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Nick Lyon

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## Protecting Patients' Autonomy: Supporting the "Right to Die"

By Nicholas Lyon

As medical techniques have increased in complexity, death can be delayed more and more, and the debate over euthanasia has become increasingly important. Patients with chronic ailments such as AIDS or cancer can now receive treatments that allow them to survive for far longer than what was possible even only a few decades ago. Through the use of modern genetic analysis tools, companies like 23andMe have allowed people of all ages to know what diseases and infirmities they are prone to long before the onset of symptoms. Despite these advancements however, society's definition of "survive" remains purely having the body's mechanical processes continue, and fails to incorporate the patient's suffering and quality of life into the discussion. Due to the intrinsically subjective nature of such complaints from a patient, the critical factor to be considered in the ethics of requests to die will be how the patient views their suffering and quality of life, not the observations of third parties. In this essay I will argue that if a patient makes a considered request to die rather than suffer prolonged physical or mental agony, then those who have the capability to do so should honor that request. I further argue that such an action is entirely morally justifiable. For the purposes of this essay I will use euthanasia to mean "directly or indirectly bringing about the death of another person for that person's sake," with passive euthanasia being synonymous with "letting die" and active euthanasia involving a direct action.<sup>1</sup>

When using the term 'suffer' most people understand what is meant, but when pressed can only present examples from their own lives with complete certainty. With respect to the loss of a loved one, for example, it is generally agreed that 'everyone mourns differently,' in that

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<sup>1</sup> Vaughn, L. (2013). *Bioethics: Principles, issues, and cases*. (2nd ed., pp. 594-609). New York: Oxford University Press.

some people may outwardly show no change but internally be dealing with the complex emotions such an event can bring up. It can be extremely challenging to guess exactly what anyone is feeling at a given time, and impossible to definitively ‘know’ even if the person attempts to relay his or her feelings to you. In addition, for the person suffering there is little difference between mental anguish and physical agony. To the sufferer, severe depression is just as real as a broken arm, despite the heavy societal emphasis placed upon physical suffering. Because pain can be physical or mental, or both, and to the sufferer the origin of that pain can be irrelevant, it is remiss not to consider prolonged mental anguish as an equally valid reason to ask for euthanasia as physical pain is.

The obvious fear here is that people with mental disorders that cause them to ‘feel’ emotions more (e.g. bipolar disorder, depression, etc.), and hormone-filled teenagers will, in a flight of dramatic passion, plead to be freed from the trauma and tragedies of life. It is tempting for outside observers to refuse such a request because we ‘know’ it gets better. As described earlier however, it is not possible for anyone to definitively know that, as the best such observers can truly do is compare the sufferer’s current situation to something that they lived through. This does not mean that these observers have any idea of the level of suffering another person can bear or that they have a right to force the victim to live through to the better days the patient may fail to see. As bioethicist John Lachs explains, “It would indeed be tragic if medicine were to leap to the aid of lovelorn teenagers whenever they feel life is too much to bear. But it is just as lamentable to stand idly by and watch unwanted lives fill up with unproductive pain.<sup>2</sup>” Such a premise is applicable to any demographic group suffering mental anguish. It is often more palatable to discuss physical suffering in regards to euthanasia as a treatment for persistent pain,

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<sup>2</sup> Lachs, J. (1994). When abstract moralizing runs amok. In L. Vaughn (Ed.), *Bioethics: Principles, issues, and cases* (2nd ed., pp. 630-634). New York: Oxford University Press.

so subsequent examples in this essay will revolve around the corporeal, but it should not be forgotten that mental and physical anguish are often interchangeable when viewed from the perspective of the sufferer.

There are many factors that are called into question when considering the validity of a request for euthanasia, and several of these fail to account for the goal of such an act: to end prolonged suffering. Typically the age of the patient is associated with the validity of a request for euthanasia because of a misinterpreted link between age and experience. This inequity only becomes clear in practice. In the abstract, one might well agree with bioethicist Lewis Vaughn that in the case of a terminal patient “if her pain is unbearable and untreatable, and she makes an autonomous request to die, then active euthanasia may be a blessing—and therefore within ethical bounds,” regardless of who “she” is in this case.<sup>3</sup> However, in practical examples, distinctions are made often based solely on age. Consider an 80-year-old person suffering from cancer who tells a doctor that his suffering is too great and asks for euthanasia to end the agony. If it were legal, such as in Oregon and Washington, the state would likely respect this request as legitimate, leaving aside the responsibility of the doctor for the moment. On the other hand, consider a child of 10 who contracted HIV in the womb and subsequently developed AIDS. If this person made the same request of a doctor, the state would likely argue that the killing of this child would be neither legal nor moral, regardless of the patient’s wealth of experience with suffering. This argument would likely be couched in an argument pertaining to the innocence of youth, coupled with an insistence that a child does not have the mental capacity to make such a choice. Assume then that the child’s request is denied, as the child grows, when would he be able to exercise the right to ask for an end to suffering through euthanasia? At 16 when the state trusts him behind the wheel of a potentially extremely dangerous machine? At 18 when he can vote or

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<sup>3</sup> Vaughn, L. (2013), pg. 601

21 when he can drink? These ages seem arbitrary (a distinction reflected by their international and state-level variances), and as the state delays for some pseudo-significant age the patient has no choice but to wait for his *illness* to do the moral thing and kill him, and by so doing, free him of his agony.

