Clinical Neuroethics Initiative: Improving the Quality of Patient Care at CPMC

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Neuroethics is a young field that discusses the rights and wrongs of treatments and procedures involving the human nervous system. Currently, it is estimated that 1 in 6 Americans is affected by neurological disease. This statistic hits close to home. In the Program in Medicine & Human Values (PMHV), the largest number of requests for ethics consultations involve patients who have neurological problems.

Applying what this means in the real world of patient care is why PMHV, with startup funds from Sutter Health and generous philanthropic donors, developed the Clinical Neuroethics Initiative (CNI). CNI is a unique program providing education, training and expertise in ethical consultation services to specifically address the ethical dilemmas that arise in caring for patients with neurological diseases and disorders.

As the first Clinical Neuroethics Fellow, I am completing a schedule of rotations in the neurological subspecialties, which includes: Neurocritical Care (both at CPMC and San Francisco General Hospital), Neurorehabilitation, Behavioral Neurology, Neuromuscular Diseases, Mental/Behavioral Health, Movement Disorders, Epilepsy, Deep Brain Stimulation Clinic, Palliative Care and the Pain Clinic.

My role has been to identify the particular ethical issues physicians face when working in these subspecialties. With this information we have already begun developing projects to address problems that will lead to improved quality of care for patients with neurological diseases.

Four projects stemming from these rotations include:

Improving Communication Between Physicians, Families and Patients in the Stroke Intensive Care Unit

Patients admitted to the Neurologic Intensive Care Unit for severe brain injury are especially vulnerable and often have a compromised ability to communicate. For this reason, the stress and uncertainty of decision-making frequently falls to the family. This project invites family members and patients to complete an anonymous survey assessing their perceptions of how physicians communicated factual information and the manner and emotional environment in which the physician delivered the information. We will use the families’ and patients’ feedback to design educational interventions aimed at assisting physicians who treat severely brain injured patients in evaluating their own communication skills and, where indicted, improve their performance.

Improving Care for ALS Patients by Assessing Their Attitudes Toward End-of-Life Decision-Making

Patients diagnosed with the fatal neuromuscular disease amyotrophic lateral sclerosis (ALS) suffer progressive paralysis and respiratory failure. Currently there is no established, effective treatment. An option was created by the...
The Case
Mr. Smith was an 86 year old man complaining of shortness of breath who was brought to our emergency room from his ranch in the Central Valley. He was a lifelong smoker, drinker and independent widower who had not required previous hospitalization, despite his chronic lung disease. His condition worsened. He became unresponsive and required transfer to the intensive care unit where he was placed on a respirator. Due to his underlying lung disease, it became increasingly evident that his condition would never improve to a point at which he could be removed from the breathing machine.

At times Mr. Smith seemed to be alert, and sometimes he was combative, but most of the time he just laid there. The nurses thought he was calmer when the TV was on. The neurology consultant felt that he had suffered significant brain damage during his illness and would unlikely recover the ability to make decisions for himself. Both of Mr. Smith’s sons insisted, however, that their father would want to keep on fighting and urged the medical team to “keep on going.” When it was time to discuss specific medical treatments, however, the sons became increasingly difficult to reach.

The Ethicist’s Role
Our ethics consultation service was called because the medical team did not think the patient’s sons understood the severity of their father’s condition and had unrealistic expectations for what modern medicine could accomplish. The ethical question was, “Is it in Mr. Smith’s best interest, given his poor prognosis, to have a surgical procedure called a tracheostomy so he can remain on a ventilator long-term?” The alternative course of action was to focus on Mr. Smith’s comfort and allow for a natural dying process. All of the physicians felt that a tracheostomy was not a good option, as ventilator support was not likely to improve Mr. Smith’s overall prognosis, nor would it likely improve his quality of life.

Before I could begin to address the ethical question, it was necessary to help the team re-establish a working relationship with Mr. Smith’s family. I considered what could have been done differently to help foster a more functional relationship between the family and the medical team. I considered how a physician could approach the initial discussion with a family regarding the plan of care and what information should be conveyed to build the foundation of a relationship capable of shared decision-making.

