

Truth, Post-Truth, and Quackery

WILLIAM S. ANDERECK, M.D., FACP

Roger Bacon was ahead of his time. An obscure English friar who died in 1292, Dr. Mirabilis, as he is also called, (I always thought he was the older brother of Francis and Oscar) revolutionized the way modern Americans and Europeans see the world. He told his readers to reject all their preconceived notions about the reality of the world around them and instead believe only those things that can be observed directly and verified by others. We now call his approach the Scientific Method, and its application to research and scientific discovery has been responsible for the development of the modern world, from agriculture to zoology.

What went unsaid was that this 13th century philosopher had the boldness to redefine the concept of how something would be considered “true.” Previously, and for some time thereafter, the “truth” was something promulgated by a higher authority and justified by a belief in the power of that authority, king or god. Bacon proposed a new standard of truth dependent on observation and verification, which was not simply belief driven, but evidence based. Thus, when I say, “I am telling the truth,” the sense of that statement is that what I say can be objectively and independently verified.

The challenge to the concept of “truth” today is that the body of information available to objectively verify any statement

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is seemingly endless. In order to filter the data available online, search engines allow people to choose sites that support their belief, thus reinforcing rather than challenging their opinions.

Now the tables have turned. Belief is driving the data that defines “truth,” rather than the other way around. Any data that contradicts one’s belief is labeled “fake news.” We all smiled approvingly when Patrick Moynihan said, “Everyone is entitled to his own opinion, but not his own facts.” But I am not so sure this is still the case. Post-Truth has become belief based again. If truth is now grounded in belief, the role of evidence becomes secondary or even superfluous. What does this mean for the concept of “Telling the truth”?

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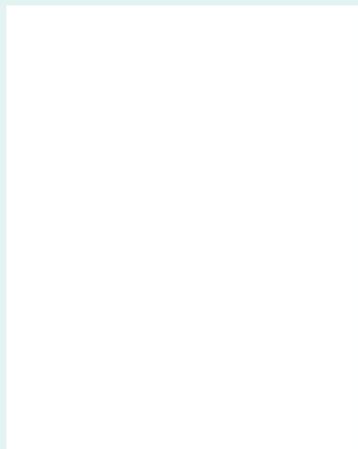
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The Ethicist Is In

SHAYLONA KIRK, M.D., M.A.



The Case:

Recently, an ethics consult was requested for Helen, an elderly woman whose neighbor found her unresponsive on the floor of her apartment and called 911. When Helen arrived at the hospital, it was clear she had experienced a massive stroke and that several of her organs, including her kidneys and heart, had been seriously damaged. Due to her condition, Helen was not able to make medical decisions for herself, and there was no known relative or friend to act as her surrogate. In the Intensive Care Unit, she was provided with life-supportive treatment, including being put on a respirator. Helen's prognosis was extremely poor, so the medical team recommended that she be transitioned to comfort care, which meant that life support would be stopped and treatment would be redirected to making her as comfortable as possible as her life ended.

The Ethicist:

That evening, I visited Helen's room and, as always, was deeply saddened to see a patient alone without the comfort of loved ones during a time of crisis. The ICU social worker told me she had spoken to the patient's building manager who described Helen as "a loner" without any family. A message the social worker had left for the neighbor who had called 911 had gone unanswered. Unfortunately, it is not uncommon for us to encounter unrepresented patients in our hospital. Nevertheless, the social worker used her resources to continue the search.

The following morning, I was pleased to receive a message letting me know that Helen's ex-husband, Theo, with whom she had maintained a friendly relationship, had been identified. Theo was contacted and eager to help with decision-making. At that point, with a surrogate in place, I assumed that my participation in the case was no longer needed. However, as soon as I stepped into the ICU, the social worker anxiously told me that another ex-husband, Najib, had been found. Najib also claimed a good relationship with Helen and firmly expressed his belief that she would want him to make decisions for her.

When the medical team turned to me to help determine who would be the most appropriate surrogate, I learned that both ex-husbands were in the ICU waiting room. Before the social worker and I had even made it down the hall to meet them, a call came in advising us that Helen had a partner, Lisa, who

typically saw her every day, but who had been out of the country for the past week.

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The caller was adamant that Helen would want her partner to make her medical decisions, so we left a voicemail for Lisa. Although the discovery that Helen was not alone was heartening, a new concern was brewing. I began to wonder if this unrepresented patient case was about to turn into an overrepresented patient case. I knew from previous experience that having multiple people vying to make decisions can make a difficult case even more complicated.

To everyone's surprise, potential surrogates continued to appear. In addition to Helen's ex-husbands, six of her friends were also in the waiting room. I sat with the group and shared my deep appreciation and relief that Helen had so many people who cared about her. I reviewed the medical information and explained the surrogate decision-making process. I let them know we were awaiting a call from Lisa, who, it turned out, they all knew. I asked them to tell me about Helen and listened to their emotional descriptions of a truly remarkable woman. When I asked what Helen would want if she were able to make her own decisions, the group deferred to Theo and Najib. The ex-spouses agreed that Helen would never want to be kept alive long-term on machines nor would she want to be dependent on others

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I first encountered this paradox while dealing with a rug merchant in New Delhi. I asked him if the claims he made about the rug he was offering were true. “Truth,” he told me, “is what you believe it is. I am telling the truth when I tell you something you want to hear.” This respectful, but “feel good” concept of the truth is not uncommon to people who have traveled in different parts of the world. It is playing to my belief and emotion rather than my reason and objectivity. Nevertheless, I bought the rug.

