

End of Life or Ending Life: The Difference Unspoken, is Crucial

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Abstract

“End of life” is typically a code for ending life, either by physician-assisted (or directed) termination or the withdrawal of hydration and nutrition. Here “end of life decision care” is critiqued not only for its imprecision—what does it mean, really? but because it permits ethicists and gerontologists to ignore the potential for care that can be provided those with chronic progressive conditions. Understanding the bias inherent in the phrase may result in different outcomes, and additional treatments, as cases cited by the author attempt to demonstrate.

Introduction

“End of life” is one of those terms many use but few define with any rigor. It is variously used to describe the entire disease course following a presumably terminal diagnosis (for example, Amyotrophic Lateral Sclerosis), the life course of one with a debilitating but not immediately fatal disease (stroke), and more strictly the last days, weeks, or months of a person with a progressive and necessarily terminal diagnosis. In some cases it is presented at the onset of a diagnosis for patients who may, in fact, live for years if appropriate treatment is provided [1].

“End of life” is often used to assert a context in which physician-assisted or directed termination are the principal “care” options to be considered [2]. Elsewhere, the truly voluminous, end-of-life literature focuses on whether and when it might be “ethically justifiable to forgo medical treatment,” including hydration and nutrition [3]. Applications of “end of life” appellations while clinical in their focus are often embraced by bioethicist, and occasionally theological [4].

Evocation of an “end of life” scenario most typically focuses not upon necessities of care but instead upon a patient’s right to forgo life prolonging or enhancing treatment while seeking active termination in the face of sooner or later futile medical conditions [5]. It was this supposed right of choice at the end of life that underlay the Canadian Supreme Court decision *Carter v. Canada* [6]. In that decision a constitutional right to physician-assisted termination was asserted for those facing a reasonably foreseeable and inevitable death from a chronic and irreversible condition. Not discussed, however, was the necessity for assuring a range of hospice, medical, homecare and social services to assure a choice to life with dignity rather than to simply die quickly and painlessly would be provided.

The issue of patient autonomy and “end of life” choices related to it are not age-based or age-related. For example: The age of persons seeking physician-assisted death from Jack Kevorkian ranged from 27 to 82 years among the first 85 deaths, with a mean age of 56.5 years [7]. Petitioners in most court cases arguing for physician-assisted termination in Canada and elsewhere have historically been under seventy years of age, and often far younger. None were in the terminal stage of a progressive disease.

Irrespective of age, “end of life” protocols are typically invoked whenever a person’s cognitive, physical, or sensory characteristics are permanently restricted. Almost without exception, the literature blames resulting care conundrums on modern medical science for enabling the survival of persons who otherwise earlier would have died “naturally” from a disease or injury. What results, in Callahan’s words, has been “the tyranny of survival” [8] as a costly and mixed blessing for modern society at large. In this vein, the patient’s choice to combat that tyranny, either through a refusal of life-prolonging treatment or the active solicitation of physician-assisted termination, becomes not merely understandable but a somehow heroic response to costly, one might say, “medically induced” longevity.

Emerging themes

Across the rather vast literature on “end of life care” (Google.com lists 11 million hits in .80 seconds), and “end of life decision making” (239 million hits in 0.63 seconds) several broad themes emerge. Among them is the assumption science has permitted us to unnaturally prolong lives of persons with chronic progressive conditions who sensibly will seek termination either through

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active interventions or a passive withdrawal of medications, nutrition or hydration.

In the focus on “end of life” questions about continuity and levels of care become, by default, about terminating life whether or not a person’s life is inevitably near its end point. Those who object to a request for termination or withdrawal of care in such cases are assumed to be either religious fanatics or possessors of an ethical and moral system out of sync with bioethical, civil, and judicial ethical frameworks.

In the next section of this paper several of the assumptions and suppositions by which “end of life” care is defined are discussed and critiqued. These then are considered briefly in the context of cases in which the author has been engaged.

Concepts

Autonomy

In theory, all agree that “None of us should feel that we have to die to have dignity, that we have to die to be relieved of pain, or that we should die to stop burdening our families or society [9].” Almost nowhere in this vast literature, however, do authors pay any more than occasional lip service to the potential of a life “with dignity” for those with chronically limiting and perhaps progressive but not yet terminal conditions. They therefore do not argue that as a predicate condition to ending life that hospice, palliative, psychological and social services be available for fragile patients. Without such resources, a patient’s ability to live a dignified life with limits is restricted and a premature death becomes the default response to a continued life lived with untreated pain, unnecessarily limited life quality, and a guilty sense of burden imposed on loved ones who are principal caregivers.

