the social- and private value of a life, when there is altruism within and across families.

4.1 Altruism within Families

Altruism within families operates in two ways in affecting the social value of a life. First, altruism towards children means that the value of life is reduced by bequest motives as the person dying values resources left behind. Second, altruism from children raises the value of life since people other than the dying patient value his survival.

More precisely, consider when a parent is terminally ill but now both the parent and the child share the payment that is undertaken to have the parent face survival S' rather than death $S=0$. Let the infra-marginal value of the parents life v be split between the parent and the child according to the shares $(s, 1-s)$. Let $V^p(Y^p, S)$ and $V^c(Y^c)$ be the indirect utility functions of the parent and child, with the latter ignoring the child's survival prospects which are assumed to remain constant. The infra-marginal value v of the parent's life is then defined by

$$(1 + a^c)V^p(Y^p - sv, S') + (1 + a^p)V^c(Y^c - (1-s)v) = (1 + a^p)V^c(Y^p + Y^c) \quad (12)$$

where a^c is the altruism of the child towards the parent and a^p the altruism of the parent towards the child. The right hand side is the child's welfare when no treatment is undertaken for the parent, the parent dies, and all the wealth of the parent is left as bequest. The left hand side is the joint welfare of the two when the new life, and its payments, is shared. This may be rewritten as

$$(1 + a^c)V^p(Y^p - sv, S') = (1 + a^p)[V^c(Y^p + Y^c) - V^c(Y^c - (1-s)v)] \quad (13)$$

This simply equates the gain in welfare of the parent surviving with the foregone consumption of the child. Clearly, for large enough altruism of the child and low enough altruism of the parent, we may have that altruism raises the willingness to pay above the self-interested level of the parents wealth

$$v > Y^p \quad (14)$$

and for low enough altruism if the child and high enough altruism of the parent, it lowers the willingness to pay beyond the self-interested level

$$v < Y^p \quad (15)$$

If altruistic spending rise with income, the two side nature of altruism may therefore even raise spending above wealth levels of the sick individuals if the children are richer than the dying parent. Reversely, terminal care for children financed by their parents is likely to be far greater than the self-interested level of the wealth level of the child.

4.2 Altruism across Families and Public Pay-As-You-Go (PAYG) Health Care

Clearly an important determinant of the high levels of spending on terminal care is due to public subsidization of demand, in the United States mostly through Medicare and Medicaid. To consider the determinants of the size of public subsidies, consider the public pay-as-you-go (PAYG) insurance that finances most health care spending in the developed world. This is a natural extension of the analysis under altruism with children, except that now each parent is being subsidized by the average child in the economy as opposed to their own child in the previous section.

The classic effects of any demand subsidies are of course to raise the supply-price, lower the demand-price, and raise quantity. Consequently, terminal care spending, the product of the supply-price and the quantity, will be positively affected by demand subsidies. Demand subsidies for health care in many countries, including Medicare and Medicaid in the US, differ from classic demand subsidies in that they also involve third-party (administrative) pricing. Nevertheless, and particularly for the poor, the demand subsidy aspect through third-party financing is clearly an important factor in determining the high level of terminal care spending.

However, we here argue that there exists evidence that suggest that even in absence of demand subsidies, the level of terminal care spending would be higher than accounted for by existing value of life estimates. Indeed, there is a large literature in health economics, the most prominent study being the RAND Health Insurance Experiment⁹, that has attempted to estimate the effect of co-pays on health care spending. Interpreting co-pays as unsubsidized care, this literature has implications for the counterfactual spending that would take place in absence of demand subsidies¹⁰. In particular, consider the benchmark RAND experiment estimate under which spending under full co-pays is about 70 % of spending under no co-pays or fully subsidized care. In this benchmark case then, terminal care spending would be about 70% of observed levels. But even when discounting spending due to subsidies in this manner, it appears that terminal care spending is higher than common estimates of the value of a life. Even if we assume that for every 100 thousand dollars spent on public terminal care, 70 thousand would be spent without public subsidies, spending levels on terminal care are many times still very high relative

⁹ Other more recent studies on the effect of public demand subsidies include Card, et al (2004), Finkelstein et al (2005).

¹⁰ Indeed, The RAND Health Insurance Experiment was ideally suited to study public subsidization as premiums were never collected by participants, mimicking the effects of differentially generous tax-financed plans. The experiment therefore had less implications for private demand of care as it also involves an elastic ex-ante demand for insurance itself, rather than the studied demand for care ex-post.

to existing value of life estimates. Therefore, this suggests that using standard co-pay estimates to predict unsubsidized demand may not alter our basic argument. This is particularly true, if as often found, acute hospital inpatient care is less elastic to co-pays than is other forms of care.

