

Dying a “Good Death”

A critique of the biomedical technocracy and its role in end-of-life care in the United States

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Introduction:

Biomedicine has achieved a positive reputation for being a valiant warrior in the battle against death. Physicians spend their careers working towards sustaining life, while the community seeks solace in medicine's potential to delay or even halt death. Despite biomedicine's technological advancements, when death comes banging at the door, people seem to prefer a quieter way out. When surveyed regarding where people prefer to die in the face of terminal illness, a majority prefer dying at home¹. Sadly, biomedicine's determination to achieve the impossible tends to overshadow patient preference. Despite the low cost and patient-centered care that hospice provides, health care spending in the United States is disproportionately higher during the last 6 months of life. This is primarily due to the time and money spent providing aggressive end of life care in the ICU³. Are these statistics warranted? What changes must be made to match the goals of biomedicine to patient preference at the end of life?

This paper attempts to demonstrate how perceptions of death and dying in the United States are largely influenced by the powerful, technocratic institution of biomedicine. The drive to save lives at all costs oftentimes overrides care with compassion. This paper offers a critique of biomedicine as historically trending towards a certain pursuit of excellence which dehumanizes the patient experience and glorifies the medicalization of death. It is argued that such hegemonic influence of biomedicine over American society has interrupted the quality of the dying experience, has stifled patient-physician communication, and has resulted in tremendous economic burden largely contributing to our exorbitant healthcare spending. Finally, this paper offers suggestions to improve care at the end of life in an era of evolving healthcare policy. These suggestions include system-level changes to reimburse quality over quantity, improvement of medical training programs to encourage preparedness at the end of life, increased use of palliative care, and increased acceptance of shared-decision making. As a result,

a commitment to bring back the humanistic sentiments of social medicine to supplement experimental medicine will help to provide the gift of dying a “good death.”

The rise of biomedicine as a hegemonic, technocratic institution:

Over the course of history, biomedicine has achieved its authority in society by closely associating itself with science and technology. 19th century advancements in physiology and bacteriology were artfully intertwined with the current healing practices of the day. As a result, patient care improved and life expectancy increased, instilling a sense of societal trust in biomedicine⁵⁻⁶. As such, the clinician’s claim to biological experimentation in diagnosis and treatment of disease helped to transform medical practice from a trade into a profession. Linking the bench to the bedside also shifted explanatory models in medicine from a holistic approach to a more focused, molecular basis of health⁵. This mindset paved the way for a surge in biomedical research that focused on the development and integration of pharmaceutical therapeutics and diagnostic tools into biomedical practice⁵. Thus, the art of medicine was transformed into a technocratic institution where technology and medicine were one and the same, and the standard of care became defined by efficiency, accuracy, and perfection.

From the home to the hospital:

Prior to the advent of modern, life-saving treatments, patients died prematurely and at home. As a result, a physician’s work more closely resembled modern-day palliative care in which standard of practice was to provide comfort through pain management⁷. However, the advent of technology and sophisticated treatments made care at home logistically impossible. As a result, care shifted to be hospital-centric, and the process of dying became institutionalized⁸. Life expectancy rose with improved public health protocol, and the trust in biomedicine as a

technocratic institution climbed as well. Reduction in premature death became commonplace, but the sentiment that death was unnatural and required treatment, remained. Moreover, scientific advancements tremendously increased optimism in saving lives and shifted towards the normalization of life-saving technologies at the end of life. Americans saw the miracles of modern medicine and technology and grew not only to accept, but demand the use of state-of-the-art curative treatments and technologies. As Finkelstein notes, technology began to medicalize many aspects of health which indirectly “served to promulgate the view that medicine can perfect human life” (Finkelstein 1990: 13)⁶. The medicalization of natural phenomena also resulted in the over reliance and aggressive use of technology⁹. What eventually emerged from this paradigm shift, was a “death-denying society” that preferred intervention over conversation regarding care at the end of life⁹.

Despite the tremendous value of advanced technologies in providing state-of-the-art care for patients, the technocratic model indirectly espouses a profit-driven business model and rewards aggressive intervention which is oftentimes at odds with the desires of the patient¹⁰. The technocratic model also reinforces biomedicine’s power structure to provide space for hierarchical organization, aggressive intervention, focus on short term goals, and most importantly, seeing death as defeat¹⁰. In short, technological advancements have served as the stepping stool in biomedicine’s quest for excellence. Furthermore, the biomedical technocracy has distanced itself from the average person by formulating terminology and medical jargon that alienates the patient from the healing process.

