Palliative Care and Patient Autonomy: Moving Beyond Prohibitions Against Hastening Death

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ABSTRACT: The National Hospice and Palliative Care Organization (NHPCO) upholds policies prohibiting practices that deliberately hasten death. We find these policies overly restrictive and unreasonable. We argue that under specified circumstances it is both reasonable and morally sound to allow for treatments that may deliberately hasten death; these treatments should be part of the NHPCO guidelines. Broadening such policies would be more consistent with the gold standard of bioethical principles, ie, respecting the autonomy of competent adults.

KEYWORDS: palliative care, end of life care, physician assisted suicide, continuous sedation until death

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Introduction

The National Hospice and Palliative Care Organization (NHPCO) upholds policies prohibiting practices that deliberately hasten death. We find these policies overly restrictive and unreasonable. We argue that under some circumstances, namely, those patients who have a terminal illness and whose life expectancy is less than six months, it is both reasonable and morally sound to allow for treatments that may deliberately hasten death; these treatments should be part of the NHPCO guidelines. Broadening such policies would be more consistent with the gold standard of bioethical principles, ie, respecting the autonomy of competent adults. In order to support this thesis, we provide an overview of current policies/practices of the NHPCO. We then show how these policies can be broadened to include three practices that would allow for hastening death, namely, voluntarily stopping eating and drinking (VSED), continuous sedation until death (CSD) upon request, and physician-assisted suicide (PAS). We will show how including VSED, CSD upon request, and PAS (where legal) as part of the official NHPCO guidelines will better serve the needs of dying patients by expanding options that are both morally sound and reasonable.

Current Practices of the NHPCO

Unwarranted prohibitions on hastening death. The policies and procedures outlined by the NHPCO are based on the principle that no healthcare worker will engage in an activity that deliberately hastens death (for more information on the NHPCO policies prohibiting practices that hasten death, see their position statement on physician-assisted suicide. Available at: http://www.nhpco.org/sites/default/files/public/PAS_Resolution_Commentary.pdf. Accessed August 22, 2016. Also see their position statement on palliative sedation therapies in Ref. 1). For patients who do not want to hasten their death, these policies are appropriate. Under that choice, hospice should attempt to provide maximal relief from symptoms combined with the highest achievable quality of life. The problem occurs for patients who no longer wish to live through their terminal illness. For these patients, the restrictions on practices that hasten death are likely to result in an undue burden. Rather than engage in treatments that will hasten their death such as PAS, CSD, or VSED, these patients may be forced to endure symptoms, suffering, and undesirable states of consciousness. Requests to hasten death to avoid such potentially difficult states are reasonable and morally sound for dying patients.[a]

Transparency of communication is lacking. Terminally ill patients who are receiving palliative care or who are already enrolled in hospice are provided information and policy statements that may be misleading. For instance, consider this statement from the NHPCO regarding its position on PAS:

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[a] Euthanasia also hastens death but requires that another person, usually a healthcare professional, deliver a lethal dose of medication with the intent of killing the patient in order to achieve relief from intolerable symptoms. Recognizing the moral and social policy difficulties that result from any form of state-sponsored killing, we concentrate on practices that center on the voluntary choices of competent adults. Assistance from healthcare providers would be indirect by either providing the means to hasten death through a lethal prescription as in PAS, or by providing comfort care during CSD or VSED.

> When symptoms or circumstances become intolerable to a patient, effective therapies are now available to assure relief from almost all forms of distress during the terminal phase of an iwithout llness purposefully hastening death as the means to that end.[2]

What the NHPCO leaves out is that in a significant number of cases, patients may experience refractory symptoms. For instance, Afsharimani et al[3] stated that 10%–20% of cancer patients experience refractory pain. Levine et al[4] used the figure of 5%–35% for the number of cases that result in refractory symptoms.[b]

Leaving out information of this type is unfair to dying patients because it downplays the distress a patient may face. The disclaimer used, "… to assure relief *from almost all forms of distress* …" (emphasis added) makes it sound like the inability to relieve distress is rare or insignificant. This is hardly the case. Patients can only make informed choices if they are provided reliable information about the chances that management of their symptoms may be unsuccessful. Furthermore, a statistic such as "5%–35%" involves a wide range. What does this mean? The lower end means that at least 1 in 20 patients would experience refractory symptoms, which is significant. The higher end would mean that more than one in three patients experience the kind of suffering that may be unacceptable. At the midpoint of the range, one in five patients experience unacceptable suffering.