The overall analysis of PAYG insured terminal care is analogous to multiple children and parents who exhibit heterogeneous altruism towards each others, where presumably within-family altruism is stronger than across-family altruism. Therefore, such altruistic and PAYG financed terminal care have many analogous features to the analysis of a single family before. Again, it is the relative altruism of the old relative to the young that matters for whether a PAYG financed health care program has a larger value of saving an adult from dying compared to the adult himself. If younger generations cannot tolerate old people dying without state of the art terminal care more than the older generations care about public deficits, then optimal spending levels may be well beyond the average wealth of the dying generation.

Section 5: The Quality of a Life Year and the Value of Extending It

It is often argued that life-extension should be allocated towards individuals in good health rather than poor health. In this section we analyze rational terminal care as a function of the level of health or “quality” of life. We stress that terminal care often is larger for frail patients than commonly argued. Even though a person may be frail and in very ill health, it may nevertheless be rational for him to value life-extension as much as a perfectly healthy person. A special case of this is the analysis above where the opportunity cost of wealth is zero for a dying self-interested individual, regardless of whether that individual is frail or healthy.

Valuation of a Quality Dependent Life

More precisely, consider when the annual utility function $U(c, q)$ is extended to depend positively on both consumption c and quality of life q . For a given quality of life, consider the indirect utility when full consumption smoothing takes place over time

$$V(Y, S) = AU(Y / A, q) \quad (16)$$

The infra-marginal value of life $v(q)$ for a given level of quality q is then defined by

$$A'U(Y / A - v(q), q) = AU(Y / A, q) \quad (17)$$

This has the direct implication that the quality of life has two *offsetting* effects on the value of life. First, quality raises the value of life by raising the level of utility under the improved survival (left-hand side) because living longer is enjoyed more when the quality of that life is higher. However, note that as a second effect it also raises the value of the remaining life at the lower survival (right-hand side). Therefore, a higher quality of life means the new life is enjoyed more but also means the old life is as well. The second

effect is due to that the cost of foregone consumption used to finance life extension rises with quality. Dependent on the complementarity between consumption and the quality of life, the cross partial of U , the value of life $v(q)$ may be falling or rising in the quality of life. It can be shown that for particular utility functions, the two effects will be fully offsetting making the value of life independent of the quality of life; $dv(q)/dq=0$.

Note that this result does not imply that holding constant quantity of life a rise in quality is not valued. It is still true that an increase in q is valuable holding constant the survival S . Rather, the two offsetting effects above are about the interaction and states that the value of prolonging life may not depend on the level of quality; the value of changing S for different levels of q .

Section 6: Insurance for Terminal Care

The previous analysis considered the ex-post allocation problem of terminal care conditional upon a disease occurring. We here consider the ex-ante allocation problem of deciding how much wealth to allocate towards a potential future disease occurrence involving expensive terminal care. This will determine the willingness to pay for an insurance policy that covered terminal care were it to be necessary in the future.

Let f be the probability of a terminal illness occurring in which case the person faces death unless treated. Assume for ease of exposition that no care is purchased if the person is uninsured and that if he is insured he is treated and his survival prospects are S' as before. The individual does not contract the disease with probability $(1-f)$ in which case he faces the normal survival S . The willingness to pay for such coverage, v , is now determined by how much wealth the individual is willing to give up ex-ante in order to obtain the survival S' if the terminal illness would occur in the future. This willingness to pay for terminal care insurance is determined by

$$fV(Y - v, S') + (1 - f)V(Y - v, S) = fV(Y, 0) + (1 - f)V(Y, S) \quad (18)$$

If the individual was to give up all his wealth today for terminal care when needed in the future, the left-hand side would be zero and the right-hand side positive. Therefore, as opposed to the case for the ex-post willingness to pay for terminal care, the ex-ante willingness to pay is not equal to the individuals' level of wealth; $v < Y$. This is of course because the individual trades off other uses of the wealth when making the ex-ante decision, in particular consuming the wealth if the individual does not become terminally ill.

The effects of the parameters facing the individual on the willingness to pay for terminal care insurance are illustrated in Figure 1 below. It depicts three indirect utility functions as a function of income; one for each of the survivals $V(Y, S) > V(Y, S') > V(Y, 0)$.

