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Vulnerability: A Contentious and Fluid Term

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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.

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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.

H1N1, important ethical considerations remain unaddressed regarding the inclusion and recognition of persons and populations designated as “vulnerable” in pandemic planning and response. Therefore, we were pleased to see Anna C. Mastroianni highlight the importance of understanding how social context adds to the potential effectiveness of pandemic response (“Slipping Through the Net: Social Vulnerability in Pandemic Planning,” Sept-Oct 2009). Rather than relying on static, predetermined categories of vulnerability, Mastroianni proposes a robust evaluation of *social* vulnerabilities that may impact an individual’s or community’s capacity to respond to public health directives, thus drawing attention to the shifting and contextual nature of vulnerability.

The need for a more nuanced understanding of the interplay between social context and vulnerable populations in pandemic influenza response has emerged as a key preliminary finding from recent research undertaken by the Canadian Program of Research on Ethics in a Pandemic (CanPREP). These findings are taken from two data sources: a national telephone survey and focus groups held across Canada in 2008 and 2009. This research shows the label “vulnerable” to be contentious and fluid. Communities often described as vulnerable have the resources and capacities to take care of themselves in an emergency situation, if given the space and support to do so.

First, as Mastroianni articulates, “broadly defined categories of vulnerability tend both to exclude people who belong in them and include people who do not.” This sentiment was reflected in many of our focus groups, as participants explained that a variety of different conditions might make a person more vulnerable at a certain point during an influenza pandemic, and that the condition of vulnerability may change as circumstances evolve. One participant articulated the conditional or situational context of vulnerability by stating: “You

may look at me and think I’m vulnerable. I am the head of a family, I am the wage earner. I’m only vulnerable when you take away my personal support worker.”

Further, our findings to date suggest that the wholesale categorization of older persons and persons with disabilities as “vulnerable” is unhelpful. One participant explained: “I somewhat resent using the term ‘vulnerable’ for [older] people . . . Am I vulnerable? Well, some of my colleagues are much younger than I am, and are very vulnerable.” Another participant with a physical disability described his difficulty with the label “vulnerable,” given his significant personal responsibilities: “I have a dependent child, a nine-year-old, an aging mother. You know, we have some responsibilities and responsible jobs, too. I’m managing a program that funds seven hundred people across the province.” The contextual nature of vulnerability also sometimes makes those vulnerable who are normally deemed otherwise. For instance, health care workers were identified in our focus groups as potentially vulnerable in a pandemic due to the very nature of their profession.

Second, understanding the unique resources and capacities of communities helps us address the needs and gaps of community responses to an influenza pandemic. Mastroianni argues that community participation leads to greater effectiveness in responding to pandemics, as communities are more aware of their vulnerabilities and existing resources. Contrast this with simply allowing local health departments to set their own priorities independent of community participation. Focus group participants suggest that communities *want* to be involved. One noted: “I guess my key point at this point is to say, let us participate—we *must* participate—because we can contribute.” Furthermore, engaging communities will empower their members and thereby perhaps decrease their situational vul-

nerability, while also engendering a sense of trust with decision-makers. The need for community engagement was highlighted by another participant, who stated: “Let them be part of the planning, and they can be part of the delivery.”

As the H1N1 pandemic progresses, we must provide opportunities for moral deliberation and problem-solving among “vulnerable” persons to address the issues facing their communities. CanPREP is currently conducting further focus groups with vulnerable populations, whose oft-neglected views are necessary for thorough and ethical pandemic planning and response. Through these groups, we aim to form networks with our community partners to continue conducting publically relevant research and to best inform decision-makers on the views of the entire public, particularly those who are marginalized by social and political circumstance.

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