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### The Value of Life: Explaining High Spending on End of Life Care

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## The Value of Life: Explaining High Spending on End of Life Care

### **Abstract**

This article examines literature published regarding insurance and end of life care and combines it into one, comprehensive overview of the state of unprecedented spending on healthcare, specifically, terminal care treatments. This focus allows for an examination of particular areas of causation of high medical spending at the end of life and provides some insight for solutions of how to curb this spending. The article also addresses the need to be mindful that these solutions do not compromise quality or equity of care to patients.

### **Keywords**

medical care, terminal care, end of life care, healthcare economics, insurance economics

### The Value of Life: Explaining High Spending on End of Life Care

The value of life is difficult to put a price on. Similarly, determining the extent of care to provide to sustain any given individual's life is an equally objective process. Whereas some would argue saving the life of a child warrants more resources than saving the life of a ninety year old, it is impossible to make this claim with any sort of hard evidence. When it comes to making decisions regarding resource allocation for end of life care, there are many people involved, all with conflicting missions and end goals. Insurance providers, doctors, nurses, the patient's family, and the person who is terminally ill all participate in deciding what care to provide or withhold. Though there are no definitive answers about which of the participants is best fit to make final decisions about care allocation, all can play a role in managing end of life care spending as part of the health care budget. Spending on end of life care is extremely high, but understanding the issues and causes can aid in devising a feasible solution to curb costs that does not compromise the quality of care.

In order to understand how to value life one must first understand the aspects of life that are considered valuable. In other words, what is really being said when someone states he or she values being alive? Speaking from a strictly biological level, "Life can be seen as the process of functioning and/or as existence with the tendency to function" (Watt, 2015). All the systems of the body, from the circulatory to the digestive to the pulmonary, work together to allow for life. Because people value when all of these systems are operating efficiently—or healthily—people value health and thus value life. On a more social level, life can be valued relatively; it can hold intrinsic value or be compared with the value of other lives or goods (Menzel, 1990). Though this aspect is more difficult to measure than functionality of systems, it is nevertheless important to consider. This relative value of life is often where a dollar amount is used as a measuring tool, but the accuracy is easily questionable.

Also inherent in valuing life is a respect for it. This idea becomes complicated when connected to issues such as abortion and the right to die movement. Ignoring all partisan arguments surrounding these two controversial topics, the serious question of how to maintain a respect for life even in cases where it is purposely, willfully ended is a serious one. The idea that allowing physician-assisted suicide may lead to euthanasia is not unfounded: "Much as we should sympathise [sic] with the family in their plight, to treat the very existence of their relative as a 'problem' for which death is seriously offered as a 'solution' is surely not an acceptable approach on the part of health care personnel" (Watt). In order to maintain a respect for life when coupled with the right to die, the main distinction that needs to be made is that the right to choose either cannot be assessed on the same plane. Whereas life is given, presumably for and by an unknown cause, "death does not share the same inherent value. . . There must be another layer of moral

reasoning, one that asks: *Should* this person's life be ending? (Bruenig, 2015). In recognizing life holds value that is different from death, another layer of worth is added to the definition.

With all these complicated and conflicting views, how can end of life care that is both cost effective and aligned with ethical values be provided? The easiest place to begin to answer this question is at the roots of health care. The three-legged medical stool is often cited when referring to the main goals of health care. Focusing on cost, health, and care, achieving these aims is “. . . an exercise in balance. . . The most important of all such constraints. . . should be in the promise of equity” (Berwick, et al. 2008). With the resources currently devoted to end of life care out shadowing other areas of medical spending, this equity may possibly be achieved, but it comes at the expense of cost. Insurance does a great deal to distort the cost to the consumer, adding to the problem of controlling spending. Though the goal is equity, Mark Pauly made the point early on in healthcare economics that “some uncertain medical care expenses will not and should not be insured in an optimal situation.” Though he doesn't give any definitive answers in his short commentary on Kenneth Arrow's original article, non-beneficial care, or care that would provide a small benefit relative to its cost, should warrant an out-of-pocket expense rather than an insurance claim.

The idea that some people should not have access to care is not well taken in America despite agreements that costs must be reduced. Understandably, doctors are wary to enact any sort of rationing, even when they feel it would be best for the patient to forgo a procedure. End of life care is particularly tricky because, “Although the interests of the patient are always primary, at the end of life there are times when the interests of the patient begin to wane, while those of the family intensify” (Truog, 2010). Though it may seem wrong from a cost standpoint alone, Truog explains some procedures that are non-beneficial to a patient are performed anyway for the peace of mind of the family. Doctors feel a real pressure to exhaust every option to provide the best care while also being conscious of the cost of doing so. This conflict of interest also plays into the high bills surrounding end of life care.

