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DIGNITY

THE NEWSLETTER OF THE CENTER FOR BIOETHICS AND HUMAN DIGNITY

Christian perspectives on bioethical challenges such as end-of-life care, euthanasia, genetic and reproductive technologies, and the changing face of health care.

REFLECTIONS FROM THE DIRECTOR OF THE NATIONAL HUMAN GENOME RESEARCH INSTITUTE

Francis S. Collins, M.D., Ph.D. *(Bethesda, MD)*

The time is ripe for a serious discussion about the pathway that genetic science is leading us down. It is a pathway that I as a physician and as a Christian have a great deal of hope for because of its promise for alleviating human suffering – which is surely one of our strongest mandates. However, it is also a pathway which poses certain troubling risks. Such risks are real possibilities that we must attempt to address effectively. When we have done so, we can move this exciting field forward in a way that maximizes the benefits and minimizes the risks. In studying the genes that we carry, we are trying to learn the "parts list" for human biology. Historically and philosophically, this is profound. Our human biological instruction book allows us to do all the biological activities we carry out from the time that we are single-celled embryos until the end of our lives. It is an exciting notion that we now have this instruction book in front of us and are able to read it, even if we don't understand it very well.

To understand hereditary factors, we must understand the wonderful molecule called DNA, the double helical structure of which Watson and Crick figured out some forty-seven years ago. It is a very elegant system of encoding information. What a privilege it is for a physician-scientist to do research that uncovers something about our creation and gives us a glimpse into the elegant way God thinks! DNA is certainly a remarkable way of coding information in a very efficient, elegant and digital fashion, allowing us to carry around an enormous amount of information in a very modest space.

In each individual's genetic code, there are three billion base pairs, where each base can be either adenine (A), cytosine (C), guanine (G) or thymine (T). A always pairs with T and G always pairs with C. The four possible choices for each one of these three billion positions yields a huge potential coding capacity. In light of all the things that we have to do as human beings three billion base pairs may not seem like quite enough, but this number must be sufficient. Astonishingly, much of our DNA doesn't have an obvious function, as an estimated 70% or more does not contain genes and just seems to be along for the ride. However, we will never know which part of the genome is the functioning part without studying all of it, and this justifies the broad, all-encompassing approach to the Human Genome Project.

Reading out the sequence of the human genetic code – a feat which has been nearly accomplished – is not, of course, the end of the story. This is really just the end of the beginning. The interesting and challenging part is figuring out what it all means. These three billion letters seem to make up somewhere in the neighborhood of thirty thousand genes, each gene being a packet of information that conveys a certain instruction. The fact that we are not even sure what the actual number of genes is, even though we have most of the sequence in front of us, reveals just how hard it is to stare at page after page of A, C, G and T and figure out what it is telling us. If we printed out the whole sequence and stacked the pages on top of each other, these three billion letters would

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PALLIATIVE SEDATION: MAY WE SLEEP BEFORE WE DIE?

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Sedation is a clinically important therapeutic intervention in the imminently dying patient. As the patient with an advanced, irreversible illness nears the end of life, symptoms accumulate that are progressively more difficult to manage and that may become unresponsive to standard medical interventions. The most common of these intractable symptoms are pain, agitated delirium, dyspnea and existential or psychological distress. Although sedation is a risk-laden procedure, it is sometimes necessary and maintains the physician's twin obligations to benefit patients and to "do no harm" when practiced by trained, dedicated clinicians.

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Terminal sedation is a recent addition to the lexicon of palliative care. Based on a survey of 61 selected palliative care experts, Chater et al. arrived at the following definition: "Terminal sedation is ... deliberately inducing and maintaining deep sleep but not deliberately causing death in very specific circumstances." The "specific circumstances" were defined as intractable symptoms at the end of life, including "profound anguish" for which standard palliative care intervention had failed to provide adequate relief. The definition excluded "planned temporary" sedation that is reversed. "Terminal sedation" was criticized by those surveyed for being grammatically ambiguous, as it could be interpreted as meaning either sedation intended for terminally ill patients or sedation for the purpose of terminating a patient's life. The latter interpretation has led to other vague and ambiguous terms, such as "slow euthanasia." "Sedation for intractable distress in the dying patient" (SIDD) was proposed as an alternative terminology. This author prefers the simpler phrase "palliative sedation" and will make reference to it throughout this article.