A focus on “end of life” scenarios, as now advanced, does not promote the resources necessary for a dignified supported life with chronic and limiting progressive conditions. For example: While 96 percent of Canadians are supportive of hospice care for patients with late and end stage conditions fewer than 30 percent of all Canadian patients have access to hospice care [10]. Those living in major cities are far more likely than those in rural areas to have access to hospice, or home-based hospice-like care. In 2015 there were 200 registered palliative care medical specialists in Canada, 0.28 percent of all Canadian physicians. By contrast, palliative specialists included 0.38 percent of all Australian physicians and 0.52% of all U. S. physicians [11]. Palliative physicians have as their priority the reduction of pain and discomfort and, where possible, the increased quality of life of those diagnosed with chronic and often progressive conditions.

Similarly deficient, in many Canadian communities, were resources required to assure the best possible quality of life for those living with limiting spinal (paraplegia, quadriplegias, etc.) or traumatic brain injuries as well as those with chronic progressive conditions (Amyotrophic Lateral Sclerosis, dementias, Multiple Sclerosis, Parkinson’s, etc.). Absent for many are the rehabilitative, psychological and social support resources that would enable persons with these conditions to live with dignity rather than die for it. In many such cases, end of life becomes the default category becomes the default category when options for supportive care are limited.

Authors advancing patient choice in areas of physician-assisted termination or withdrawal of medications in “end of life

decision making” assume patients are given a real choice. If the goal is autonomy then the choice offered by end-of-life authors to chronically ill patients is, in the main, false. The option of living with disease or disability as fully as possible rather than dying because of limited life quality is often unavailable, its lack rarely discussed [12]. To advance autonomy and choice, alternatives to physician-assisted or directed termination must first be clearly offered.

Advanced directives

While promoted as a cornerstone of patient autonomy and choice, advance directives, a major subset of the end-of-life literature, is similarly incomplete. The assumption is that persons in health can make informed decisions about the care they would choose in extremes. The problem is that these decisions are usually made in ignorance of the realities and the potentials of a life lived with chronic limits [13]. Physician/ethicist Barron H. Lerner describes this as a common conundrum in which “patients who have fiercely favored a particular course of action over a prolonged period suddenly change their minds--often at a time of crisis [14]”. What might have seemed, in health, unendurable and unacceptable becomes, in the reality of a lived experience, potentially enjoyable and fruitful.

Many with either post-traumatic injuries (paraplegia, quadriplegias) or chronic conditions report a good and sometimes better life quality than that previously enjoyed [15]. When asked, most report that with sufficient home support and medical care a different but at least equally meaningful life in their changed but still viable circumstances [16]. It was not what they expected or anticipated in health but, after a period of adjustment, one they appreciate and whose benefits they can articulate.

Fearful and reasoned choices

It is for this reason that so-called “disability” organizations like *Not Dead Yet* (previously cited) have opposed both physician-assisted or directed termination and the withdrawal of nutrition and hydration in most cases. Simply, people in health do not know what they might want and thus fear what they see as potentially limiting. Across the literature fear--for oneself and one’s potential carers--has been a driving force in constructing end-of-life scenarios urging patient termination. This was first evident in a retrospective analysis of the first 85 deaths attributed to Jack Kevorkian [7]. Few of those seeking his ministrations did so not because of the limits of a rapidly terminal, limiting condition but instead because of a fear that they might in the future be limited. Thus patient Number 33 was a woman whose cancer was well controlled and showed, on autopsy, no evidence of metastasis; Patient Case 62, the Canadian philanthropist Natverlal Thakor (Case number 62), had early onset, well-controlled Parkinson’s disease. He could have lived ably for many years but chose premature termination because he feared a “painful and ultimately miserable condition wherein I will be reduced to the indignities of childhood diapers, spoon-feeding, and semi-death”. More recently, the fear of incontinence was a stated motive of a plaintive in *Carter vs. Canada*, previously cited.

Clearly, in many such cases the situation is not “end-of-life” but ending life either because of a future state one fears or the inability to adjust to a new physicality that has emerged. In the former situation, the distress is psychological, the fear of an eventuality that many others

have accommodated. In the latter, it is usually about a condition that seems at first to be humiliating but can become, as it has for others, rapidly commonplace and commonsensical. As Harriet McBryde Johnson told a US Senators when testifying on proposed legislation: "Senator, if you need a urinary catheter inserted every time you need to go, say three to six times per day, that becomes a routine procedure -- for you [16]."

Were incontinence a rationale for ending of life arguments the range of persons who would be eligible includes not only thousands of patients with spinal cord injuries but the millions of women (and men) whose periodic urinary "leaks" have fueled the multi-million dollar in absorbent undergarments.