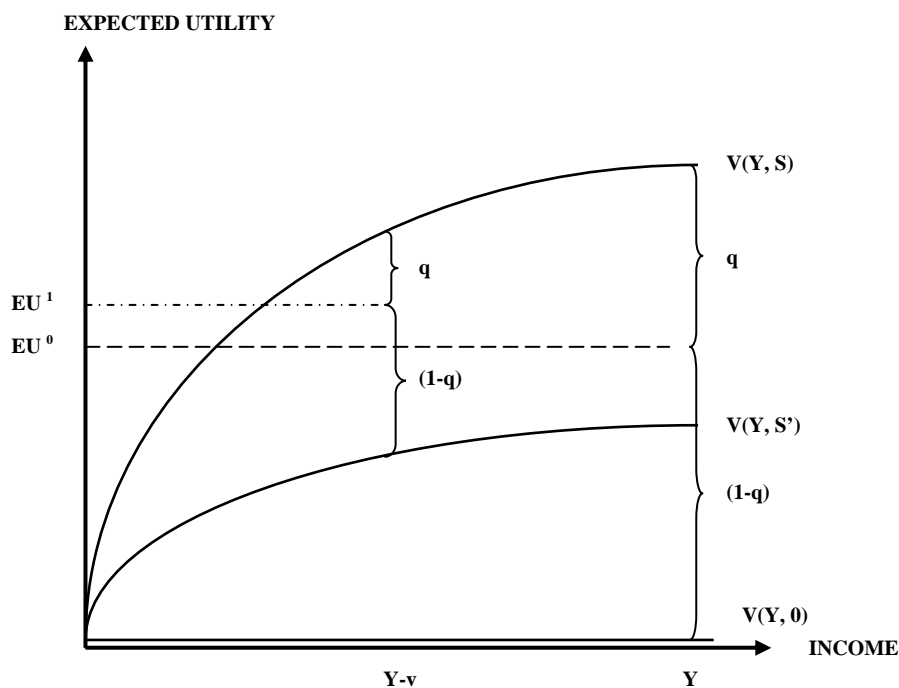


FIGURE 1: TERMINAL CARE INSURANCE

If the individual goes uninsured then he is faced with the expected utility EU^0 indicated in the figure, which is a f -weighted average of $V(Y, S)$ and $V(Y, 0)$. If he pays v for the insurance he is faced with the expected utility EU^1 in the figure, which is a f -weighted average of $V(Y-v, S)$ and $V(Y-v, S')$. Consequently, the maximum amount v that the individual is willing to pay is the amount that brings down expected utility of being insured EU^1 to the level of expected utility of being uninsured EU^0 in the figure.

The figure illustrates directly that the willingness to pay ex-ante for terminal care is only equal to wealth in case of the illness occurring with certainty making up the special case of the previous analysis. More generally, the figure reveals that the willingness to pay for the insurance rises with the probability of terminal illness; v rises with f . In addition, naturally, the individual is not willing to pay anything unless there is a chance of the illness occurring, so that $f=0$ implies $v=0$, and is willing to pay his entire wealth when it occurs for sure, so that $f=1$ implies $v=Y$. Naturally, terminal care insurance is more valuable for common terminal illnesses, e.g. cancers, than for rare ones.

The figure also illustrates the straightforward implication that the willingness to pay for terminal care insurance rises with the survival enabled by the terminal care, that is, v rises with the survival S' . This is because a rise in the survival S' that takes place in presence of care raises the expected utility of being insured EU^1 but does not affect the expected utility of being uninsured EU^0 . Consequently, the willingness to pay to be insured rises.

Lastly, the figure illustrates that the survival of the person absence the occurrence of terminal illness, S , has an indeterminate effect on the willingness to pay for terminal care insurance. This is because better health in absence of the illness occurring raises both the

expected utility of being uninsured and insured. Dependent on the shape of the indirect utility function, the willingness to pay for terminal care insurance rises or falls with S . This is analogous to the indeterminacy of the quality of life affecting the ex-post valuation of life and terminal care discussed earlier.

Section 7: Research and Development of Terminal Care Technologies

Our analysis stresses the high value of terminal care given the existence of technologies to extend life when it is threatened. This section considers the incentives for bringing such technologies to exist in the first place through medical R&D. The major issue we discuss is how the presence of altruism affects optimal R&D. The presence of altruism in affecting the efficient amount of technological change is poorly understood by economists¹¹, but seems central to understanding whether health care spending is growing at the appropriate rate.

We previously discussed the difference between the social and private value of life given the existence of a technology. There is an important aspect of terminal care, indeed for health care in life-threatening conditions in general, which concerns the desire to avoid denying treatments to dying patients. Indeed, many times doctors express concerns that it is “unethical” to deny any patient the use of existing technology in life-threatening situations and this has led to sharp disagreements between doctors and economists on appropriate care. Terminal care is perhaps the starkest case where this issue arises. We here stress that such preferences have important implications for the appropriate technological change over time, and hence for the appropriate change in health care spending over time. The issue we focus on is when there is an aversion to denying existing technologies to care for dying patients, which seems central to the issue of terminal care.

Consider when this takes the form that an altruist prefers someone not receiving care in the *absence* of a technology to denying care in the *presence* of a technology. Such interactions of the demand for altruistic care with new goods have important and unrecognized effects for the optimal degree of technological change, and hence for the optimal growth in health care spending. It is often true that when a new good appears in the utility function, here a new technology being consumed by the patients and altruists, it affects demand for other goods, as e.g. analyzed for the case of advertising by Becker and Murphy (1994). In particular, let W^1 be the social surplus when using the developed terminal care technology and W^0 when not using the developed technology. Now let N denote the social surplus when the technology is not developed at all and thus cannot be used. We assume that there is a social surplus from using the technology if it gets developed so that $W^1 > W^0$. This surplus may come from patients themselves or from altruistic payers of that care. In a standard analysis, it would be the case that not using a developed technology or not having it developed would entail the same ex-post surplus; $W^0 = N$. The terminally ill patient would be indifferent because he obtained the same

¹¹ See Philipson, Mechoulan, and Jena (2006) for an analysis of this issue.

health and the altruists would be indifferent because their wealth would be unchanged and the health and wealth of the patient would be as well. However, if it is the case that the willingness to pay for care by altruists interacts with the presence of a new technology then this equality may not hold. In particular, if altruists prefer no technology to not using it when available then $N > W^0$.