Because of the emotional nature of these kinds of questions, it is helpful to consider an analogous situation to more objectively address the issues at hand. Imagine a hunter walking in the forest who sees someone being mauled to death by a bear. The bear cannot be killed or driven away, and the hunter sees that he can shoot this person and save him the agony of being brutally killed. Regardless of what you think the moral course of action would be, it is clear that the demographic identity of the victim has no place in the hunter's decision. It would not further complicate the hunter's choice if the person being mauled to death were male or female, young or old, poor or rich, simply *because* they are being made to suffer terrible agony before they will assuredly die. Now imagine the victim sees the hunter and begs to be shot and therefore spared continued suffering. To stand by and do nothing at that point would certainly be morally wrong, and as Lachs points out, "In the end, our lives belong to no one but ourselves."<sup>4</sup> This statement again holds true without the caveat of 'unless you're a child,' and can be extended to medical applications. Even if the hunter in this situation was also a bear expert and *knew* the bear would leave without killing the victim, the pleas of the person being mauled to death would still supersede the objective knowledge of the hunter that the person would ultimately 'survive'.

The other issue this analogy raises, however, is the contentious point of whether or not medical professionals should be required to actively assist patients who wish to die. Opponents of euthanasia argue that, "medicine should limit its domain to promoting and preserving human health," and should not begin to enter into the relief of "suffering which stems from life itself,

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<sup>4</sup> Lachs, J. (1994).

not merely from a sick body.<sup>5</sup>” I would argue that medical institutions have never been purely about healing the injured and curing the sick; doctors work towards developing a positive ‘bedside manner’ and have for centuries sought to help their patients and the families of their patients emotionally cope with the news of disease or other tragedy. In this way, doctors have *always* been responsible for handling the suffering of their patients. True, this relief of suffering does not typically include helping the patient die to avoid further suffering, but if death is assured and suffering will be a constant until that time, a quick death seems to be the last resort that a doctor can provide for her patients to relieve their pain.

Also, as with many bioethical issues, intention matters. If euthanasia were allowed by society for the purpose of relieving the anguish of terminal patients, where death is only the end result rather than the goal, it does not follow that society would respect life any less (as is often insinuated by opponents of euthanasia). If a policy were instituted to control these decisions, extensive checks and balances within the system could control for such a distinction. The moral arguments here do not culminate in a suggestion of over-the-counter cyanide pills available at every chain grocery store. The issue of when it is, or is not, acceptable to pursue euthanasia as a viable choice for the end of suffering should *never* be taken lightly, and it seems unlikely that it will be even if the arguments and conclusions of this paper are accepted and drastically expanded. It is more likely that society would become more compassionate as the limitation of an individual’s mental or physical suffering became a higher priority than the brute preservation of the mechanical functions of the heart and brain.

Even when this argument is taken to an extreme, and a legalization of euthanasia with few limits is suggested, what actually happens in places that have legalized euthanasia flies in the

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<sup>5</sup> Callahan, D. (1992). When self-determination runs amok. In L. Vaughn (Ed.), *Bioethics: Principles, issues, and cases* (2nd ed., pp. 625-629). New York: Oxford University Press.

face of the fears of those who argue against euthanasia on principle. A definitive study conducted by Margaret Battin in 2007 in Oregon and the Netherlands on legalized euthanasia found “no evidence” that legalized doctor-assisted suicide lead to increased rates of abuse of the system, and furthermore that even “people with psychiatric illness—including depression and Alzheimer’s disease—are not likely to die in lopsided numbers.”<sup>6</sup> Opponents of euthanasia often argue that if doctors could assist their patients in dying they would begin to lose sight of the value of human life and perhaps even mete out death as they saw fit due to some narcissistic overestimation of their power. The Netherlands legalized euthanasia and has long been touted for the compassion of its doctors and the careful and considered way in which they approach all requests for euthanasia, and the data collected thus far do not tell a tale of brutality and abuse. In the abstract as well, if euthanasia is viewed as a relief of critical suffering and not the ending of someone’s life, then it is not likely to be ‘abused’ because of the compassion necessary to understand the patient’s motives in making such a decision.

Another issue raised is the relationship between a patient’s description of his own suffering and the course of action taken by a doctor. The gray area lies in the point at which a patient’s suffering merits death as a tool to relieve that suffering. Fortunately, “Physicians have developed considerable skill in relating subjective complaints to objective conditions,<sup>7</sup>” and this skill is as applicable to euthanasia as it is to any routine ailment common in hospitals today. In some cases doctors need not be involved in the actual act, as Lachs suggests, “Even limited access to deadly drugs, restricted to single doses for those who desire them and who are certified to be of sound mind and near the end of life, would keep physicians away from dealing in

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<sup>6</sup> Battin, M. (2007). Legal physician-assisted dying in oregon and the netherlands: evidence concerning the impact on patients in “vulnerable” groups. *Journal of Medical Ethics*.