Well, some would say: "That's their right." But it seems a poor right when fear of the unknown and a sense of ignorance and pride create an end of life scenario for non-care ("just let me die") or physician-assisted termination. And, too, it is no right—and not a free choice—if the instruments of a full life are denied those with newly diagnosed cognitive, physical, or sensory limits. These would include, in a partial list, communication technologies, mobility aides, home support services, and support for family caregivers.

All this irrevocably muddies discussion of "end of life" scenarios and resulting medical interventions. What was once about treatment during the last days or at most weeks of a patient's life now is used to consider termination for existing conditions that would not otherwise be terminal.

Life Quality versus the Quality of Life [17]

The rejoinder typically is that patients live in the day and that what might be needed for their comfort is less important than the "quality of life" they experience and might refuse. This begs consideration of the means by which life quality can be changed through medical, psychological, or rehabilitative services. A recent case illustrates.

Walter (a pseudonym) is a sixty-two year old academic and scholar diagnosed five years ago with an aggressive prostate cancer. On medical leave from his college, the cancer had progressed to stage four metastases despite repeated chemotherapy and radiation treatment. He was "about two weeks from giving up," in his words, less because of the failure of treatment than because of concerns over the burden his care imposed on his wife and their family. Better for her and them, he said to me, if he just "...let it go." He was then offered a new drug targeting his particular form of the disease. The results were remarkable but the cost, \$120,000 a year, seemed prohibitive. He would not sell his house, beggaring his family, to buy a few more months or years.

In this case a combination of professional and provincial health plans eventually covered, at least for the short term, the annual cost of the drug. His "end of life" scenario resolved into one of continuing life with a chronic condition manageable with ongoing medical support. At last visit he informed me that he would have to return to teaching, at least part time, or lose the critical, added employer insurance coverage. Whether he will be sufficiently recovered to do this is at this writing, uncertain.

In this case the "end of life" scenario of a late stage cancer patient was changed through the provision of a new, expensive drug whose cost was born by private and provincial insurers. Had that not

been provided he would likely have "given up," refusing additional treatments and perhaps seeking medical termination? Fortunately he was employed in Canada and not the United States were at this writing more than 23 million Americans have no health insurance and millions more have employer-based coverage that would not support this level of continued treatment.

Physician support

Often the invocation of a stated desire to end life can be resolved through appropriate care. Too often, however, family and general physicians are untrained in cases where pain and chronic limits reduce unnecessarily the life quality of a patient. A recent case made this clear.

Carl, a contractor, asked me to speak to his wife Sophia (all names are pseudonyms) who was coming to pick him up. "She starts most days in bed, crying, saying, 'I want to die. I can't live like this.' Can you help?" When they arrived I invited Sophia into the office but she said it was too painful to get out of the car. In two sessions, the first conducted by telephone, I later learned she had suffered serious spinal injuries in a 1986 automobile accident resulting in some incontinence, modest limits to her mobility, but after several spinal surgeries, no long-term pain.

After a fall in 2016, however, she developed excruciating pain only partially controlled by prescription Opioids (Percocet) her family physician continually threatened to withdraw ("so I don't become an addict"). The pain was especially severe in the mornings when she couldn't get out of bed to get to the bathroom. A neurologist reviewing her case said her spine was "a mess" and that it was likely that either screws or plates implanted in 1986 procedures were causing her pain. He said there was nothing he could do for her and no further referrals were ordered.

Understandably, Sophia was discouraged and would have considered physician-assisted termination ("I wake up and say 'I can't live like this'" except for her love of her grandchildren and her husband's continued insistence on her continuance. We first reordered the time schedule for her use of pain-relief drugs to increase and target effectiveness. I then encouraged her to keep a "pain and symptom book" in which she would list daily when the worst pains occurred, when her medications were taken, and when her actions were most limited. In her next visit with her family physician she was to review the pain book, medication times, and then ask for advanced consultation at a specialized pain clinic (including a neurologist, palliative care specialists, and psychological counselors) for a more complete assessment. The name of several clinics was provided.

The daily record keeping gave her a sense of empowerment. It also encouraged her to take her medications in a manner calculated to better limit pain episodes. It helped her physician understand the patient's daily life quality and her use of pain medication. A referral was ordered for a full neurological and palliative assessment at a regional pain clinic. With the intermediate assistance ("I can do something for myself," she said), a better informed family physician, and the promise of potentially curative care, her life quality and perspective has improved greatly. At this writing, reports from the advanced assessment are currently pending but suicidal ideation has disappeared. Her suicidal sense that the life lived was unbearable and should be ended has diminished.

Surrogate choices

In a final case, I was consulted by a U.S. lawyer serving on a hospital ethics committee. A nurse complained that physicians had removed the respiratory support for an unconscious, seventy-two year old man who had suffered an anoxic brain injury five days earlier. The patient was terminated when his respiratory assistance was removed with the agreement of his surrogate who said the patient had signed advanced directives against a life supported by artificial means. This was done late on a Friday afternoon and brought to the ethics committee the following week.