I reached out to three physicians who each serve as chair of their respective hospital’s ethics committee for insight on what information would be necessary to bring about shared decision-making between Mr. Smith’s family and the medical team.

“In the first meeting between doctor and family, it is necessary to share the diagnosis or, if needed, how the diagnosis will be clarified with tests or treatment trials, the possible side effects or complications of the diagnostic tests and treatment options, and whether a long-term prognosis can be estimated. That is a fair amount of information, so the physician will likely have to reinforce the information at the next meeting, as well as incorporate the results of tests done and the response to treatment. Coordinating communication among the various physicians and informing the family of the physicians’ different roles is also essential to prevent mixed messages that may cause confusion.”

— Barry S. Mann, M.D., Eden Medical Center
As Dr. Mann points out, it is important to share a basic summary of the patient’s diagnosis and prognosis, or what diagnostic tests need to be performed to better assess the patient. This information is crucial to support shared decision-making between the patient’s family and the medical team.

After discussing the patient’s diagnosis or the necessary diagnostic tests, it is advisable for the physician to explain the different roles and responsibilities of the physician and the patient’s healthcare decision-maker or surrogate, who are the sons in this case. For example, it is the physician’s responsibility to use clinical expertise to diagnose a patient and discuss recommended treatment options based on the patient’s diagnosis and prognosis.

It is also important to discuss the sons’ roles and responsibilities when acting as joint surrogate decision-makers. Mr. Smith’s sons needed to understand that all decisions should reflect their father’s personal values and treatment preferences, as best as they could be known, not the values of the surrogate. In addition, it is a surrogate’s responsibility to participate in ongoing discussions with the physicians and various members of the medical team involved in the patient’s care as the patient’s hospitalization progresses.

“A physician should discuss goals and try to establish trust while listening to the family to gain some understanding of the family’s expectations. It is necessary to express the importance of cooperation between the family and the medical team. This cooperation begins when the physician provides the clinical outlook and recommended treatments, assesses the family’s understanding and then interprets the family’s willingness to cooperate with the medical team based on the information that has been shared.”

— William S. Andereck, M.D., FACP, California Pacific Medical Center

Of course, there are possibilities of disagreement between the parties involved, and if the physician believes this is likely to occur after the initial meeting with the patient’s family, the physician should clarify that the physician’s responsibility is to advocate for treatments most likely to benefit the patient. As a patient advocate, the physician is responsible for informing the patient’s family about the limitations of modern medicine. In certain situations, the medical team may determine that certain treatments are unlikely to benefit the patient.

“Physicians should explain their clinical expectations and then listen to the family’s expectations to determine if those expectations warrant further discussion about what modern medicine can and cannot provide.”

— Wilson Tong, M.D., Sutter Delta Medical Center

Though time is often limited during these initial introductions, and additional information is likely needed prior to lengthy discussions regarding goals of care, it is recommended that the physician begins to assess the family’s expectations as soon as possible. Listening to the family will strengthen the relationship between the physician and family and give the physician the opportunity to involve other members of the healthcare team early in the hospitalization. These might include palliative, ethics or pastoral care teams if there is concern that the family might have unrealistic expectations about the patient’s diagnosis and prognosis.

It is critical that the physician emphasizes the responsibility of family members to cooperate with all members of the medical team, as modern medicine relies greatly on shared decision-making. For example, the medical team must provide information about a patient’s condition and appropriate treatment options to obtain informed consent, which is necessary to respect patient autonomy. This does not mean that patients or surrogates have the right to force physicians to perform medical interventions that the physicians believe, based on their clinical expertise, will not benefit the patient.
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The potential for disagreement is high when a patient’s family desires to do everything they believe may help the patient, especially if the family is having a difficult time accepting the patient’s poor prognosis and the limitations of medicine. At the beginning of a patient’s hospitalization, having a specific discussion with the family about sharing decision-making with the medical team helps build an atmosphere of trust between physicians and surrogates and increases the likelihood of a more effective relationship.

