

# ISSA Proceedings 1998 - Arguing About Dying



## 1. Introduction

That each of us will die is a given, and thus there is no argument to be made about dying. But we do argue about some aspects of the dying process: how we die, whether we ought to or can have some control over the time and manner of our death, who (if anyone) should be allowed to help us die, even what counts as “help” – questions like these are being more openly debated than ever.

The most basic questions are thrust before us with increasing frequency, in the United States, thanks among other things to the repeated headlines generated by Dr. Jack Kevorkian (whose invention of a “suicide machine” several years ago helped “set the stage for a national debate on physician-assisted suicide” (Brunelli 1998: B3). Though he is an extreme example of someone who thinks matters of life and death are for individuals to decide, Jack Kevorkian has dramatically and undeniably done much to force the issue of a putative “right to die” onto the public agenda (Tye 1998: A1; Editorial 1998: A14).

On the other hand, although hospice care continues to receive largely very favorable press in the United States (“Hospices are Best . . .” 1998: A28), as recently as early in 1998, the *New York Times* had a major article entitled “As Life Ebbs, So Does Time To Elect Comforts of Hospice” (Stolberg 1998: A1), highlighting some of the ways that even dying patients who do (eventually) have access to hospice care may end up with precisely what they and their families were trying to avoid: a death burdened with procedures and machines, discomfort and distress of several kinds.

The issue I wish to consider here is this: To what extent do the hospice movement and the right-to-die movement – separately or together – adequately reflect values held to be central in contemporary United States society, and do these movements (again, separately or together) give appropriate room for physicians to exercise the compassion towards the dying that the dying desire? Since it is clearly impossible in the time available to explore all the ramifications of this matter, I wish to concentrate on one salient feature of the debate. I will focus on

the opposing views of two dominant movements, broadly defined: the Hospice movement (under which umbrella I include such institutions as the Center for Care of the Dying at George Washington University), and the Right-to-Die movement, to which I shall give the umbrella term “Hemlock” – borrowed from the classically allusive Hemlock Society (and exemplified by such organizations as Compassion in Dying and the Voluntary Euthanasia Society); my emphasis today will be on *the differences in the kinds of arguments* the two movements rely on to bolster their positions. By making those differences explicit – more specifically, by making the underlying claims (the hidden premises) explicit – I hope it will be possible to reduce the confusion and tension that arise for casual observers. The confusion stems largely from the fact that the two movements – though ostensibly concerned with the same issue – generally seem to be at loggerheads. Their respective approaches to the dying process appear incompatible; my aim is to see whether and how a passable bridge between the two can be built.

## 2. *Why Hospice vs. Hemlock?*

The object of my attention at times appears to be a moving target. Even the “Hospice Movement” is by no means a monolithic entity – though there is a “National Hospice Organization” in the United States that represents roughly 3000 hospices. As for “Hemlock,” I include under that heading not only the organization that calls itself the “Hemlock Society,” but also individuals and organizations that quite probably would not approve of the direct use of a killing potion like hemlock despite sharing a commitment best expressed by the idea that each of us has a “Right to Die.”

A brief word is perhaps in order about the very different origins of these two loosely knit groups. Hospice grew out of the very religiously based convictions of a particular individual – (now Dame) Cicely Saunders – who sought to improve care of the dying as a Christian duty. Saunders insisted from the outset that palliation of pain – but not release from pain by a drug-induced death – should be the end goal. Just as sympathetically, Saunders and others in the Hospice movement have repeatedly spoken out against therapies that chiefly have the effect of prolonging the dying process. Hemlock (as I am using the term), quite in contrast, grew out of a generalized societal interest in personal rights and autonomy.

When, why, and how these rather abstract concepts moved into public consciousness is itself a major topic, well beyond the scope of this paper. Briefly, I suggest that the sharp increase in what medical technology has made it possible

to do for patients at the end of life and the concomitant rush to what Daniel Callahan has called “technological brinkmanship” (Callahan 1993: 40-42 et passim) not only raised consciousness and concern about death and dying but suddenly made matters of autonomy and rights a critical personal issue for many individuals. Physicians and patients alike quickly saw that the right of a patient to refuse unwanted treatment had implications for the end of a patient’s life.

