

## **Attending to the pain of the dying: an agenda for science<sup>1</sup>**

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The medical treatment of the dying is almost invisible today, an embarrassing situation that can only get worse as the rest of medical science succeeds in allowing a greater fraction of the population to live into old age with sufficient residual mental and physical capacity to understand their situation. For the sake of these lucky people — may we all be among them — medical science is obligated now to begin a research effort focused on making dying itself as brief, and as healthy, as possible. This is no joke: the hospice movement — not a product of scientific medicine but a reaction to it — has shown that a dying accompanied by a minimum of pain and a maximum of social interaction is healthier and better by far than the typical dying of today, accompanied as it so often is by prolonged agony and isolation.

For most of my life, and for all of my thirty years as an experimental scientist, I scrupulously avoided my own personal and professional responsibility to attend to the dying. It is not that I had no chances to make the connection between science and dying; I simply chose not to take them. In my own confusion, I lost sight of the fundamental truth that dying is as distant from death as any other stage in life is.

The deaths of my parents bracketed the period in which I came to see how a failure to acknowledge death properly distorts the practice of medical science. My father died of a respiratory infection acquired in the hospital a decade after he had lost his senses to Alzheimer's disease. During his last years I did not see him at all, and I did not understand that he was dying, for I already imagined him as dead. He lived for many years in a home for the demented, his body kept alive by strangers because his family — myself included — could not carry the burden of caring for him after he ceased to know who we — or anyone else — were. He was allowed to die at last, of pneumonia, because my parents had signed papers in advance, asking that their lives not be extended by heroic measures once they had crossed an irreversible threshold of pain or dementia.

My mother survived him, and in her last months, and even in her last days, she gave me and my family ample evidence of the difference between dying and being dead. She became stronger as she became weaker, became increasingly generous and wise with me and my relatives, and with a host of new and old friends, in ways that she could not while she was more fully alive. This stunning emergence of a kinder and wiser person from the dying body of my mother came to a halt only in her last few days, when the pain of her tumor began to require such high doses of morphine that she was unable to speak with any lucidity. Even then, she clearly accepted her death, said good-bye, and, with the help of hospice care at home, died peacefully.

Hospice care is still controversial at many major medical centers today, for its goal is not to provide good treatment for the dying but to provide a good death. At their best, hospices excel at delivering what they promise: control over pain, dignity to the end, and the assurance that no one need spend their last moments alone.

The current hospital response of science to the dying reflects my own attitudes during those decades I worked in my lab. It goes something like this: “You have had the misfortune to be born too soon to benefit from science's ever deeper comprehension of nature. That is too bad, but since we can know how everything works, certainly one day we will know how to keep a death like yours from happening. Until

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<sup>1</sup> This paper is based upon my book “The Missing moment: how the unconscious shapes the agendas of Science,” Houghton Mifflin, 1999. It was presented at the Symposium “Dignity of life at the end of life: Jewish medical, religious, legal and personal perspectives,” Columbia University, May 22, 2005.

then, you will understand if we do not spend much time on the relatively uninteresting matter of how it is to die.”

Today, medical scientists treat very old age, dying, and death with equally fastidious disdain, as if they were all somehow intrinsically uninteresting. If they are as frightened of death as everyone else, then their disdain for aging, death, and dying is a prophecy that keeps them from confronting their fears. A good deal of interesting science lies waiting to be done by scientists able to admit their fears of death and look beyond them to study dying on its own terms.

The questions to be asked are familiar: which parts are painful and may therefore be made better by the easing of pain; which parts are inherited through the genome and may therefore be made better by the manipulation of the genome or the addition or subtraction of a gene or a protein; which parts are conscious, and which are unconscious, so that we may better understand how it feels to be dying and learn how to alleviate the worst of those feelings. Those questions would form a minimal agenda for research on the dying stage of life.

