

pensable injuries from clinical trials would presumably range much more widely than vaccine-related injuries. Also, because payments to subjects would all come from a shared pool of money, this type of program would create no incentives for individual companies to minimize the risks of their own trials.

Pike argues persuasively for a modified version of the system used in much of the rest of the developed world, in which sponsors are required to buy insurance or agree to indemnify injured research subjects before the

research can proceed.² Such a system would be easier to harmonize with those in place in other countries and would create financial incentives for sponsors to minimize the risks of their trials. Most important, it would ensure that the ethical obligations of research sponsors to injured subjects would finally be satisfied.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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1. Stark L. *Behind closed doors: IRBs and the making of ethical research*. Chicago: University of Chicago Press, 2011.

2. Pike ER. Recovering from research: a no-fault proposal to compensate injured research participants. *Am J Law Med* 2012;38:7-62.

3. The Lewin Group. Task Order Proposal No. 2: care/compensation for injuries in clinical research. Draft of the final report prepared for the Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation. Falls Church, VA: The Lewin Group, May 18, 2005. (Contract no. HHS 100-03-0005.)

4. Moral science: protecting participants in human subjects research. Washington, DC: Presidential Commission for the Study of Bioethical Issues, December, 2011 (<http://www.bioethics.gov>).

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How Far Do You Go? Intensive Care in a Resource-Poor Setting

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A previously healthy 12-year-old girl arrives in our emergency department with labored breathing and right hemiplegia. Her mother tells us the girl has been unresponsive since the previous day — that though the mother washed her daughter's face and tried to make her drink some tea and juice to stimulate her, nothing changed. It took 36 hours for the family to find transportation to bring her down the mountains of Kenscoff to Port-au-Prince for help.

When the child reached the hospital, her respiratory drive was depressed; she was gurgling and completely unresponsive. We intubated, ventilated, and stabilized her. Over the next couple of days, we attempted unsuccessfully to wean her off the ventilator, despite the fact that she was awake and responding to commands. A CT scan of her brain revealed a large stage IV pontine glioma — a diagnosis that confers a poor prognosis even when therapy is

available.¹ It was clear that she was going to die.

I sat with the family in our intensive care unit (ICU) and, in Creole, explained the condition of their young daughter and beloved niece. The mother was despondent but submissive; her husband and brother did all the talking and asked all the questions. “Can we take her home?” they finally asked. “If she is going to die, we want to take her home.” Such a request is not unusual in Haitian culture. The challenge was going to be finding a way to get her home without her dying on the way.

When I began working as the chief medical officer at Hospital Bernard Mevs Project Medishare, I didn't realize that part of my job would involve palliative care, especially in an environment where the focus is on saving lives. Narcotics such as morphine and fentanyl are not freely available in Haiti, and effective palliation is essentially nonexistent, as it is in many resource-poor settings.²

Often, patients who are nearing the end of their lives are taken home to die; there, they often experience air hunger and pain. Since we have one of the few functioning ICUs in Haiti, we must view decisions about palliation through a lens quite different from the one that's taken for granted in the United States. In our ICU, we never see the cachectic 85-year-old grandfather or grandmother with metastatic cancer and a tracheostomy who is on dialysis and whose sons and daughters plead, “Do everything, Doctor.” Rather, our typical patient is the 16-year-old with abdominal tuberculosis and draining fistulas who is dying of starvation because there is no total parenteral nutrition. Or the 7-day-old full-term baby with complicated cardiac disease or severe meconium aspiration. Or the 20-year-old man or 14-year-old girl with severe head trauma from a motorcycle accident. Or the 30-year-old first-time mother with

peripartum cardiomyopathy who has a sudden cardiac event from which her heart hasn't the strength to recover. We can proudly say that in our hospital, premature death from sepsis, pulmonary edema, or stroke is not automatic just because one lives in Haiti. Here, the question becomes: How far do you go to extend life, especially in this environment?

In many ways, we are better equipped than U.S. physicians to serve as midwives through the dying process, as Timothy Quill has described it.³ In the Western world, decisions regarding palliative care are often driven by the availability of a plethora of resources that can prolong the agony of everyone involved — the physicians, the family, and most important, the patient. In Haiti, there are no nursing homes, facilities for long-term ventilation, or home hospice services. But our new capability for intensive care has allowed us, to some extent, to redefine “futility” and has brought a second chance to our patients; some will succumb, and some will overcome. We tell ourselves that those who overcome with our help were meant to do so — and, sadly, that those who do not were not. Each case, as in the developed world, merits its own unique decision, and we should neither give up prematurely despite limited resources nor be aggressive in the face of true medical futility if resources are accessible. Nevertheless, in

Haiti, “Do everything, Doctor” can mean only so much. The answer to the question “How far do you go?” is therefore much simpler: As far as you can with what you have.

Death in Haiti can be cruel, raw, and often devastatingly premature. There is often no explanation, no sympathy, and no peace, especially for the poor. Death's ubiquity, however, does not mean that it deserves any less attention or thought. We kept our young patient sedated with small doses of diazepam and morphine. We arranged transportation with our drivers for the 2-hour trek to the mountains of Kenscoff, a beautiful area of Haiti southeast of the capital city. We disconnected our patient from the ventilator and bagged her with oxygen all the way to the foot of her hometown's hills. Her family and friends lifted her out of the hospital's Land Cruiser and transferred her to a transport cot they had prepared for her.

“OK, let's go,” I said, with every intention of hiking with them to their home.

“Dok, ou pap kapab” (Doctor, you won't be able to) was the reply. The trail to her home was too difficult, they explained. They were obviously judging by my feet, which looked American despite my Haitian blood.

“So you want me to disconnect her here?” Everyone was silent. It was, appropriately, my decision. I asked my colleague and

good friend who had accompanied me on this expedition to hand me an alcohol wipe, and I began the process of removing the tape that held the endotracheal tube in place.

The universe was merciful that day; the child's pulse had already been progressively diminishing. I removed the tube, she took perhaps three agonal breaths, her pupils dilated, and she was gone.

Removing that endotracheal tube was one of the hardest things I have ever had to do. But the deep appreciation the child's family and friends expressed for our participation in her dying process somehow transcended the sadness. Although our resources were limited, they had been well allocated. Even in the face of death, the art of medicine lives on. Even in Haiti.

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1. Pollack IF. Multidisciplinary management of childhood brain tumors: a review of outcomes, recent advances, and challenges. *J Neurosurg Pediatr* 2011;8:135-48.
2. Lamas D, Rosenbaum L. Painful inequities — palliative care in developing countries. *N Engl J Med* 2012;366:199-201.
3. Quill T. *A midwife through the dying process: a story of healing and hard choices at the end of life*. Baltimore: Johns Hopkins University Press, 1996.

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