The result is the growth, essentially side by side, of a movement that emphasizes “caring” for dying patients when “curing” is no longer a feasible goal, and of a public sensitivity to the individual’s right to do what he or she wants with respect to death. “Hospice” and “Hemlock” – though concerned with the same issues – are “in very different places,” as current jargon would have it. The time has come to look more closely at what those places are.

### *3. The Heart of the Matter*

A prior step to analyzing the appropriateness of a position is identifying the key principles underlying that position. Only when we understand the tenets of the hospice approach to dying and of the more general right-to-die approach can we fairly assess, let alone compare and contrast, the conclusions drawn by adherents of each approach. For purposes of discussion, I have constructed two statements for each of the movements that I believe express basic tenets of the position maintained by supporters.

Since an essential feature of the point I want to make is that – despite the shared goal of making the dying process as little burdensome as possible – there are fundamental differences between the two approaches, I have expressed the tenets in blunt and direct language that highlights both the connections and the disconnections. Doing this will help draw attention to the differences – which are what need to be reconciled if a meeting ground between hospice and hemlock is to be found.

Let’s take a look at all four statements, without commentary. Hospice first:

#### A. Hospice and the End of Life: Basic Tenets

(1) Dying is a natural process that ought not to include being distracted by suffering, the fear of suffering, or loneliness; no one should have to die alone or in pain.

(2) Affirming life means doing nothing to prolong or delay the dying process; human dignity is maintained by living life fully to the end.

The Hemlock statements look like this:

## B. Hemlock and the End of Life: Basic Tenets

(1) Everyone has a right to make decisions about when and how to alleviate the pain that may accompany his/her own dying; no one should interfere with an individual's efforts to manage pain or seek help in managing it.

(2) An individual's life is his/her own - and only the individual in question can know when that life has reached its tolerable limits, when the maintenance of personal dignity requires making a choice in favor of one's own death.

As they stand, these four statements are mere assertions; a very generous interpretation indeed would be required to see even enthymatic arguments in the positions thus stated. Let us try, however, to turn these assertions into arguments.

The greater differences appear in the pair of tenets A (2) and B (2); each relies on a very different idea of what "dignity" means. In the remainder of my remarks, I shall confine my attention to the first of the tenets in each pair, A (1) and B (1), because they deal with what is basically the same issue - viz., pain. Nevertheless, closer analysis reveals that the two statements in this pair are by no means identical; the emphasis is certainly different.

For ease in reference, I shall use a kind of short-hand and call the assertions under discussion "Hospice (1)" and "Hemlock (1)."

Let's take a look at one way the argument might be sketched in these examples, bearing in mind that a similar exercise could - and needs to be - carried out as well for Hospice (2) and Hemlock (2).

Hospice (1), it will be recalled, looks like this:

Dying is a natural process that ought not to include being distracted by suffering, the fear of suffering, or loneliness; no one should have to die alone or in pain.

The premises required to turn that into an argument might look something like the following:

A. Dying alone or in pain is extremely unpleasant and therefore undesirable.

B. It is undignified (unworthy for human beings, etc.) to have to go through this kind of unpleasantness.

C. It is unnecessary to have to go through this kind of unpleasantness.

D. As members of a community (the community of human beings - implicit in the sweeping "No one should have to") we have a collective responsibility to spare each other from unpleasantness that is undignified (unworthy of our status as human beings) as much as possible; when the unpleasantness is unnecessary, the

burden of that collective responsibility is especially heavy.

Steps should be taken (to the extent possible) to reduce the pain that may accompany the natural process of dying, and to assure that those who are dying are not left alone.

Hemlock (1) was this:

Everyone has a right to make decisions about when and how to alleviate the pain that may accompany his/her own dying; no one should interfere with an individual's efforts to manage pain or seek help in managing it.

The argument for this tenet might look like this:

A. Knowledge of and experience in pain control are not the monopoly of the medical establishment (witness the successes of faith healing, alternative medicine, New Age holism, etc.).

B. The medical establishment in any case manifestly fails to manage pain adequately (numerous anecdotes testify to this fact).

C. Each individual knows his or her own pain limits (toleration level) better than anyone else.

Individuals should be free to decide for themselves when and what they need in the way of pain medication; the decision should not have to be filtered through anyone else (most especially not through the medical establishment).