The argument here is not, however, to overlook the benefits of scientific innovation. It is important to acknowledge the significant contributions that technology has provided in advancing medical practice. However, this paper argues that it is important to acknowledge the

scope of this advancement. History has largely applauded the advent of innovation in medicine. The conversation regarding the consequence of innovation is not as pervasive, and is therefore, the focus of this paper. Consequently, as we begin to unravel the impact of biomedicine as a technocratic institution, we also begin to understand how perceptions of death and dying are shaped.

Medicalization of Death:

Although death is as natural as birth, death and dying have become medicalized and are treated more like a diagnosis than like a fact of life. A natural and inevitable reality is now perceived to be something that can be procrastinated and averted at all costs. The consequences of the medicalization of death have changed over time. Prior to World War II, the medicalization of death had some utility due to the high incidence of communicable disease. However, this aggressive sentiment holds a different value in the present day, where chronic diseases are more prevalent and where medicalization of death leads to decreased patient autonomy and prolonged death¹¹.

Medicalization of death seems to have had an impact on the public's understanding of death and dying. One study found that 27% of American seniors believe that the possibility to cure any and all disease is possible with the right kind of medical technology. Only 11% of seniors in Germany shared the same trust and optimism in biomedicine¹¹. Acclimatization to the excessive use of technology in the United States may be contributing to these aggrandized expectations. For example, the United States tends to conduct more procedures such as angioplasties and catheterizations and invests in more high-tech machinery such as CTs and MRIs in comparison to most countries¹¹. Taken together, these data demonstrate the powerful

influence of biomedicine not only our choices and actions but also on our perceptions of the futility of technology in saving life and averting death.

The medicalization of death also has led to a redefinition of death. Although death is nuanced by biological and social factors, biomedicine tends to declare death in primarily scientific terms. For example, when asked at what point a patient is determined to be “dying,” a physician responded that it is the point at which no known medical intervention exists to improve the condition of the patient¹³. Although it would be unfair to presume that all physicians agree with such a definition, this response speaks to the general sentiment that is pervasive in current medical practice. Such an aversion to death causes for preoccupation with intervention until the very end, leaving no room for conversation. For example, excessive use of intervention has been documented to result in haphazard referrals to hospice care, oftentimes too late for the patient to reap the benefits of hospice care².

Additionally, the terminology used to define death and dying in biomedicine is revealing, particularly in cases of terminal illness. Declaration of death in the United States tends to be based on quantifiable terms and is scientifically-based. In terminally ill patients, terminology is generally based on the failure of vital organ systems, at which point removal from life support is discussed. Countries based in the Eastern philosophy, such as Japan, do not attempt to assign solely biologic criteria to declare the death of a patient¹⁰. The mind and body are seen as one, and the social aspects of death and dying are also addressed. For example, when the brain is no longer functional, Japanese rarely refer to patients as brain dead because they recognize that there are other components to the dying process as well. Biomedicine, on the other hand, tends to focus on quantifiable characteristics that can be monitored and manipulated with medical treatment. As such, language surrounding end of life care reaffirms biomedicine as a technocratic

institution that takes the natural phenomenon of death and makes technological intervention imperative to death's definition and understanding. This form of thinking may be important when making difficult decisions regarding removal of life-support, but makes for a very narrow-minded perspective with which to start conversation about the desires of the patient at the end of life.

Barriers to communication at the end of life:

Medicalization of death negatively influences patient care at many levels. It ultimately reaffirms the hegemonic nature of biomedicine and undermines the importance of patient-centered informed decision-making at the end of life. At the cultural level, unrealistic expectations of the efficacy of technology to keep people alive causes for fear of mortality. Moreover, seeing death as the enemy and biomedicine as the infallible savior makes honest and open discussion about death and dying quite difficult. Additionally, biomedicine's overemphasis on intervention at the end of life serves as an excuse to procrastinate meaningful conversations about a patient's needs and desires. As a result, patients and their families are often unprepared for the difficult decisions to be made in the final days, ultimately leaving the family confused during the difficult bereavement process. For example, one study showed that 90% of Americans are in favor of having conversations related to advanced care planning, but only 30% have actually taken part in such conversations with their loved ones¹⁴.

At the systems-level, the fee-for service reimbursement of physicians, profit-driven hospital business models, fear of malpractice suits, and lack of medical training in delivery end of life care are just a few of the deficiencies that impede patient-centered decision making¹⁵. Fee-for service reimbursement of physicians incentivizes physicians to value high patient volume over quality of service per patient. Consequently, the need to see more patients in a limited

amount of time leaves no room for conversation. It is quicker to intervene or run a diagnostic test as opposed to sitting down with a patient and having conversations about his or her needs and concerns.