Lack of precision also occurs in the NHPCO position statement on CSD. "Most symptoms can be managed with an excellent knowledge of physiology, pharmacology, and complementary therapies."[5] This statement is vague. What does *most* mean? In terms of logic, it would mean anything over 50%. In an everyday dictionary sense, it refers to the "highest degree of cases."[6] Given the dictionary meaning of the term, we expect that dying patients will infer the latter meaning and be inappropriately assured that their symptoms will be controlled since, after all, that occurs in most cases. But even by their own measurements (5%–35%), this is not the case.

Double effect and hastening death. The most common way healthcare providers insulate themselves from accusations that their actions directly and intentionally cause death is to invoke the principle of double effect. The basic argument distinguishes foreseeable but unintended consequences of one's actions from those that are both foreseeable and intended (for a more detailed examination of how double effect is used to justify the actions of healthcare providers, see Ref. 7). A healthcare professional who administers pain medication to a patient for the intended purpose of reducing pain with the foreseeable consequence that it will likely result in death can be justified morally and protected legally.[8,9] This is also consistent with the stance of the American Nurses Association (ANA). "Relieving pain, even if it hastens the death of a terminally ill person, is considered the ethical and moral obligation of the professional nurse; it is not euthanasia or assisted suicide. When consistent with the patient's wishes, the position of the ANA is: "Nurses should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient. The increasing titration of medication to achieve adequate symptom control, even at the expense of life, thus hastening death, is ethically justified."[2] Relief of pain, not death, is the objective of the intervention."[10] The ANA statement suggests that the primary goal is pain relief and that this may require medication that does suppress respiration, leading to a hastened death. While hastening death may be atypical (reproduced with permission of the author and the publisher, Mary Ann Liebert, Inc., see Ref. 11), this may be due to the measured approach to pain medication as called for by the World Health Organization (WHO).[12] There is no reliable way to determine the extent to which pain relief hastens death. As Susan Anderson Fohr states, "It would be difficult to design a definitive study to determine whether opioid analgesics (or other central nervous system [CNS]-depressant drugs) hasten death."[11]

The unintended hastening of death due to pain medication is to be distinguished from actions where the actual intention is to cause death, which is what occurs in voluntary active euthanasia (VAE) and PAS. Even if proponents of the NHPCO claim that the difficulties we are citing here can be adequately dealt with by invoking double effect, they miss an important aspect of our thesis, namely, that we are advocating for the justification of participating in actions that intentionally hasten death. So regardless of one's view of double effect, in our estimation, it does not go far enough to adequately deal with the needs of competent adult dying patients. Instead it masks the underlying fundamental issue at stake, ie, it is reasonable and morally sound for competent adult dying patients to request assistance from healthcare professionals in hastening their deaths.

Difficulties with proportionality. An inherent difficulty with the current state of palliative care and hospice involves the principle of proportionality.[13] This principle means that the minimum amount of medication will be used in order to achieve the desired effect of pain relief. This sounds like an effective way to deal with pain. However, in order to achieve proportionality in cases of severe pain, medication may be titrated, starting with a relatively low dose of one or more medications and gradually increasing the doses until pain is hopefully controlled. Achieving proportionality through titration risks discounting the intolerable suffering a patient may endure while various doses and types of medication are prescribed. In addition, it should be pointed out that the median hospice stay is around 18.7 days. A total of 34.5% stay less