Similar discrepancies exist between the premises - the kinds of arguments - that would surface were we to look behind the scenes at the second of the two assertions made on behalf of each movement; time does not permit taking that step here. But this one example should make clear the usefulness of having the arguments made explicit. That usefulness lies primarily in the way possibilities for rational discussion emerge. Agreement on what norms society should respect has so far proved elusive; with strong proponents defending the Hospice positions and others equally strongly defending "Hemlock," it is no wonder. What remains to be considered are two issues - whether unpacking the arguments in this manner can point us in the direction of a workable compromise and whether a better understanding of the arguments behind the positions would increase the likelihood of finding common ground (or at least reaching agreements on where limits should be set for individuals who are members of a community). I turn next to a brief exploration of these questions.

#### *4. Common Ground - and Disagreement*

Let us go back to examine more closely what appears to be the common ground on which these two movements stand. Because although both speak in favor of pain control, stressing the importance of palliative care, the premises leading to the conclusion that palliation is important are very different, as we have seen. The extent to which the similar conclusions that stem from these different premises settles the matter at hand - whether one can appropriately seek medical assistance in dying - also turns out to be distinctly different. And these discrepancies in turn shed light on the other, larger differences we know exist between the two movements - as, for example, in Hospice (2) and Hemlock (2).

Let's look at pain control, where the agreement seems strongest. Even here, the common ground turns muddy once pain has been successfully alleviated. For Hospice supporters, palliation - an important goal - is not an end in itself. Rather, it is (perhaps primarily) merely a means of making it possible for patients to live life fully until the end; for that to happen, it is taken as a given, it is imperative that patients die without the distraction of pain. For many within the Hospice movement, the period when life is ebbing but pain has been (largely) controlled is first and foremost a period for spiritual growth, for taking care of "unfinished business" with God and/or with family and friends.

For Hemlock supporters, palliation comes closer to being an end in itself; being as free from pain as one can reasonably be made to be is no more than what any rational individual would want for him- or herself. But there is another, far more important, issue for Hemlock supporters. Even when pain has been satisfactorily dealt with, it is not spiritual growth that is the main consideration, but rather the firm conviction that one has a right to dispose of one's own affairs - including making choices about ending one's life.

For some, making decisions of this sort may well be part of a spiritual journey, but it is a form of spiritual journey with which many adherents of the Hospice philosophy are uncomfortable. Hospice supporters seem far more certain that they know what the final journey should look like for everyone, though they certainly allow for great individual variations in the details. Hemlock supporters believe that no one can know for someone else what the end should entail, and that no one should have the right to impose on another his or her conception of what is appropriate.

Herein lies the central element of the disagreement. Hospice supporters see getting rid of pain as important, but as a step toward something else of even greater importance; Hemlock supporters see alleviation of pain as a good, but as one that is in the final analysis almost incidental to the real point: the autonomous

person's freedom of choice and right to self-determination. Thus, although Hemlock proponents would welcome - would applaud - the removal of pain, they will not be likely to change their minds about who should be making the end-of-life decisions. In other words, their position would be this: take away my pain (thank you very much), but I still want to make decisions about the end of my own life. Indeed, I have a right to do so. The crux of the matter is in the rights and autonomy of the dying - but it is only when the arguments have been spelled out in at least the degree of detail I have given here that the divergence in rationale becomes manifest.

### *Acknowledgments*

A longer version of this paper was presented in a public lecture at the University of Iceland in Reykjavík in March 1998; some of the still earlier thinking behind it was presented in a seminar at Middlesex University in England in November 1997. The author is grateful to the audiences at those two institutions for the stimulating discussions that followed, as well as to several individuals who made comments and asked probing questions. Particularly helpful were Richard Andrews, Vihljálmur Árnason, Hugo Adam Bedau, Jane Seymour, Howard Solomon, and Tony Walter.

### REFERENCES

- Brunelli, Mark A. (1998). "West Roxbury man is latest apparent Kevorkian suicide." *Boston Globe* (Mar. 7).
- Callahan, Daniel (1993). *The Troubled Dream of Life*. New York: Simon & Schuster.
- Editorial (1998). "Kevorkian's dangerous dominion." *Boston Globe* (Feb.28).
- "Hospices Are Best Hope in Caring for the Dying" [Letters to the Editor] (1998). *The New York Times* (Jan. 8).
- Stolberg, Sheryl Gay (1998). "As Life Ebbs, So Does Time To Elect Comforts of Hospice." *The New York Times* (Mar. 4).
- Tye, Larry (1998). "Focus shifts in assisted-suicide debate." *Boston Globe* (Feb. 9).