In this case, the surplus conditional on developing the technology does not correspond in a standard manner to the value of R&D investments to generate the technology in the first place. In particular, let $P(R)$ be the probability of discovery of the technology given R&D investment R . The expected surplus of developing the technology is then

$$\max_R P(R)W^1 + (1 - P(R))N - R \quad (19)$$

This has the necessary first-order condition for an interior solution

$$P_R(W^1 - N) = 1 \quad (20)$$

As this makes clear, the marginal benefit on the left-hand side, the difference $W^1 - N$ drives efficient R&D. However, the difference $W^1 - W^0$ is usually how the ex-post value of a new technology is assessed, by assuming that the pre-innovation surplus W^0 is the welfare for which the price is sufficiently high to make the demand for the innovation vanish (for an empirical example, see e.g. Hausman (2000)). However, the difference, $N - W^0$, which can be taken as a measure of the aversion to denying care, determines how efficient R&D diverts from traditionally discussed efficient levels of R&D. In the standard extreme case when there is no denial aversion, $N = W^0$, then the ex-post surplus guides optimal R&D investment in a standard manner. At the other extreme is when denial aversion is so large that optimal use of the technology when developed is dominated by no use of an undeveloped technology; $N > W^1 > W^0$. In that case, even though the technology is demanded ex-post and generates a surplus *larger than R&D costs*, there should be no R&D. In health economic jargon, a technology may well be cost effective in that measured health benefits are lower than costs, but nevertheless should not have been developed. In the intermediary case, denial version lowers the value of R&D and provides a wedge between the size of the generated surplus ex-post and the optimal amount of R&D. Put simply; extensive and valuable ex-post usage of expensive terminal care technologies does not necessarily warrant more R&D to develop them.

Note that under denial aversion many of the canonical aspects of the classic economics of innovation do not apply. This is because the interaction between the willingness to pay for care from the introduction of the new good. First, ex-post social surplus does not determine the optimal amount of R&D ex-ante. A technology can generate a social surplus ex-post even though it should never have been developed in the first place. Second, welfare analysis of new innovations usually assume that they are price-reductions from a pre-innovation price that makes demand vanish. However, denial aversion implies that an innovation is not merely a price reduction but also represents a

shift in the social demand curve, a shift which may well be consistent with a meta-utility function covering both undiscovered and discovered goods..

Indeed, this aspect of technological change has important implications for the worldwide incidence of R&D. It is well known that US is about above 60 percent of world sales for pharmaceuticals, as opposed to average industry in which it is considerably lower as about 23 percent of worlds income is generated in the US. This fact is often used to argue that US markets drive drug R&D spending in US or elsewhere and that the positive external effects from US R&D are not paid for by foreign countries. However, under denial aversion countries outside of the US may well be hurt by such technological change, if they are better of not providing care in absence of a technology than they are denying care in its presence. In other words, there may be negative, as opposed to positive external effects of US driven technological change.

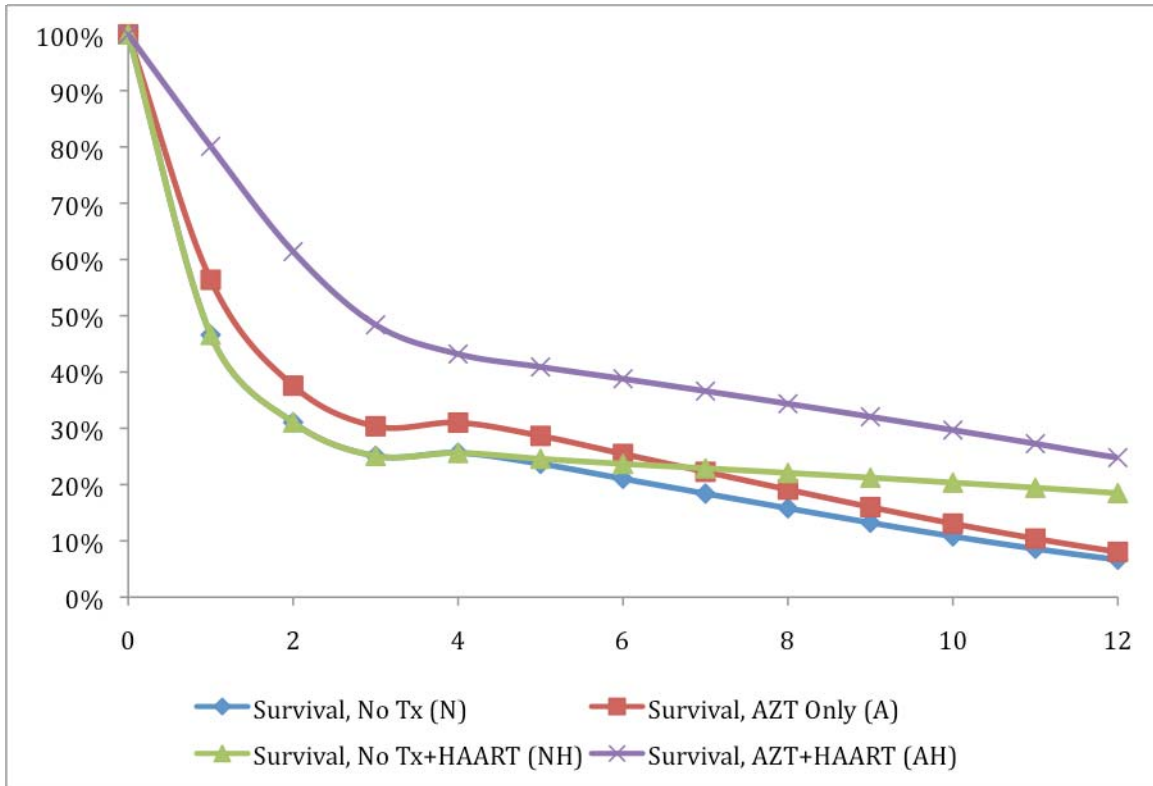
Section 8: Calibrating the ex-post value of hope due HIV innovation