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[b] It should be noted that Levine cites Quill et al. Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. *Ann Int Med*. 2000;132:408–414. Quill cites Coyle, Characters of terminal illness in the advanced cancer patient: pain and other symptoms during the last four weeks of life. *J Pain Symptom Manage*. 1990;5(2):83–93. The main point here is that a significant number of patients may experience intractable suffering, and this information is not clearly communicated to them.

than seven days.[14] This short time frame exacerbates the issues outlined here. Since the patient will likely die in less than three weeks while in hospice, and since medication cannot be given with the expressed intent to hasten death, dying patients in hospice care are at risk of having their last days spent attempting to determine the proper pain management protocol. This precludes dying hospice patients the opportunity to have their deaths hastened. In short, they are denied respect for and compliance with their reasonable and morally sound choices.

We offer an example from the study by Gallagher,[15] who pointed out that standard pain treatment should be pursued progressively until the optimum balance between pain and side effects is achieved, in effect until proportionality is reached. "Opioids need to be titrated up by percentages rather than fixed amounts. If pain is uncontrolled, the dose should be increased by about 25% of the total dose with each titration."[15] Gallagher[15] recounted the case of Karl, an 84-year-old man suffering from chronic pain due to osteoarthritis. A month after the titration process started, Karl's pain remained uncontrolled. At that point, a fentanyl patch was added. Over the following month, hydromorphone was added. Karl then complained not only of pain but also of confusion, muscle twitching, drowsiness, and inability to sleep at night.

A full titration process does not guarantee that pain will be controlled. After explaining that total pain involves physical causes and also anxiety, depression, and anger, the WHO offers a reason for the lack of universally effective pain relief: "Recognition of the complex nature of cancer pain makes it easier to understand why some patients continue to experience intolerable pain even when given increasing amounts of analgesic medication."[16]

The point we are making is that using titration to achieve proportionality can lead to an unacceptably long period of uncontrolled pain, and refractory suffering for some dying patients.

Lack of respect for autonomy. In position statements, the NHPCO downplays what may actually turn out to be the case.[17] They claim to uphold the value of respect for patient autonomy and dignity, but reject PAS. They refuse to engage in practices that intentionally hasten death, even at the request of a fully competent dying patient. For instance, in their closing statement regarding their refusal to support PAS they state, "NHPCO looks forward to participating in and guiding the ongoing dialogue and debate to continuously improve upon and promote comfort and dignity in life closure and affords the highest regard for patient choice and self-determination."[17] It is not consistent to promote comfort and dignity in the dying process and promote patient self-determination in "the highest regard", while simultaneously refusing to support PAS. The position statements should more accurately characterize the result of their policy decision. If they do not support PAS as a choice for dying patients then they should also not claim to have the highest regard for patient self-determination. Their regard for patient self-determination has significant limits. In the following section, we argue for expanding options for dying patients, offering a more genuine respect for patient self-determination.

Expanding Options for Dying Patients

We propose that the options for dying patients be expanded to include options that may hasten death, even intentionally. For guidance, we refer to Dr. Timothy Quill's list of six ways by which terminally ill patients can hasten their deaths:

- intensive pain and symptom management;
- withholding/withdrawing life-sustaining treatment;
- VSED;
- CSD;
- PAS; and
- VAE.[18]

The list moves from procedures that have been accepted as morally sound and reasonable to those that are questionable and on which there is no consensus. There is little debate among mainstream bioethicists over intensive pain and symptom management as well as withholding/withdrawing life-sustaining treatment. These are also supported by law in the United States (for more information on the legal right to refuse life-sustaining treatment, see Ref. 19). Because of this, we expect that patients are informed about these alternatives. There is also sufficient information regarding how these options are consistent with the general mission and policy statements of the NHPCO.[17] VAE is illegal everywhere except for Holland and Belgium (for information on euthanasia policies in the Netherlands, see Ref. 20; for information on euthanasia policies in the Belgium, see Ref. 21). We recognize the moral difficulties inherent in any VAE protocol and will not try to justify it here (see footnote a). This leaves VSED, CSD, and PAS. We argue that all three are morally sound and reasonable options for patients who have been diagnosed with a terminal illness.

