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Craig Luekens

Hastings Center Report, Volume 40, Number 1, January-February 2010,
pp. 4-5 (Article)

Published by The Hastings Center

DOI: <https://doi.org/10.1353/hcr.0.0223>

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An Unbearable Task

To the Editor: My awareness of the barriers in our current system and my support for the emergence of palliative and hospice care move me to respond to John Hardwig's essay, "Going to Meet Death: The Art of Dying in the Early Part of the Twenty-First Century" (July-Aug 2009). Hardwig seeks to counsel those who, in light of medical technology, are forced to grapple with a death that comes "too late." This counsel is laden with one distinctly modern assumption surrounding autonomy—that we determine life's meaning, and thus, its length—and one unfortunate conclusion for those "blessed" with this freedom—that we now must bear the burdens in a loveless and graceless world. Seeking to liberate his readers for autonomous action, Hardwig ironically destroys the reason for seeking autonomy and enslaves his readers in a hopeless mire of guilt at the end of their lives. In this, he does a disservice to the palliative care movement.

The stark individualism that decides for itself the meaning of life (and the time of its expiration) leads Hardwig to a justification of suicide, not in the face of unbearable pain and suffering, but in the proud self-determination of our own musings. Although Hardwig wants to limit this argument to those at the end of their lives, he provides no reason throughout his article why it *should* be so limited, provided we find ourselves in a "long stretch of perfectly lucid and pain-free though meaningless and purposeless days." In his fight for free choice and action, he provides an argument that, quite literally, collapses upon itself. Dostoevsky's Kirillov puts it this way in his book *The Devils*: "Man's been unhappy and impoverished up to now because he's been afraid to express the essence of his self-will; . . . For three years I've been seeking the attribute of my own divinity and now I've found it:

the attribute of my own divinity is—Self-Will! That's all I can do to demonstrate in the highest degree my independence and my terrifying new freedom. For it is very terrifying. I shall kill myself to show my independence and my terrifying new freedom." Life is a gift, so my autonomy is not fully actualized until I can take my own life. Hardwig's own defense of suicide ends with the same conclusion, albeit presented in a more placid and—perhaps for that reason—crueler form. He further asserts that if we can "make peace" with our decision, surely it is a right one: "In any case, *if one can truly make one's peace with it*, suicide can clearly give one a

"better," "more active," or "creative"?) actors.

Another irony of Hardwig's essay is that it seeks to liberate patients from "pathetically wrongheaded" and "pro-life" religious traditions only to reinstate a more burdensome moralism bereft of grace. A striking feature of his essay is the number of "shoulds" that appear amongst the burdens he places on the dying—suffering we *should* not encounter, obstacles our beliefs *should* overcome, facts with which we *should* be able to reconcile. Hardwig effectively refuses to place any burden on family or health care system—is there nothing to say to a family that seeks to move their

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much better death than most alternatives." Hardwig is able to justify suicide, but refuses to recognize the horror his argument demands. An irony of Hardwig's view of autonomy is that once the fight for autonomy ad infinitum has triumphed, it has merely won the right to kill itself, and to do so guiltlessly.

Moreover, Hardwig offers little to distinguish his defense of suicide from deciding when someone *else's* life has also exhausted its meaning. Indeed, Hardwig declares as much for one elderly man: "He is not supposed to stand—or lie in a nursing home bed—in the corner, trying to stay out of the way of the story developing around him but distorting the entire drama despite his best efforts." In other words, please exit the stage and make room for other (or,

loved one "off-stage," or to a nursing home environment that induces thoughts of suicide?—and instead adds to the burdens of the dying person. Rather than sympathizing with our dying fellow humans or seeking to identify with their struggles, we are called to convince them to die quicker.

In theological terms, this essay exemplifies one who seeks to ignore the all-too-real effects of sin (all we have to do is make peace with ourselves), and as a result loses any true ground for providing love and grace (you have to make peace *yourself*). In the Christian tradition, "sin" is actually a hopeful concept. It expresses our need for and dependence on the love of God, which alone redeems us. Without God, our freedom is "very terrifying," as Kirillov puts it. Hardwig hopes to liberate our con-

science and prepare us for the autonomous decisions we ought to make, but in doing so he assigns us an unbearable task and offers little consolation aside from that “we know what to expect.” By not taking sin seriously enough, Hardwig rids us of love.