In this section, we estimate the value of hope comprised of living into future innovation. We consider patients with HIV before the new break through medicines were developed in the 1990s. Before these breakthroughs occurred, we show that there was a significant value of receiving terminal care that only marginally improved survival for these patients as this enabled living long enough to see the breakthrough treatments that came on the market in 1996. Our major finding is that the ex-post option value was as much as 5 times as large as the traditional value of the marginal therapies used.

Before there was any therapies developed, HIV patients used to have very little time left to live once diagnosed with AIDS. Then in April 1987, mono-therapy Zidovudine (AZT) was licensed and soon became widely available as the first antiretroviral drug that improved survival (Fischl et al. 1987; McLeod and Hammer 1992). However, the improvement was as marginal as between several months to 1.6 years (Lemp et al. 1990; Moore et al. 1991; Vella et al. 1992). About 9 years later, in 1996, HAART (highly active antiretroviral therapy) emerged as a major breakthrough for AIDS treatment and has been improving life expectancy of AIDS patients markedly by around 10 years (Walensky et al. 2006; The Antiretroviral Therapy Cohort Collaboration 2008). Any AIDS patients who were diagnosed between April 1987 and 1996 had a choice whether to receive AZT or not. We consider to what extent the value of receiving AZT differs from its traditional value, as it increased the likelihood living to see HAART in the future.

Figure 1 illustrates the data used on US cohorts diagnosed with AIDS. As an illustration, it contains the cohort of AIDS patients diagnosed in 1993 and their survival prospects for various treatment regimens before HARRT arrived in 1996.

Figure 1: The option value of taking AZT for patients diagnosed with AIDS in 1993



In Figure 1, there are four survival curves. From left to right, the survival curve S^N for those who took no treatment after being diagnosed, the survival curve S^A for those who took only AZT after being diagnosed, the survival curve S^{NH} for those who took no treatment after being diagnosed but took HAART once it became available, and the survival curve S^{AH} for those who took AZT first and then HAART once it became available. In the terminology of the previous section 5.2, S^N corresponds to S , S^A corresponds to S' so that the standard treatment effect is the difference between these two. Also in that notation, we have that S^{NH} corresponds to S_a and S^{AH} to S'_a with the arrival year of the HAART innovation being $a=1996$.

The impact on life-expectancy of adopting AZT compared to no treatment is revealed by the Figure. This is the area between the survival curves S^A and S^N . As the figure reveals, this area is rather small as AZT only extended life by about one year. It corresponds to the standard value associated with the marginal therapy AZT.

The impact of taking AZT when it may run into the breakthrough HAART is comprised of the area between the survival curves S^{NH} and S^{AH} . This area indicates the gains from going on AZT in hope of HAART compared to not taking anything but still receiving HAART when it emerged. This value corresponds to our non-standard value of the marginal treatment AZT due to that it enables time for innovation. We call the difference

between this value and the standard value of the marginal treatment the option value of the marginal treatment.

8.1 Estimating AIDS survival curves under alternative therapy regimens

To estimate the option value of AZT, one would ideally want survival curves that cover the entire life spans of AIDS patients under the various combinations of antiretroviral therapies needed to estimate the survival curves S^N , S^A , S^{NH} , and S^{AH} described above. However, there are several obstacles. First, most clinical trials and observational data do not follow patients for more than 5 years, so it is necessary to extrapolate long term survival probabilities. Moreover, since AZT was available in 1988 and HAART was available in 1997, to varying extents, each of these curves represents an idealized scenario which is not directly observable. For example, it is difficult to estimate S^{NH} , the survival of patients who received no therapy for a period of time followed by HAART therapy, based on the direct experience of AIDS patients, because there are very few patients who received no treatment for their disease, followed by HAART. Therefore, it is necessary to find some way to use observed AIDS survival data to construct survival curves under the each of the therapy scenarios outlined above.