To begin our justification, we clarify that we accept for the purposes of this paper the definition of "terminal illness" proposed by the NHPCO: "… a life expectancy of six months or less."[22] This definition is consistent with the Oregon Death with Dignity Act, which outlines the protocol for PAS.[23] Four of the five states in the United States where PAS is legal also use the six-month time frame.[24]

We turn to an examination of VSED, CSD, and PAS.

VSED. In an earlier article, we argued that VSED is not a medical option in the sense that it requires no medical expertise.[25] What would require medical expertise is assistance with pain management as patients begin to deny themselves nutrition and hydration. In an analogous way, terminally ill patients might engage in any number of activities that would hasten their deaths and could be assisted medically with pain management, for example, requesting a local anesthetic before cutting one's wrists. We assume that most acts of suicide would not be supported by such medical care. In effect, acts of suicide put the burden on dying patients, as does VSED. We consider the occurrence of VSED to be an unfortunate consequence for terminally ill patients. This burden is covered in detail by Schwarz in *Hospice Care for Patients who Choose to Hasten Death by VSED*.[26] Her troubling account focuses on the case of an 83-year-old E.M.[c] It is clear from the background provided that E.M. is competent and is ready to die. "E.M. told them [the healthcare team] that she had lived a good life, achieved all that she had hoped to accomplish, and was now ready to die-without fear or regret. She concluded that the burdens of living consistently outweighed the benefits."[27] We are told that E.M. found out about VSED serendipitously from other patients. It is unfortunate that dying patients may have to rely on word of mouth from people outside the healthcare profession.

After reviewing moral issues both in support of and against VSED, Schwarz concluded that VSED is consistent with NHPCO guidelines mission and values.

> After considering the prospective benefits and concerns about informing patients about this option, the [hospice ethics] committee concluded that, on balance, providing comprehensive information about VSED permits a patient to make an informed decision that reflects their personal values and wishes. The decision to stop eating and drinking was thought to be consistent with the ethical and legal right to forego unwanted life-prolonging measures.[28]

The means chosen here, VSED, is morally sound and reasonable, as Schwarz concluded. Some terminally ill patients may desire to hasten their deaths via VSED. Other means of hastening death are also reasonable and morally sound. We sense, though, that when used, VSED is mainly imposed on patients due to limited options. Patients such as E.M. may prefer PAS, but it is illegal in most places. We find this unfortunate. E.M. turns to VSED because she has no other options. We propose that an expanded set of options that include hastening death will increase the quality of care that dying patients receive and improve the overall caring for the terminally ill.

CSD. In an earlier article, we argued that it is reasonable and morally sound for terminally ill patients to request CSD at any time in their terminal illness. We support this by pointing out that the terminal condition is reason enough to request CSD.[29] We reject the reasons often offered that hastening death is immoral in such circumstances (common arguments used against hastening death are slippery slope concerns, sanctity of life views, and the role of healthcare practitioners, some view as precluding participation in intentionally hastening the death of patients. For more information on these arguments and how they can be addressed, see Ref. 29). Since PAS guidelines commonly use a life expectancy of less than six months for patients to be eligible to request PAS, we use the same guidelines for requesting CSD (for a detailed justification regarding requests for CSD, see Ref. 29).

PAS. We support legalizing PAS because it promotes respect for the autonomy and dignity of dying patients. We propose that it be expanded to the federal level and that it be included in regular conversations with terminally ill patients. The fact that it has grown from one state (Oregon) to five over the last 20 years[30] is a sign that the momentum will continue. More states will, in all likelihood, be developing some form of legally sanctioned PAS. This will in turn put pressure on those states that do not have such legislation as was ultimately the case with the abortion issue.[31] For now, we argue that PAS be included in options for dying patients where it is legal. Further, we contend that those patients desiring PAS but live in a state where it is still prohibited be given guidance on how to establish residence in states. The case of Brittany Maynard is an example of such a scenario. Ms. Maynard was diagnosed with terminal brain cancer on January 1, 2014. At that time, California had no PAS statutes. Since it was important to Maynard to die on her own terms and in what she considered to be a dignified way, she took the necessary steps to establish residency in Oregon. This was no easy task, as she attests:

> I met the criteria for death with dignity in Oregon, but establishing residency in the state to make use of the law required a monumental number of changes. I had to find new physicians, establish residency in Portland, search for a new home, obtain a new driver's license, change my voter registration, and enlist people to take care of our animals, and my husband, Dan, had to take a leave of absence from his job. The vast majority of families do not have the flexibility, resources, and time to make all these changes.[32]

Dying patients should be made aware of their options to establish residency in states that allow for PAS. That would maximize the autonomous choice of dying patients desiring PAS while the legislative approval process continues to move through the states. However, the obstacles to do so show the inherent unfairness of the current availability of PAS.

One may argue that we are unfairly projecting an increase in PAS when it is legal in only 5 of 50 states. We would like to point out that if there were inherent difficulties with the original PAS legislation enacted in Oregon in 1994, these would be obvious by now and no further states would have passed similar legislation. We see the opposite instead. PAS legislation in Oregon has been used since its inception in a reasonably sound manner with no indication of a slippery slope or abuse of the vulnerable in their society.[33] It also promotes a fundamental value of our culture, ie, respect for the autonomy of competent individuals. As a result, more states have come on board since 1994, and from this, we infer that the trend will continue. This is further reinforced by the recent Supreme Court decision of Canada, which allows for PAS in all Canadian Provinces.[34]

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[c] The patient has a life expectancy of less than one year. We grant that the argumentation we develop would not apply until E.M.'s life expectancy would be less than six months.

Further Justifications for Expanding Options for Terminally Ill Patients

The official guidelines of the NHPCO regarding terminally ill patients should include a list of options for hastening death. These options should include VSED, CSD, and PAS (or how a patient can relocate to a state where it is legal). There are significant advantages to offering these options to terminally patients. The first is that these are morally sound and reasonable options to pursue. This does not mean that it would be acceptable to all terminally patients and healthcare practitioners.

The second advantage is that these options do not preclude offering all of the other options currently in place for terminally ill patients. This is not a zero-sum game. Offering expanded options does not mean offering fewer options with respect to the current practices and procedures. Some patients may prefer to select options that are consistent with the current guidelines and practices of the NHPOC. Other patients may want to hasten their deaths and still be cared for in the process. We should not abandon patients who want to hasten their deaths. We make the following proposal with respect to expanding NHPOC guidelines for terminally ill patients.

- Keep in place all current guidelines concerning the mission of caring for dying patients through their illnesses and managing their symptoms.
- Inform patients of their options for hastening death, which include VSED, CSD, and PAS where legal or relocation is feasible.
- Expand PAS to all 50 states.
- Continue the prohibition on VAE.

Concluding Remarks

We have yet to reach consensus on the reasonableness of hastening death. Recent expansion of PAS legislation indicates that PAS will likely be legal in most if not all states in the foreseeable future. Some dying patients are already taking matters into their own hands by requesting PAS and, where not available, engaging in VSED. The desire on the part of dying patients to be more in control of their deaths is unlikely to diminish. If anything it will increase, especially as our population ages and the ability to maintain our physiological corpus continues to improve. NHPCO policies should be consistent with respecting the morally sound and reasonable wishes of dying patients, which may include hastening death.

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Conceived the concepts: SHLP and JPDM. Analyzed the data: SHLP and JPDM. Wrote the first draft of the manuscript: SHLP and JPDM. Contributed to the writing of the manuscript: SHLP and JPDM. Agree with manuscript results and conclusions: SHLP and JPDM. Jointly developed the structure and arguments for the paper: SHLP and JPDM. Made critical revisions and approved final version: SHLP and JPDM. All authors reviewed and approved of the final manuscript.

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