But, the nurse said, the patients was improving, his neurological signs of activity increasing, and termination was premature. Recovery was still possible. Indeed, the physicians told members of the review committee that had they waited through the weekend the patient likely would have started breathing on his own. The physicians justified their action on the basis of patient autonomy based on an advanced directive and surrogate decision maker support.

In the case review I argued that a directive prohibiting maintenance by artificial means did not mean cessation of care during a period following a severe injury. Improving neurology, the likelihood in the short term of independent respiration and in the mid-term of at least partial cognition required continued treatment and support. I advised that the physicians be reported both to the local medical board and to the local district attorney. The case was presented informally to an assistant district attorney who concluded it was too “confusing” for a lay jury and would be unlikely to result in a conviction. The hospital ethics committee decided not to report the physicians to the local medical board.

In this and several other cases in which I have been engaged, an “end-of-life” designation was a mask for an “ending-life” scenario that in theory if not in reality reflected a patient’s prior wishes. It was unclear whether the patient surrogate understands his partner was improving or the degree to which additional time might have permitted both independent respiration and a return to consciousness. Nor was it clear the degree to which the surrogate’s acquiescence to ending life involved other issues (the cost of care, the need for home support). Simply, issues of the potential for continuing care and recovery were not considered by the ethics committee.

Discussion

“End of life” decision making is most typically a code for ending life. It assumes, erroneously, that all possible avenues for a continued if restricted life have been provided. Offered in the name of patient autonomy and choice, the choices offered therefore are not full and unrestricted. Rather the code phrase focuses only on one alternative, physician assisted or directed termination.

In 2016 I was engaged by a regional hospice to discuss “end of life” choices in the context of the Canadian Supreme Court’s decision in the Carter case, previously cited. Attending physicians served both in-hospice patients requiring end-stage palliative care and home patients with chronic and usually progressive diagnose (ALS, Dementia, Multiple Sclerosis, Parkinson’s disease, etc.). The session began with all staff members being asked what they thought of the idea of “end-of-life” care and of physician-assisted termination.

All defined “end-of-life” as a period only occurring at the inevitably terminal stage of a progressive disease to be measured, at most, in weeks. All described patients, mostly in home care, whose chronic conditions were well managed through a combination of home assistance, medical and social support services. That said, all described a patient under his or her care for whom effective palliation and treatment were difficult. All were equally adamant, however, that these were the exception and in all other cases patients in later stages could be cared for appropriately in hospice or at home with sufficient support.

Seminar participants all sought the means with which they might assure better care for the fragile across the time frame of a limiting condition, which might span years, and better facilities for treatment of late or end-stage patients. All worried that the expansion of “end of life” as a diagnostic conclusion for which termination or withdrawal of treatment might be reflexively offered violated the ethics of care they professed as well as the best interests of fragile patients. And it seemed clear, at the end of the discussion, that an embrace of “end of life” termination as a common provision would affect negatively the calls for financial and social support within the public health service.

Review

In this review the literature on “end of life” decision making is critiqued for its failure to balance the potentials of a perhaps restricted life with that of a life whose limits make its ending seem both rational and desirable. It has argued that a patient’s choice in complex cases is not “full” or “autonomous” when hospice, palliative, rehabilitative, and social sources are not made available. Paying lip service to patient choice, advocates of end-of-life decision making do not consider the means by which the fragile be aided to live a life enriched by a range of resources not available today to all or most Canadians.

In the cases presented, issues of both autonomy and the quality of physician care were raised. In Walter’s case, the issue of cost is first and foremost. A desire to not burden family carers was to be a rationale for ending life until support was provided. In Sophia’s case, the family physician was neither expert in chronic conditions nor knowledgeable about the palliative resources available to her patient. The result was pain and life limits resulting in suicidal ideation. In the final case, the assumption that an advanced directive was sufficient to remove ventilation assistance from a patient recovering from an anoxic brain injury was offered to demonstrate the limits of what seem to be simple directives insuring autonomy in “end of life” situations.

Conclusion

“End-of-life” is not a simple concept. It is often invoked simplistically, however, as the context in which physician assisted or directed termination is advanced. In some cases it is presented at the onset of a diagnosis for patients who may, in fact, live for years if appropriate treatment is provided [1]. If the role of medicine, and the goal of society, is to assure the life, liberty, and security of persons then the protocols for care, and the methods to achieve them, first must be provided before an end scenario can be enacted. “End-of-life” should refer only to the last days of a terminal condition for which nothing but palliative support is possible. And it should only be evoked in health care contexts when all necessary supportive necessities permitting a life with dignity despite restrictions is accorded to fragile persons diagnosed with chronic and limiting conditions.

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