As a starting point, our analysis begins with the AIDS survival curves by year of infection estimated by Philipson and Jena (2006)¹² for each year between 1979 and 2000. We then combine these curves to obtain the four survival curves of interest S^N , S^A , S^{NH} , and S^{AH} , as follows. Since AZT was introduced in 1988 and the data from Philipson and Jena (2006) suggest that less than 15% of AIDS patients diagnosed in 1979 survived at least 9 years, we used the survival of 1979 AIDS patients to estimate S^N , the survival curve for AIDS patients who received no therapy. Moreover, since AZT was followed by HAART in 1996, S^{AH} , the survival probability of patients who initially received AZT and then received HAART, can be simply estimated as the observed survival for patients diagnosed with AIDS between 1988 and 1996.

Estimating S^A , the survival for patients who received AZT only, is more difficult. Although one approach might be to use the survival of AIDS patients who were diagnosed in 1988, the year when AZT was introduced, we rejected this approach because nearly 20% of these patients survived long enough to receive HAART. Instead, we used the following specification to estimate the effect of AZT on survival probabilities:

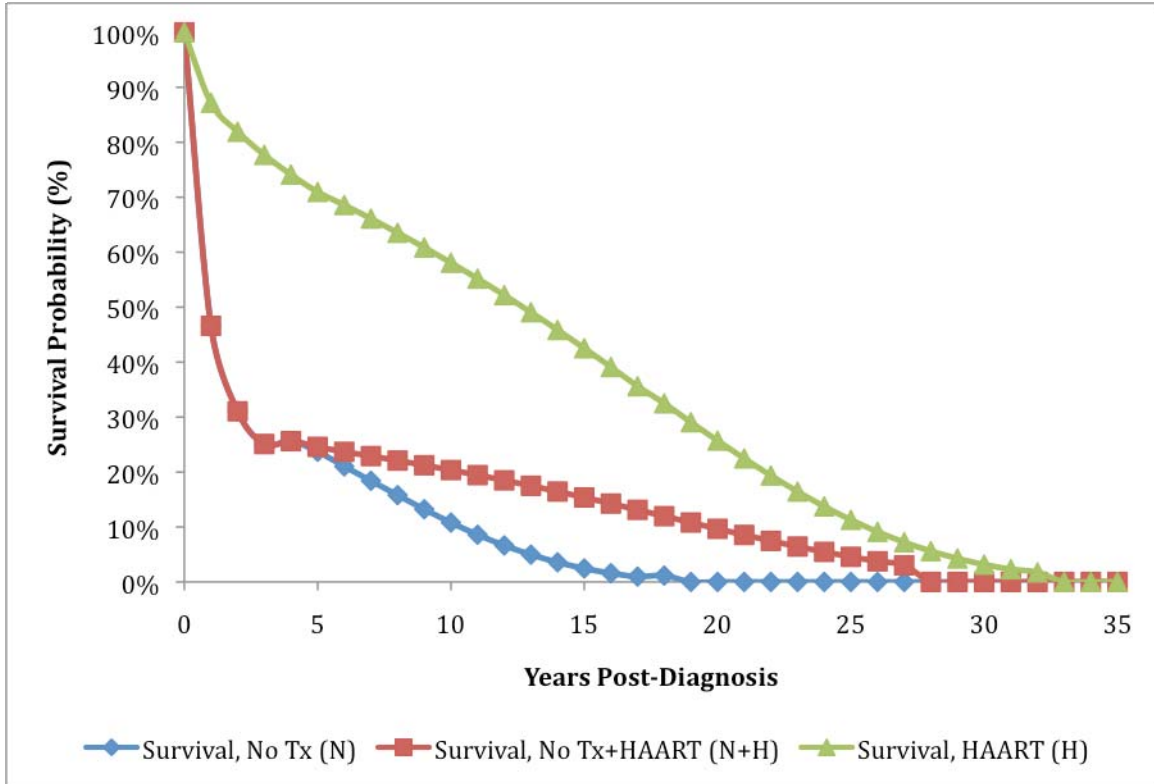
$$\ln(S_{t,j}) = \alpha + \sum_{j=1}^{50} d_j + \gamma AZT_{t,j}$$

¹² We adopt these estimated survival curves because they avoid problems intrinsic to extrapolating parametric models such as exponential, Weibull, or Gompertz. (See Appendix of Philipson and Jena (2006))

where $S_{t,j}$ is the probability that a patient who is diagnosed with AIDS in year t survives to at least j years post-diagnosis, d_j is a fixed effect for the j th year post-diagnosis, and $AZT_{t,j}$ is a dummy variable which equals 1 if AZT was available in the j th year post-diagnosis for patients diagnosed in year t . In estimating the equation above, we limited ourselves to periods in which HAART was not available, i.e., $t+j < 1997$. Since γ is therefore the relative increase in survival due to the introduction of AZT, we estimated S^A as the 1979 curve multiplied by γ .¹³

