End-of-life care

Its founding purposes and values

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In the midst of divisive public debates, we frequently look to history and past epochs to gain guidance and understanding, to explore the genesis of our ideas and practices, and to critically compare them with alternatives.

— Ezekiel J Emanuel, MD, PhD¹

THE VALUE OF HISTORICAL IDEOLOGY

The article from which this idealistic quote was taken from was published in 1994; however, one can question whether it was ever a habit of human thinking in these past couple of centuries to extract guidance from historical occurrences. CS Lewis in his 1955 book *Surprised by Joy* denounced the problem of “chronological snobbery”, which he defined as “the uncritical acceptance of the intellectual climate of our own age and the assumption that whatever has gone out of date is on that count discredited.”² He cautioned of the danger of chronological snobbery in another book. The premise was that if human civilization were currently heading down the wrong path, it is imperative that we return to that ill-chosen junction and “restart” our history on the right path. However, if we ignore the timeline of the previous stages of our journey, we risk losing the opportunity to return and start over.³ Quoting now a member of our own profession, Eugene F Cordell, President of the Medical and Chirurgical Faculty of Maryland in 1904, he lamented in an address that “it [was] rare to find the subject [history of medicine] even mentioned in the curricula of the medical schools.”⁴ He then attributed this phenomenon to an unhealthy obsession with novelty, the unwillingness to make time for reflection, and the increasingly utilitarian and mechanical nature of human mentality.

An appreciation of historical ideology is crucial to a rigorous and unbiased study of that branch of geriatric medicine which is so ubiquitous and fiercely debated: end-of-life care. This is because end-of-life care is not only a medical science, but also a philosophy. It is a value-laden specialty with a complex past. Currently, there exist several approaches to end-of-life care, and in every case where a patient is enduring his or her last few days, these approaches seem to compete for primacy. Proponents of each argue for their case, but rarely do they appeal to the historical values behind the method. Yet it appears obvious that if we choose to use the term “end-of-life care”, we should at least explore the ideas and motivations of the predecessors from whom we inherited the term. This article will discuss 3 approaches to end-of-life care—palliative care, life-sustaining therapy, and euthanasia—and illustrate how attention to the historical evolution of their philosophies can enrich our

understanding of them. It is hoped that the reader will emerge with a deeper knowledge of the rationale behind each approach, as he or she explores their genesis and development.

PALLIATIVE CARE

Something can be learned about palliative care simply from studying its linguistic roots. The term palliative derives from the Latin verb *palliare*, meaning “to cover up” or “to conceal.”⁵ In the context of healthcare, that which is covered up is the pain and suffering associated with end of life. The first record of palliative care came from 4th-century Rome, where a Christian matron named Fabiola opened her home to pilgrims, the sick, and the destitute.^{6,7} She called her home a “hospice.” During the Middle Ages, it became a Christian tradition to take in the sick, poor, pilgrims, and crusaders. While none of these primitive hospices cared specifically for the dying, they do illustrate that the underlying principle of the earliest palliative care was charity.

During the 19th and 20th centuries, hospices specializing in end-of-life palliative care opened in France (1842), Dublin (1879), and London (1905). But it was not until 1967 that Dame Cicely Saunders established St Christopher’s Hospice in London, considered to be the first modern research and teaching hospice. It was founded on three principles: openness, mind together with heart, and freedom of the spirit. Saunders was trained first as a nurse, then later as a physician. In her early days she cared for a terminally ill cancer patient who endured a horrendous measure of suffering before his eventual death. Touched by their interaction, she came to realize the importance of symptom and pain control for the dying. At the same time, she saw an even higher need for the dying to come to terms with their mortality, a goal which requires both emotional and spiritual support.⁶

These historical revelations led to Saunders’ definition of “total pain,” a term familiar to many ears today. This was a new model of medical suffering which incorporated the biological, psychological, social, as well as spiritual natures of the patient. After completing her medical training, Saunders conducted an extensive amount of research on palliative care. Her research style consisted mostly of listening to patients and studying their narratives, by which she was able to pinpoint the individual needs of every patient as they lived out their final moments. Our capsule summary of Dame Cicely Saunders’ work shows that many concepts in modern palliative care that we take for granted today derive from her philosophy. No understanding of palliative care can be complete without a study of her life and motivation.⁶

LIFE-SUSTAINING THERAPY AND EUTHANASIA

The modern controversies surrounding life-sustaining therapy, such as artificial nutrition or hydration and cardiopulmonary resuscitation, are anything but “new.”⁸ Due to advancements in medical technologies and the management of chronic disease states as early as the 19th century and early 20th century, there resulted a shift in the culture of medicine from care to cure.⁹ Life-sustaining therapy allowed medicine to keep a patient alive indefinitely in the hopes of eventually finding a cure. However, in a desperate attempt at cure, palliation of pain and symptoms is often sacrificed, a concept recognized even in the 19th century. Simeon E Baldwin, in his 1899 Presidential Address to the American Social Science Association, recounted the tale of a patient, terminally ill with stomach cancer, who was sustained by injections of mutton broth. Her agony was so great that “her stomach refused to retain anything but a little water; and even that caused great pain.”¹⁰

On the other extreme of the end-of-life spectrum is euthanasia. Whereas life-sustaining therapy aims to maintain life indefinitely, euthanasia seeks to terminate life altogether in the face of suffering. Although some may see euthanasia as a recent issue, referring to its legalization in 2002 in the Netherlands, the ethics of euthanasia has actually been debated for at least several centuries.^{11,12} Familiar arguments for euthanasia include that it is a human right born of self-determination and that it brings an end to suffering which has otherwise no hope of alleviation. In fact, the Flemish Palliative Care Federation believes that “euthanasia may [...] be part of palliative care.”¹³ Indeed, the philosophy of euthanasia emphasizes pain relief and listening to patients’ individual needs, virtues seemingly in line with historical values of palliative care.

Notably, much of the continued resistance to euthanasia may also refer to historical sources. It has been questioned as early as 1936 whether euthanasia truly provides biopsychosociospiritual support, as it essentially puts the patient that is being “supported” out of existence.¹⁴ In the Netherlands, 33% of the patients who opt for euthanasia do so because of a repulsion of being dependent on others.¹⁵ However, this seems to defeat the entire underlying principle of the earliest palliative care, which is that people ought to help one another in the name of charity.¹

Therefore, modern arguments both for and against euthanasia may in fact be rooted in historical philosophy. Proponents advocate for pain relief and respecting patients’ personal needs, concepts established by Dame Cicely Saunders. Opponents question its true nature and whether it is really designed to support patients at the end of life for the sake of charity. However, it is noteworthy that most of those who support euthanasia do so with the intent of upholding those values that form the foundations of palliative care. As shown throughout history, the nature of end-of-life care evolved from an innate desire to help, not to ruthlessly eliminate.

CONCLUDING REMARKS

The purpose of this article is not to promote an opinion on which approach to end-of-life care is optimal. Rather, it is meant to briefly foster an appreciation of the historical purposes and values behind each approach. In a day and age where end-of-life care is in-

tensively debated, advocates of each option are eager to voice their own opinions based on the most current research and experience. However, they often forget that “no generation can bequeath to its successor what it has not got” (CS Lewis),¹⁶ which implies that our ideas and thinking are actually a product and accumulation of those that came before us. By studying the quality of their philosophy and arguments, we may come to a deeper understanding of both the rigour and fallibility of our own. This is imperative in the exploration of end-of-life care, a branch of medicine possessing hundreds of years of tradition and change.

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