Despite difficulties to place a monetary value on a human life, something most commonly perceived as priceless, the need for a value is real. Traditionally, one year of human life has been valued anywhere from \$50,000 to \$100,000, meaning any treatment that cost more and did not supply at least one year of life would be considered non beneficial and therefore should not be covered by insurance (Kingsbury 2008; Becker, et al. 2007). The basis for this number can differ, pulling from estimated wages, GDP per capita, and other monetary measurements. Many people argue this figure is too low, especially considering the rate of inflation for medical goods and services relative to other industries. A newer calculation, based on the cost of dialysis and its health outcomes attempts to take

inflation and changing technology into account: “. . . they arrived at \$129,000 as a more appropriate threshold for deciding coverage” (Kingsbury). Yet, there are still people who say a year should be worth more. Perhaps the most difficult aspect of any widely implemented standard is that every person and every case is different. One size does not fit all.

As stated previously, end of life care provides unique challenges to those wishing to curb spending and ration care. With these unique circumstances, some argue the cost per life year should actually be higher at end of life than any other point. With end of life care, it is understood that death is near, and any procedures done are for the sake of prolonging life, not curing disease. With that in mind, some argue the complimentary relationship between life and consumption would motivate people to completely exhaust their financial capacity in order to buy as much time as possible; “As consumption is worthless without life, all of it will be sacrificed to gain more life” (Becker, et al.). For this reason, some argue for the greater valuation of end of life care because the dollars used to purchase it are worthless if the patient dies.

The concept of diminishing marginal utility also has a role to play in the argument for allocating more dollars to end of life care. Becker, Murphy, and Philipson argue that the change in perception alters utility from additional life. When a terminally ill person has the prospect of additional years of life, those few years hold more utility than any number of years added to an otherwise healthy life, increasing the “. . . value of the remaining life at the lower survival” (Becker, et al.). Overall, this change in perception leads to a change in utility, which is not accounted for in blanket life-valuation calculations and may explain some of the high spending in this area of medical care.

Not only does living longer provide utility to the terminal patient, but the extension of their life also has a societal effect. Positive externalities result for family and friends from the additional time the patient is able to glean from various treatments. These externalities affect cost because if the family receives some benefit from the extension of life of their loved one, they are bound to be willing to pay a price for it: “If younger generations cannot tolerate old people dying without state of the art terminal care more than older generations care about public deficits, then optimal spending levels may be well beyond the average wealth of the dying person” (Becker, et al.). Considering that these “younger generations” are most likely the ones who will make health care decisions for older ones, the trend of spending more on end of life care may be partially explained with this notion as well.

As is apparent from the evidence provided so far, end of life care has a very inelastic demand curve. Who ends up paying is an important factor to addressing the high spending on terminal care. People demand high quality medical procedures that are often exorbitantly priced in regard to how much life they

provide, but an inelastic demand curve implies that end of life care should be insured at a higher rate: “if the estimates suggesting an inelastic demand for specialty drugs or biologics generalize to other forms of terminal care, terminal care should [be] highly insured” (Becker et al.). This raises questions regarding Pauly’s statement that some care should not be insured under any circumstances. It seems that terminal care is an area insurers need to gather more information on in order to determine optimal rates and co-pays.

Intrinsic in insurance is the idea of moral hazard, and it is a significant concern with terminal care. As mentioned above, if consumption is a compliment to life, then patients, and sometimes their families, will use all of their resources to provide care, even if it is considered non beneficial. With insurance “. . . the patient’s and other involved parties’ awareness of any relationship between cost and value is greatly altered when the patient is insured” (Menzel, 2011). Not only are terminally ill patients inclined to spend all of their own money, they will also use their insurance, often Medicare, to the fullest extent possible.

With all of the factors influencing and buoying spending on end of life care, what is being done to reduce cost in the face of high consumption? Rationing care is a solution many have proposed, but some of the issues with who should enforce the ration, as well as the ethics of refusing care, have caused this response to high spending to be diminished. Muriel Gillick, a practicing doctor in Boston, is in favor of this type of rationing and argues that it would be effective: “My experience suggests that most patients do respond to realistic discussions about their future, but the way to deal with the minority of patients who might want to try treatments that have a vanishingly small chance of working is simply not to offer such interventions.” Though it may be the most effective way to ration spending, many doctors do not share Gillick’s view and are uncomfortable denying care to their patients.