To estimate S^{NH} , the survival of AIDS patients who receive no treatment until the introduction of HAART and then received HAART, we combined the survival curves of patients receiving no treatment (estimated as the 1979 survival curve) and the survival curves of patients under HAART (estimated as the 1997 survival curve, the year HAART was introduced), as follows. For patients diagnosed in a given year t , we began by assigning the 1979 survival curve for each year between t and 1996, reflecting the fact that these patients faced no treatment until the introduction of HAART. For each year after 1996, we then shifted the survival curve by assuming that the patients adopted the equivalent one year survival probabilities under HAART. Figure Z illustrates this approach for AIDS patients diagnosed in 1993. The figure shows the survival for patients receiving no treatment (“Survival (N)”), the survival for patients receiving HAART (“Survival (H)”), and our estimate of the survival for patients diagnosed in 1993 who received no treatment until 1997, and then received HAART (“Survival N+H”). This survival curve exactly mirrors the no-treatment curve for the first 4 years. However, starting in year 4, we transform this curve using the conditional one-year survival probabilities implied by the HAART curve. For example, to estimate the one year probability of surviving to a 5th year (conditional on having survived at least four years) for N+H patients, we use the probability that a HAART only patient survive to five years (conditional on having survived four years). The figure also reveals an important facet of AIDS survival: in the absence of treatment, the disease is rapidly fatal, with a one year survival of less than 50%, but survival is extremely robust with HAART. Thus, even small improvement in survival in the early years may yield a large option value, given the rapidly fatal nature of the disease in the absence of treatment and the large survival gains associated with HAART.

¹³ We estimated γ to be 0.21 (std error 0.020), suggesting that AZT resulted in a 21% relative increase in survival probabilities. S^A was therefore estimated as a 21% increase over the 1979 survival probabilities.



8.2 Calibrating the Willingness to Pay for Option Value

To calibrate the willingness to pay for survival improvements, consider when patients have an indirect utility function over annual income y and survival S given by $V(S,y)$. The annual willingness to pay for improved survival is the value of v which satisfies

$$V(S,y) = V(S',y-v)$$

Following Becker, Philipson, and Soares (2005), we assume that the instantaneous utility function adopts the following form:

$$u(c) = \frac{c^{1-(1/\gamma)}}{1-(1/\gamma)} + \alpha$$

The parameter α is a normalization factor that determines the level of consumption at which the individual would be indifferent between being alive or dead (at which point utility equals zero), and γ is the intertemporal elasticity of substitution assumed at $\gamma = 1.25$ and $\alpha = -14.97$.¹⁴ The lifetime indirect utility for an individual is given by:

$$V(S,y) = u(y)A(S)$$

where $A(S)$ is the value of an annuity that pays \$1 in perpetuity under a given survival curve. Given these expressions, it is straightforward to show that the annualized value of survival improvements is given by

¹⁴ For further justification of these parameter assumptions, please see Becker, Philipson, and Soares (2005).

$$v = y - \left[\left(\frac{1}{1-\gamma} \right) \left(\frac{A(S)}{A(S')} \cdot u(y) - \alpha \right) \right]^{\gamma/(\gamma-1)}$$

wtp reflects the annual willingness to pay for survival improvements; the lifetime willingness to pay is simply the present value of this sum and is given by $A(s)v$. In our calculations, we assume an annual (full) income of \$100,000¹⁵.

The calibrated willingness to pay for the optional value of AZT is presented in Table 1A below on a per-capita basis and Table 1B on an aggregate basis taking into account the yearly new cases of AIDS..

Table 1A: Ex-Post Willingness to Pay for Option Value of AZT: Per-Capita Values

Year	LIFE EXPECTANCY (YEARS)				WTP (\$)			
	No Drug (N)	AZT Only (A)	No Drug then HAART (NH)	AZT then HAART (AH)	A vs N	AH vs NH	Option Value	
							(\$)	(%)
1988	3.61	4.16	4.12	4.58	\$138,205	\$157,680	\$19,475	14%
1989	3.61	4.16	4.28	4.74	\$138,205	\$164,224	\$26,019	19%
1990	3.61	4.16	4.61	5.11	\$138,205	\$181,093	\$42,888	31%
1991	3.61	4.16	4.88	5.30	\$138,205	\$171,745	\$33,540	24%
1992	3.61	4.16	5.27	6.15	\$138,205	\$261,213	\$123,008	89%
1993	3.61	4.16	5.50	7.41	\$138,205	\$406,130	\$267,925	194%
1994	3.61	4.16	5.34	10.47	\$138,205	\$711,425	\$573,220	415%
1995	3.61	4.16	5.97	11.68	\$138,205	\$790,908	\$652,703	472%
1996	3.61	4.16	7.51	13.33	\$138,205	\$859,382	\$721,177	522%