Lack of medical training also hinders the patient-physician relationship. Physicians are oftentimes not trained to have conversations with patients that are nearing the end of life. As a result, physicians avoid initiating conversation, are not aware of the patients requests, and are often left dissatisfied with their failed attempt to help their patient¹⁶. Part of that fear, as discussed previously, is viewing death as the enemy¹⁵. The entire medical training process involves acculturation into a professional society whose job is to treat and to cure. In the face of impending death, physicians may feel defeated and incompetent when in reality, death is an inevitable phenomenon. A major consequence of lack of conversation can be miscommunication that results in prolonged death at the expense of the patient's wishes.

The economic burden of hegemonic biomedical technocracy:

Although many physicians enter medicine with an intrinsic desire to help others, our healthcare system works against this goal, incentivizing quantity over quality of care. As a result, not only is dissatisfaction with end of life care more likely, but costs also rise. Additionally, the fee-for-service method of reimbursement rewards physicians for aggressive treatment, not for having meaningful conversations with their patients. End of life care has comprised approximately 25% of total healthcare expenditures in the United States¹⁸.

This trend is especially evident for Medicare, a government assistance program that finances the care of a population who make up a bulk of the end of life care expenditure in our country. The consequence of poor health management at the end of life is reflected in the numbers. The cost of Medicare has increased by nearly one third between 2007 and 2012, from

\$432.8 billion to \$572.5 billion¹⁷. This trend is particularly alarming as the population of the United States is changing. In an era of aging baby boomers receiving Medicare benefits and an increased prevalence of chronic disease, the costs of healthcare are going to have an impact on our economy.

Although palliative care is not and should not be instituted primarily for the purposes of cost reduction, a secondary benefit is lower costs of care. In a literature review of studies evaluating the cost efficiency of palliative care programs, it was found that palliative programs are overall more economically sustainable and significantly reduce healthcare costs¹⁹. As noted previously, the Medicare population is on the rise. If our current spending at the end of life is not managed in some fashion, our entire healthcare system could be at jeopardy². Therefore, it is in the best interest of our entire nation to have a system in place that reduces unnecessary intervention and promotes a more humanistic and holistic approach to end of life care.

Are the tides turning?

In the past decade or so, trends towards fewer deaths in hospitals has been promising. Unfortunately, upon closer inspection, this decrease isn't as promising as once perceived. A study conducted by Dr. Joan Teno at Brown University showed that although the number of home and hospice deaths seems to be increasing, it was found that the rates of ICU use in the last month of life increased by 29% in 2009²¹.

A more recent analysis of the costs of care at the end of life among seven developed countries indicated that the US ranks lower than peer countries in number of death in the hospital

among cancer patients. However, the study also indicated that the U.S ranks as a country with some of the highest expenditures at the end of life as well as time spent in the ICU²².

Thankfully we are taking strides towards improving rates of hospice care. However, the switch from intervention to palliative care is being made in an untimely manner². One study showed that in 2009, only 29.4% of patients had a stay in hospice of 3 days, many of which where stays were preceded by ICU treatment²¹. Such a short duration is not sufficient time to reap benefits of hospice care. This study ultimately demonstrated that although it appears that we have increased palliative care in a hospice setting, we do not have definitive proof that the quality of life and needs of the patient are being met yet.

In summary current data indicates that biomedicine's hardwired drive towards innovation and intervention remains strong. However, a step in the right direction is a step forward nonetheless. We must recognize that fee-for service reimbursement system incentivizing more high cost treatments and consultations by specialists at the end of life, especially in the ICU. To improve end of life care, we must overhaul the policies that reward the wrong indicators for proper patient care.

Solutions:

I argue that a “less is more” approach to technological intervention, the promotion of patient autonomy, more culturally competent end of life medical training, and quality over quantity reimbursement, are effective approaches to reduce the influence of hegemonic biomedicine and to help individuals die a “good” death.

Physician reimbursement for quality over quantity is imperative in order to shift towards a “less is more approach” and to provide space for meaningful end of life conversations.

Unfortunately, not only has conversation surrounding death and dying been medicalized, but it is under strict political scrutiny as well. The Affordable Care Act (ACA) tried to incorporate incentives to remedy the lack of conversation. Under the ACA, Medicare would reimburse physicians for consulting patients on advanced directives, living wills, etc. However, politicization of the concept and the popularization of the idea that the government was sponsoring “death panels,” undermined these efforts². Although this fear is not unfounded, we must demonstrate that, by its very nature, the medicalization of death impinges patient-centered decision making. Managed-care systems that promote disease prevention, encourage integrated provider networks, and cap the total amount of reimbursement per patient regardless of treatment, may help to curb costs and ensure quality of care at all stages of life². I recognize that dramatic changes to our health system require an alignment of both cultural sentiments and political agenda. However, we must prove to legislatures that policies that incentivize end of life conversations both improves quality and cost of care.