In the case of Mr. Smith, the medical team and I were finally able to convince the sons to meet at the hospital. We talked for more than two hours about their father. By the end of the meeting, they had both realized that their father would not want to go on in his condition, especially since he would never get out of a hospital bed. We ultimately formed a relationship of shared decision-making, and the goals of care transitioned to a focus on Mr. Smith’s comfort.

Education Spotlight

In 2016, PMHV’s professional bioethicists and fellows conducted 72 education sessions. These presentations covered a variety of topics and were delivered to providers across the Sutter Health network and beyond. In addition to speaking to healthcare providers, bioethicists spoke at community events and patient support groups. The program’s faculty also presented at national and international meetings.
California End of Life Option Act that went into effect June 9, 2016, allowing that under certain conditions, terminally ill adult patients with the capacity to make medical decisions may be prescribed an aid-in-dying medication. It is already evident that the number of patients seeking aid-in-dying medication is increasing.

To date there has been no assessment of ALS patients’ perspectives on end-of-life decisions or the bases on which they are made. To address this need, ALS patients will be invited to complete a survey examining their attitudes on end-of-life decisions. The survey results will allow physicians to better communicate with patients, incorporate the new end-of-life option into continuum-of-care discussions and more effectively assist patients in becoming fully informed and making decisions in accordance with their own values and preferences.

**Breaking the Communication Barrier for Neurological Patients with Compromised Communication Abilities**

Patients with neurological disorders and diseases often have diminished ability to communicate through normal speech or writing channels. This makes it highly problematic for caregivers to accurately determine patients’ capacity to make their own medical decisions. The goal of this project is to work collaboratively with ALS, stroke and dementia specialists to devise a tool that will empower physicians to determine the wishes and preferences of neurologically injured patients, thus, respecting patients’ rights to participate in making healthcare decisions for themselves.

**Neurotechnology Review and Ethics Service**

The increase of novel technologies used to treat, enhance or restore human cognitive, sensory or motor functions (neurotechnology)—along with a dearth of information for patients and clinicians—poses a growing challenge to clinical medicine. The use of such technologies in the clinical setting raises an important ethical question: Should neurotechnologies be offered to patients when their effectiveness has not been fully proven?

During my rotations in neurorehabilitation, it became clear that not only providers, but also patients and families, are often faced with deciding if novel neurotechnology options should be considered over conventional physical therapy. Commercial promises of benefit can provide hope, especially when a patient lacks progress in rehabilitation. Conversely, it is necessary to explore and rigorously assess the therapeutic applications of different and potentially beneficial technologies to determine realistic expectations and offer physicians information that will be useful for their patient and family discussions.

To address these issues, the Neurotechnology Review and Ethics Service (NRES) has been created to act as the nexus between neurotechnology developers and clinical teams. This effort taps the experience of clinicians within the Sutter Health network who specialize in neurorehabilitation, neurosurgery and ALS. By combining expertise in science, technology and neuroethics with the clinical implications of using novel technologies, the service will assist the healthcare team by recommending approaches that address potential conflicts of interest and other ethical dilemmas that arise when dealing with neurotechnology and patients. This service is the first of its kind and will serve as a model within Sutter Health and beyond.

Since it was established in 2015 under the direction of Dr. Thomasine Kushner and Dr. Alan Yee, the CNI has established Sutter Health as a leader in the field of neuroethics, taking the field toward a new and much needed direction: from the laboratory bench to the patient’s bedside. If you would like to know more about the Clinical Neuroethics Initiative, please contact me at palchiga@sutterhealth.org.
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12th Annual Summer Workshop in Clinical Ethics

Say It Right the First Time: A Blueprint for Communication in Ethically Challenging Situations

Saturday, June 10, 2017
9 a.m. to 4:30 p.m.

Registration is required