Craig Luekens
Yale University

John Hardwig replies:

Craig Luekens mischaracterizes my view of our historical situation for a series of grand metaphysical claims and seems not to have understood that I am addressing the *art* of dying, not the ethics of dying or the ethics of supporting the dying. All of the “shoulds” in my paper are prudential, not moral oughts, and they are all intended for the one who is facing the end of life. These misreadings (or so I think) of my view lead Luekens to see my description of our current situation as an affirmation of completely autonomous, self-willing agents and to miss my call for greater community in dealing with our new kind of death.

In one sense, I do agree with Luekens’ characterization of our choices in the face of deaths that come too late as “terrifying.” Moreover, most of us are quite alone, our cultural unpreparedness exacerbated by our inability to talk with each other about the best responses to our new kind of death. Due to these facts of our present context, most of us will be forced back upon our own resources when we face the end of life. We must summon whatever personal resources we have to decide and then to act, usually in the absence of wise counsel and supporting institutions. I grant that there is a flavor of normlessness about our situation. Deaths that come too late are quite new and, as a result, we do not (yet) know how to do this.

We are then forced by our cultural context to be self-directing when facing decisions at the end of life. I do hold that autonomy, at least in the sense of some realized capacity to direct our own

lives, is valuable (as I’m sure Luekens does, as well). Partly because I do value autonomy, I do not offer directives for “when someone else’s life has also exhausted its meaning.” The elderly actor that incenses Luekens is primarily *me* and secondarily only those kindred spirits who find the analogy persuasive. I do not hold that autonomy is the only value, nor that it trumps all other values. And none of this implies any grand theory of the origin of values, much less a Kirillovian view that values must be self-willed. I am agnostic on this: I have no grand metaphysical theory about the ultimate source of values, nor do I feel any need for one.

Of course, we might wish for a different context. Most would prefer a cultural context that includes our current medical prowess but also greater wisdom about how our lives now end, and thus, clearer prudential and ethical norms for those facing the ends of our lives. We can argue about ways our cultural context should be modified. We might advocate for changes. Many of us would also like to see a cultural context that is more supportive, one in which suicide would be less frequently needed because health care professionals would not routinely prolong life. (Would someone please put me down when I no longer recognize my loved ones most of the time?) But I offered considerations about the art of dying in the cultural context in which I face the end of *my* life. For the younger among us, perhaps a better cultural context—and hence a very different art of dying—is a reasonable hope. Perhaps. The changes required are immense, disagreement about them goes deep (so deep as to nearly silence conversation), and life is short.

**Vulnerability:
A Contentious and
Fluid Term**

To the Editor: As governments and public health officials respond to

ON THE WEB

■ **Bioethics Forum**

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“Mammography and the Corporate Breast”

BY ADRIANE FUGH-BERMAN
AND ALICIA BELL

Fear-mongering from organizations with vested interests is preventing a public dialogue stressing that what we really need are better detection methods, especially for young women who have more time to develop radiation-induced cancers. Rather than touting an ineffective, possibly dangerous screening method, we need better diagnostic methods for younger women.

“The Silent Scream: Misdiagnosis in Disorders of Consciousness”

BY L. SYD M. JOHNSON

The diagnostic gold standard for disorders of consciousness is a bedside behavioral assessment, but accurate diagnosis can be confounded by numerous factors. Moreover, because some patients progress from one state of consciousness to another, repeated diagnostic assessment is necessary to detect subtle signs of recovery.

“Synthetic Biology Marketplace: Screening Out Terrorists”

BY STEPHEN M. MAURER

Ten years ago, synthetic biology was mostly a laboratory curiosity. Since then, however, biologists have shown that artificial DNA can be used to make dangerous viruses, and furthermore, it can now be purchased over the Internet from commercial “gene synthesis companies.” All of which raises the question: What, if anything, should these new companies do to make sure they do not inadvertently sell dangerous genes to terrorists?

Also: Nancy Berlinger explains the practice of “turfing” and why it was a factor in the Fort Hood massacre; Carol Levine continues a series of commentaries on the NFL’s position on head injury and its link to dementia; and Ross White looks for the “beef” in bioethics.