Increasing patient autonomy is an integral way to improve quality at the end of life. Although the ACA has not incentivized the use of Advanced Care Planning to date, the efficacy of planning should not be undermined. The POLST or Physician Orders for Life-Sustaining Treatment, is a new approach to advanced care treatment and planning. It fosters communication between physician and patients who are seriously ill. The set of written document outlines the type of intervention patients are willing to undergo at the end of life. Interventions are described as being either “full treatment,” “limited interventional measures,” or “comfort measures”^{2,26}. In this way, patients are able to directly communicate desires about intervention, and biomedicine can reduce costs associated with expensive treatments that have no added value for the patient. Support for patient preference was demonstrated by a 2016 paper in JAMA indicating that

families of those who were not admitted to the ICU 30 days prior to death reported better end of life care ⁴. As such, supporting patient autonomy is not only theoretically appealing, but is also evidence-based.

Assisted suicide, although highly controversial, is another form of ensuring patient autonomy. Assisted suicide allows those with terminal illness and who feel extremely debilitated by their condition, to end life on their own terms. Assisted suicide is highly controversial in the United States and is only legal in a few states. Although assisted suicide may seem unethical, it is primarily used to start conversations about the end of life. Assisted suicide was first legalized in the Netherlands in 1984. Although initially considered taboo, it has become normalized into conversations related to palliative and hospice care. One might think that the legalization of assisted suicide would be abused. However, assisted death only accounts for a small percentage of total deaths in that country. For example, in 2001, only 1 in 10 deaths could be attributed to assisted suicide²³. Proponents of legalization of assisted suicide argue that it is an important option for end of life care and can be critical in spark discourse about goals and priorities at the end of life.

Changing our cultural understanding of death and implementing policies to restructure our healthcare system are daunting and long term tasks. The biomedical technocracy teaches physicians to be overly optimistic about the efficacy of technologies and sometimes leads to overly optimistic predictions about a patient's outcome. A more readily addressable solution is to teach physicians how to treat patients at the end of life. Physician's should be taught to listen to patients, and commit to shared-decision making involving both the patient and the family. Additionally, physicians should be realistic in their consultation, able to instill hope in the patient but not make outrageous promises that mask reality. Moreover, the physician should be able to

accept the uncertainty of prognoses and be able to convey the options available to the patient in understandable terms. The American Medical Association has developed a program to help physicians develop these skills in a program known as Education for Physicians on End-of-life Care (EPEC). Physicians are also trained in palliative care, ethical decision making²⁴. Leaders in biomedicine have recognized the need to improve end of life. The Institute of Medicine of the National Academies conducted a review of our current practices and offered solutions to understand how to improve “Dying in America.” The report outlines various deficiencies in our understanding of death and dying, and provides solutions for how to address issues at both the structural and individual patient level². As such, recognition by national entities and their collaboration with academic organizations to create a learning environment that promotes conversation regarding end of life care will allow for a new generation of physicians that appreciates the intricacies of treating patients at the end of life.

Conclusion:

Biomedicine has taken us far in improving the lives of patients. Technological and scientific innovation have given life to patients that may not have had such a chance several decades prior. Although it is important to recognize these achievements and celebrate the progress we have made, a critical understanding of how biomedicine’s evolution into a technocratic institution is imperative so that the social and humanistic sides of medicine are not overshadowed. End of life care requires requires providers to balance intervention with conversation. Most importantly, end of life care requires an understanding that death is natural and is experienced differently from patient to patient.

While statistics provide the facts, it is the anecdotes that provide the story behind the numbers. Dr. Atul Gawande, a prominent author in end of life literature, describes modern

medicine's oversight of the "art of death and dying." He describes a patient with terminal cancer for whom he provided intervention after intervention in attempts to "cure" her ailment. Dr. Gawande describes regretting the decisions made to intervene when the best choice should have been to "let go." In this same manner, we must learn to let go of the hegemonic grasps of the biomedical technocracy and evaluate our priorities in healthcare. We must be wary of our overreliance on technology, and devise policy solutions that reorient our economic incentives towards quality over quantity, and ensure that we are communicating with patients in a culturally and contextually cognizant manner. It is only after such acknowledgement that we will be able to move toward patient-centric, personalized medicine that values a patient's right to dying a "good death."

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