Table 1B: Ex-Post Willingness to Pay for Option Value of AZT: Aggregate Values

Year	AIDS Incidence	INDIVIDUAL VALUE (\$)		AGGREGATE VALUE (\$, BILLIONS)	
		A vs N	Option Value (\$)	A vs N (\$B)	Option Value (\$B)
1988	29,134	\$138,205	\$19,475	\$4.03	\$0.57
1989	36,146	\$138,205	\$26,019	\$5.00	\$0.94
1990	43,541	\$138,205	\$42,888	\$6.02	\$1.87
1991	49,629	\$138,205	\$33,540	\$6.86	\$1.66
1992	60,638	\$138,205	\$123,008	\$8.38	\$7.46

¹⁵ This value corresponds to an annual monetary income of \$50,000, assuming 16 hours a day are available for leisure and work.

1993	79,754	\$138,205	\$267,925	\$11.02	\$21.37
1994	79,965	\$138,205	\$573,220	\$11.05	\$45.84
1995	73,569	\$138,205	\$652,703	\$10.17	\$48.02
1996	70,056	\$138,205	\$721,177	\$9.68	\$50.52
Total	522,432			\$72.20	\$178.25

The table reveals several basic patterns. First, the ex-post option value increases the closer the year of infection comes to the year of the break through therapy HAART as the larger is the chance that taking the marginal treatment makes a difference. Second, the impact of life-expectancy is fairly large in percentage terms, with the largest gain for the last cohort of close to 10 years from taking AZT and then HAART compared to no treatment and close to 6 years compared to no treatment followed by HAART. These large survival gains translate into similar gains in relative terms for the willingness to pay for AZT; for the last cohort the option value is five times as large as the standard value of AZT. Third, the aggregate value grows rapidly approaching the break-through year 1996 because both per-capita values and the incidence of the disease grows approaching that year.

Section 9: Concluding Remarks

In face of the skepticism the high spending on medical care at the end of life often encounters from payers and policy makers, few explanations have been offered of its benefits and why it persists and is rising. We analyzed the incentives giving rise to larger spending levels on terminal care than the existing theoretical and empirical analysis of the value of life. We stressed the low opportunity cost of spending near death, the importance of hope, the social value of a life, as well as why frail people may value life more than healthy ones. We found that incorporating the value of hope for future innovation in the case of HIV raised valuations up to five times above standard valuations of marginal treatments.

Our claim that the value of life may be higher near its end than traditionally thought of course needs more careful empirical examination in future research. There exist some existing estimates that suggest that the value of life near its end may be relatively high. Peter Neumann and colleagues (2006) have found that new oncology treatments at the end of life are valued at about \$300 thousand per life year, nearly three times the most commonly cited values of a life year of \$100 thousand. Moreover, the rapid uptake of new and expensive end-of-life treatments by patients suggests that they are highly valued. Goldman et al (2007) provides evidence on the elasticity of the demand for specialty drugs as a function of the co-pays of patients. They find that the demand for specialty drugs and end of life biologics is less elastic to co-pays than other drugs, partly explaining their relatively high prices as well as suggesting a high degree of gross consumer surplus consistent with a low elasticity of demand.

Although our aim was mainly positive, our analysis has important normative implications as well. In particular, it has strong implications for using traditional methods of so called cost-effectiveness, cost-utility, or cost-benefit criteria in adopting medical technology in private and public health plans¹⁶. CE analysis has been the major method proposed to evaluate new medical inventions and has been argued to be central in managing new technologies, their adoptions, and their impact on health care spending. Such valuation schemes are often in practice a *linear* valuation methods, which contrasts with our claim that there are important non-linearities in the valuation of life.

In addition, for purposes of insurance coverage, it is important to learn more about the elasticity of demand for terminal care in as much as it induces optimal benefit design. Moral hazard in the context of health care has focused on the tradeoff between incentives and risk in the use of medical services. On the one extreme, full insurance leads to over-consumption ex-post, because prices are below cost of production. On the other extreme, having the right incentives ex-post through cost-based pricing implies there is too much risk-bearing. Thus, as the argument goes, there is a tradeoff between risk-sharing and appropriate incentives in providing insurance that effects medical care use (Mark V, Pauly 1968; Richard Zeckhauser 1970;). This logic implies that if the estimates suggesting an inelastic demand for specialty drugs or biologics generalize to other forms of terminal care, terminal care should highly insured. The common argument that insured terminal care is wasted on people going to their grave may ignore that the demand for this type of care is very inelastic and hence should be insured.

¹⁶ The literature is vast, but for examples, see Weinstein and Stason (1977), Johanneson and Weinstein (1993), Gold et al. (1996), Meltzer (1997), Drummond et al. (1997), Garber and Phelps (1997), Garber (2000), and Cutler (2005).

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