Ira Byock has stated that "unlike many areas of medicine in which it is the occasional case that presents an apparent ethical dilemma, care at the end of life is full of ethically poignant and emotionally charged situations." It is essential to examine the ethical implications of decisions and interactions between patient, family and providers of care. Although the U.S. Supreme Court in its decisions regarding physician-assisted suicide fundamentally sanctioned palliative sedation, it remains a controversial intervention. This controversy will be touched upon in the remainder of this article.

Does palliative sedation shorten the life of the terminally ill patient who is experiencing refractory, intolerable symptoms particularly when it is accompanied by withholding of food and fluids? Most often, this is probably not the case. The little research that has been done suggests that the use of sedation in someone dying is largely irrelevant to the timing of death, though it may prolong life slightly. In a retrospective study of terminally ill patients, Stone et al. showed no statistically significant difference in survival from date of admission between sedated and non-sedated patients. They concluded that "the need for sedation is an indicator of impending death and not a cause of premature death." Patients who spend their last hours or days sedated are very sick. Even before they are sedated, these patients are eating or drinking substandard amounts, and artificial hydration and nutrition is usually contraindicated because it would increase the risk of pulmonary edema and other adverse effects. Patients are also often restless, delirious or anguished. Left alone, they would die in part from exhaustion.

Is palliative sedation really a form of euthanasia? Some believe it is, arguing that death is hastened by inducing dehydration. As we have already seen, however, most patients for whom palliative sedation is appropriate will have already stopped eating and drinking. Palliative sedation for intractable distress is not "slow euthanasia," but a prompt response to suffering based on informed consent and the principle of double effect.

The proper intent in palliative sedation is relief of pain and suffering. The importance of physician intent is debated. Some argue that outcomes arising from either action or inaction are more important than intent when considering physician behavior. If the intent to relieve suffering is discounted or dismissed, then to the extent that death is hastened, palliative sedation is a form of "euthanasia," as death results directly from the action of a physician. Quill has argued, "...clinical intention may be complex, ambiguous, and often contradictory." It is true that one cannot know for certain the internal state or intent of another. This does not prohibit one from making reasonable inferences. It can reasonably be inferred that analgesics or sedatives are administered only for pain relief or distress if they are titrated to achieve specific end points (such as the absence of grimacing or moaning in patients unable to report pain) and not beyond. In contrast, the rapid administration of massive doses of medication with no effort to titrate indicates that hastening of death was a first intent.

How can a biblical perspective inform the use of terminal sedation? Human life is a gift of God and is sacred because it bears His image. All people are created by God and are not to be understood as the products of random processes. We are therefore responsible to God for our actions. We are stewards and not absolute masters of the gift of life. A follower of Jesus Christ, the Great Physician, is called to have compassion and to suffer with and support people in their suffering. We are not to remove (kill) the sufferers in order to remove their sufferings. In Galatians 6:2, Paul writes that we should "carry each other's burdens and in this way...fulfill the law of Christ."

At the SSM Hospice of St Louis, we tell our patients that we value their lives and their worth and that we will not kill them. We are a "euthanasia-free zone." We promise to care for them and try our best to treat their symptoms and not to abandon them as they die. They are told that if their pain and other symptoms cannot be controlled, then they may choose to be sedated. This option is critical for patients who are profoundly fearful of suffocating to death or remaining delirious or confused or who have a crescendo of pain that fails to subside with the standard pharmacological and interventional techniques. Such patients may indeed sleep before they die if that is their choice.

A referenced version of this article is available on the Center's web site: www.cbhd.org. ■