Beginning with Elisabeth Kübler-Ross's 1970 classic, On Death and Dying, many serious studies of dying have been built around interviews with people in the last days of their lives. A doctor herself, Kübler-Ross broke many rules at her hospital by insisting that the dying be given a chance to describe their feelings directly; simply allowing the dying a voice was a major accomplishment. From their narratives, she produced an anatomy of the physical and emotional stages of dying: denial, anger, bargaining, depression, and acceptance. As she points out, all but the last of these five stages express a deeper and more fundamental denial, attitudes that allow one nevertheless to have some hope. Hope in the face of certain death may seem absurd, and perhaps it is, but nevertheless the dying showed her — and many studies since have confirmed — that a dying person does not lose hope until just before death.

A person's last days can be the most remarkable example of dying as an aspect of living: without hope, a dying person begins to pull away from the world, sleeping a lot, not seeing anyone, not interested in anyone. At best, and without pain, the end of life seems quite remarkably like the beginning, the clock of internal time run backward one last time, to the earliest days of infancy. Kübler-Ross counseled that hope should never be denied, that the dying should not be burdened with facts that would remove all hope before the person was ready to set it aside, and that the enemy of the dying is not unavoidable death so much as avoidable physical and mental pain. In the decades since Kübler-Ross's book came out, about a third of her readers have passed through her five stages and died. In all that time, precious little has been added to, or taken from, her five-stage formulation of dying, and almost nothing has been done in science to carry out any of her prescriptions.

There is, then, a realistic scientific agenda for the period from the moment when there is nothing that medical science can do to stop death from coming until the moment of death. It is to understand the mind and the body well enough to keep both as free of pain, and as free of isolation, as possible. Science can complement the work of a hospice by providing it with new tools to accomplish these ends.

Much dying today happens poorly, with unnecessary pain. It is time for medicine to acknowledge what torturers have always known: pain is a pathological state that mocks any pretense to health. To uncover the underlying mechanisms of pain, it is useful first to recall that no matter what part of the body is in pain, the hurt is, of course, in the head.

Pain is a brain state, and as such it ought to be as understandable, and treatable, as other unwanted brain states are turning out to be. The most effective painkillers we use today work only by dulling the senses, and all are highly addictive when taken by people whose lives are not almost at an end. Doctors who try to prescribe large enough doses of these compounds — morphine and its derivatives — are often suspected of inducing a dying patient's addictive craving.

This is a cruel joke to anyone who is dying with intractable pain and who may reasonably argue that one cannot be addicted when one is dead. A civilized medicine that fully accepted the reality of death

would also recognize that the pain itself is as damaging as any addictive state. There is another, equally ironic barrier to the straightforward study of the proper pharmacology for intractable pain: the fear that an overdose of morphine might be used intentionally to shorten the life of a dying person, with or without the person's consent. It is ironic because the most frequent reason for requesting an early death is precisely unbearable pain.

Beyond the tragedy of dying people having to hasten their death with the same compounds that might have given them a reason to live longer, the denial of proper painkillers damages a person's body. A person in pain suffers from a reduction in the efficiency of the immune system and usually cannot actively participate in any other courses of treatment. We need a major effort to find or synthesize — and then to distribute openly — a new generation of more effective painkillers. Such research would need strong government support, since the political problems of such research and development make these studies as uneconomical as vaccine production for today's pharmaceutical firms.

The “how” of mental life — the mechanisms of gene expression, protein synthesis, and cellular communication that work so well for a century in some brains but not well at all in others — are at the intersection of basic biomedical science and the right of a dying person to full membership in society until the last moment of life. It may take decades or longer to fully understand the molecular biology of mental life, but it is not too early to say with confidence that whatever the molecular mechanisms involved, people need the touch of other people's hands — those soft touches that let them know they are not alone — all their lives, to the very end. The cruelest of the paradoxical consequences of the denial of death in modern medicine is the insistence on treating a dying person in ways that destroy all chance of privacy and dignity, that deny the person the ancient right to the continued presence of friends and family.

The usual argument for leaving the dying person alone in a cold room with tubes and monitors blocking all human interaction, for allowing the rarest and sometimes the richest of words to go unheard or unsaid, is that this regimen is necessary to extend the person's life, albeit only for the shortest of times. But to extend external time by so little while removing all chance of the person's sharing any of the little internal time left with anyone else is surely another form of de facto torture, equal to withholding painkillers.