Most doctors’ problems with rationing goes back to the three pillars of medical care and ensuring equity throughout. It is indeed difficult for many to see how this can align with broader economic goals for the industry: “Efficiency will sooner or later call for restricting care that would benefit individual patients. This is ‘hard efficiency’: it is surely not just the elimination of waste, and it leaves the health economist at seemingly irreconcilable odds with clinicians and their oath” (Menzel, 1990). In order to help medical professionals with the task of rationing care, some groups are creating guidelines and new procedures to make the process slightly more scientific. The American College of Physicians is one of the leading groups to take on this task, “disseminating guidelines to help physicians refine screening procedures to prevent excessive testing and procedures” (Wexler, 2015). Even with added support from professional organizations, those in the medical field are still uncomfortable with undertaking the role of gatekeeper when it comes to determining how much care is too much.

Rationing on the doctor-patient level poses multiple conflicts of interest. Many doctors completed training that does not align with cost saving goals of today's market. Though education can be changed over time to include courses on rationing, the shift will be slow and ineffective in the immediate future. Despite Gillick's comfort level with withholding care to patients, she recognizes the problem it poses to her colleagues: "Since the focus throughout a physician's training is on prolonging life, with little attention to maximizing quality of life or to deciding when to stop, medical education will need to change." The main concern for medical professionals is that rationing will have an irreparable, "corrosive effect" on the patient-doctor relationship (Agrawal, 1998). The insatiable appetite for terminal care, coupled with doctors' unwillingness to ration to any measurable degree, will require other solutions to be examined in order to see effectual change in health care spending.

One outcome of the excessive spending that is challenging to categorize as "good" or "bad" is the spending on research and development. It is not difficult to see the link between a high demand for terminal care and increased development of technology. While having funds to allocate to research and development is important to maintain quality of care, "extensive and valuable ex-post usage of expensive terminal care technologies does not necessarily warrant more R&D to develop them. . . ex post social surplus does not determine the optimal amount of R&D ex-ante" (Becker et al.). In other words, excessive spending today on treatments that are not worth their cost may be pushing development of even more expensive treatments that are equally questionable in their cost analysis justification. Because more spending leads to more research and development, the cycle is perpetuated: "America is not paying all that much more for the medicine it formerly bought more cheaply; rather, it now has so much more medicine to buy" (Dworkin, 2000). Whether or not this will prove to be a positive or negative outcome is still being determined.

Perhaps one of the best ways to approach the problem of overspending on end of life care is to attempt to alleviate the gap between doctor and patient in the form of asymmetric information. With rationing, doctors would take on the role of gatekeeper, but with current insurance systems, there is the "implicit assumption that patients are gatekeepers in a good position to decide what care is necessary and worthwhile" (Baicker and Goldman, 2011). Rather than either playing this role, it would be best to have an open channel of communication and trust. Of course, no average person has the knowledge or experience of a doctor when it comes to health decisions, but providing a trustful and honest point of communication would allow for optimal health decisions to be made. Full disclosure, rather than sneaky rationing or greedy consumption, might help to subside high terminal care spending: "patient and physician at the initiation of their relationship should engage in a substantive discussion about a physician's values concerning their proper

balance between a patient's medical needs and the larger societal goals to contain health care costs and ensure affordable health insurance" (Agrawal). However, legislation to aid in these conversations was met with much hostility.

Comparative effectiveness research (CER) would provide detailed data regarding treatment options and results. Though privacy concerns, as well as apprehensions that unfavorable data would cause funding to be cut to certain treatments, are valid, putting data like this in the hands of doctors could help them "know in advance that patients who meet certain criteria stand to gain much more than other patients" despite prior research that may say otherwise (Ubel, 2009). While the data may show that a certain treatment is overall ineffective, CER could identify traits in patients where the procedure was effective and share that knowledge with doctors.

CER could be monumental not only in aiding doctors to help their patients choose a treatment that will be effective for the cost, but it could also close the gap of asymmetric information, which leads to a great deal of the overconsumption of medical services seen today. Research and development would also be positively impacted from a greater knowledge surrounding current technology: "Almost all new technologies these days are marginal in their benefit. To deprive our society of effective means of coping with them seems to me a disastrous 'reform' outcome" (Callahan, 2009). Overall the greatest benefit to making the research available would be to take a massive study and parse out individual results with the outcomes. As mentioned before, one size does not fit all; every case is different. Any chance to not "lump together the unlumpable" should be seized (Ubel).

When it comes to end of life care, the only detail known for certain is that spending in this area is extreme compared to other stages of life. While this may be acceptable or unacceptable given the unique circumstances of terminal care, understanding the possible causes and issues with this level of consumption is important to maintain a healthy economy and sustainable health care industry.

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