<sup>7</sup> Lachs, 1994

death.<sup>8</sup>” This method would only be applicable to patients able to minister to their own needs, so patients physically or emotionally unable to take advantage of this option would still fall to the responsibility of medical professionals.

There are good reasons for medical professionals to have the responsibility for end-of-life decisions, and the best of these is also the most obvious: physicians already have an intimate and extensive knowledge of the most painless and most efficient ways to effectively euthanize patients in need of such a service. Oncologist Timothy Quill, faced with a patient’s desire to die instead of undergoing the trauma and pain of chemotherapy, said after his patient’s death, “Although I did not assist in her suicide directly, I helped indirectly to make it possible, successful, and relatively painless.<sup>9</sup>” It is important to remember that in this landmark case, Quill did not take this decision lightly and over the months that he and his patient talked about possible alternatives he became a close friend of both his patient and her family. When she did decide to take her life equipped with the knowledge from her doctor of how much of a certain drug she needed to take, she visited Quill and informed him and her family of her final decision before taking a dignified exit from life. This example provides implicit support for the idea that terminally ill patients have the right to request euthanasia *before* the onset of serious symptoms. This is only applicable to patients who will certainly die and will otherwise experience horrific agony due to their illness or the treatment of it before that time. For any terminal patients suffering such an illness, if a physician decides to take a moral stance against actively euthanizing them and opts instead to simply ‘allow them to die,’ that action is less moral than forcing a treatment upon this patient. As bioethicist James Rachels argues, “The process of being ‘allowed to die’ can be relatively slow and painful, whereas being given a lethal injection is

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<sup>8</sup> Lachs, 1994.

<sup>9</sup> Quill, T. E. (1991). Death and dignity: A case of individualized decision making. In L. Vaughn (Ed.), *Bioethics: Principles, issues, and cases* (2nd ed., pp. 610-613). New York: Oxford University Press.

quick and painless.<sup>10</sup> It seems clear that allowing a patient to suffer for even more than a moment longer than necessary is the mark of a physician who has become truly hardened to the value of a human life with inherent worth and dignity.

My personal motivation for writing so extensively on this topic out of all the heavily debated ethical issues in the world today is also the reason why legal decisions revolving around end-of-life issues are especially pertinent to me. My family has a long history with Alzheimer's disease and growing up I often heard stories of my great-grandparents battling with the onset of dementia and the loss of their most prized memories. My father was also recently diagnosed with Parkinson's disease, and my maternal grandfather died only a few years ago of advanced pancreatic cancer. A few decades ago, the worst I would be able to say about how these illnesses would be able to effect me personally would be that I could have a genetic proclivity towards these afflictions, but I would only know for sure if I would express those traits when symptoms began to appear in my late 50s or 60s. Due to the development of personal genetic tests offered by companies like 23andMe, I now have an intimate knowledge of all of the secrets that my genetics hold. For myself I have an elevated risk (meaning some of the known genetic markers were present) of Parkinson's, Alzheimer's, and both esophageal and stomach cancer—among other, less lethal—ailments.

To know all of this at 20 is something that no other generation has ever been able to do, and despite the several decades of life between now and when the symptoms of these diseases could set in, it certainly changes my outlook on life in general and certainly my views on discussions around euthanasia. With Alzheimer's and Parkinson's especially, because neither of these diseases actually kill their patients, I am forced to consider what I would (or potentially

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<sup>10</sup> Rachels, J. (1975). Active and passive euthanasia. In L. Vaughn (Ed.), *Bioethics: Principles, issues, and cases* (2nd ed., pp. 649-652). New York: Oxford University Press.

will) do when that decision becomes applicable. I don't know if I would choose to be euthanized, and I don't think I necessarily have to know this early on, but I do know that if someone close to me told me they intended to be euthanized I would have no choice but to respect their decision, even if my love for that person made such a decision almost unimaginably hard for me personally.

The issues surrounding euthanasia are by no means easily resolved, and though much of both this paper and arguments against euthanasia operate mainly in the abstract, each case of euthanasia is unique. A standardized system for euthanasia would have to reflect this complexity and would likely come into frequent debate if it were ever instituted. These potential logistical problems should not overly complicate the issue however, because it is well worth any time spent debating this question, and others like it, if people who endure constant suffering can have even a slim chance for the relief of their pain. Whether their pain is mental or physical, if euthanasia is the only option they see as an escape, then they should be permitted this reprieve regardless of the views of the society in which they live. These requests should not be taken lightly, and in some ways the debate around euthanasia ensures that they never will be, which is undoubtedly for the best. I strongly believe that people continuing to have these discussions—in both formal and informal settings—can only help make policies better at ending purposeless suffering, and that gives me great hope for my future decision. Patients asking to die is never easy, but the cleanest principle I have been able to articulate thus far for medical institutions to follow in these cases is this: do everything possible to make sure that patients are kept *able to live* rather than simply alive, and when they are ready to die, help them to make that action as painless as possible.

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