“Everyone is entitled to his own opinion, but not his own facts.”

Medicine came late to the game of fact-based truth. In the early 20th Century, physicians and assorted “healers” were advertising their wares in newspapers and medicine shows. Mercury, opium, magnetism, electrotherapy, and even x-rays were touted for multiple ailments. Claims did not require substance if the effort to heal was believable. Abraham Flexner, in the 1910 report that bears his name, changed the ground rules of medicine by focusing it on scientific inquiry and the rules of evidence. Doctors began wearing white coats about this time in order to associate themselves with the aura of laboratory science. The snake oil salesmen of the previous decades were banished from the august societies of medicine as it took on the mantle of evidence-based truth.

“... some of the humanity essential to good medical care has been lost in the pursuit of scientific truth.”

And what a ride it has been. From the advent of antibiotics to neuro-technologies that reconnect areas of the brain, scientific medicine has produced significant advances in the health of our population. What does this mean in a “post-

truth” world however? Will medical schools reflect political or social policies in admissions and focus? Will journals be more tightly controlled by the beliefs and opinions of their editorial board? Currently, some medical journals are now asking potential authors to pay a significant sum to offset printing costs before a work can be published (i.e. pay to play). If the facts become devalued, will money replace them? In my clinical practice, can I now judge the value of a new agent released for asthma based on the enthusiasm of the drug rep?

Unproven medical technologies are being touted with abandon. Stem cells are being given for everything except the common cold, and the latest rage, rejuvenating plasma infusions harvested from healthy young donors, adds a touch of the macabre to the ruse. In a post-truth world, there is no problem with this situation as long as everyone is happy.

It is fair to say that some of the humanity essential to good medical care has been lost in the pursuit of scientific truth. But in refocusing medical care from its scientific to its human application, let us not throw the baby out with the bathwater. A nebulous concept of medical truth has its problems as well. In recent years the cultural goal of medicine has been to be inclusive. All schools of thought and belief systems are to be respected in the medical arena. Sometimes these belief systems collide, and the modern physician seems ungrounded when it comes to dealing with seemingly insurmountable conflict.

This is when today’s physician needs to understand that respect for different world views does not require blind allegiance to any of them. In a world of belief based post-truth, it is important for doctors to delineate what their medical profession stands for, the responsibilities it accepts, and the obligations it will bear. Basing these obligations and responsibilities on an objective, verifiable, scientific method has proven itself over the past one hundred years. We have an obligation to humanize medical care but never should we change its focus on the nature of verifiable truth.

The Clinical Neuroethics Initiative: Improving the Quality of Care

GUILLERMO PALCHIK, PH.D.

A 2018 grant from the Hearst Foundation allowed PMHV to embed the first Clinical Neuroethics Fellow in CPMC's departments of neurology and psychiatry in order to identify the issues physicians find most challenging in providing optimum patient care. In our just-completed second grant, we worked with Directors of CPMC subspecialties: Dr. Robert Miller, Dr. Jonathan Katz, Dr. Liberty Jenkins, Dr. Scott Rome, Dr. Alan Newman, Dr. Paul Chin, and Dr. Alan Yee, to move from identifying the issues to providing assessments and tools to address them.

This Hearst grant consisted of projects in four domains with the following results:

- 1. The Values Capacity project developed an expanded tool for assessing medical decision-making that includes the overlooked importance of determining the patients' values and the role of their preferences. Initial presentation of these results will occur this summer at the International Bioethics Retreat.**
- 2. "What Do Patients Hear?" assessed the effectiveness of physicians' communication with patients and their surrogates in the neurologic ICU. Results of this project will be presented at a Neurology Conference by Dr. Gil Palchik and Dr. Alan Yee.**
- 3. "Improving Care for ALS Patients" was developed to assess patients' attitudes toward End-of-Life decision-making. A patient interview from this project will appear in the paper "The Legacy: An ALS Patient Speaks for Himself," The Cambridge Quarterly of Healthcare Ethics, Vol 28, No 4, October, 2019.**
- 4. The Neurotechnology Review and Ethics Service offered recommendations regarding new technologies with regard to potential conflicts of interest and ethical dilemmas. This project has been presented at two international conferences, the Neuroethics Network and the International Bioethics Retreat, in 2018.**

Beyond the specifics gleaned from these four projects, we confronted an overall theme common to the issues we investigated and to the health professions with whom

we worked. We found a pervasive disquiet in the medical profession. Practitioners face uncomfortable doubts about the increasing complexity of the issues they face. The overriding question we encountered was "Did I do the right thing?" As one neurologist said, "We go home at night thinking what we might have done differently for the patient." Another physician summed up their position as "There is a gap between what we want to be and what we see ourselves doing."

From our experience in the world of neurology, we concluded that the disquiet doctors describe can be traced to the discordance between values and practices. Addressing this discordance means not just respecting a patient's disease but also incorporating their values and their personal integrity as well. Although the ethical issues involved different neurological patient populations, our investigations in the four domains of clinical care demonstrate findings that can help physicians better address their patient's needs.

The physicians who worked with us in these studies expressed the belief that they have an obligation to not only protect the patient's health, but sustain themselves as well.

An unanticipated result of our research projects on the four domains was its positive impact on easing the destructive and demoralizing effects of physician burnout. Addressing the ethically-related neurological issues eased tensions and, as reported by our physicians, proved valuable in helping them and their respective staffs deal with their own tensions and moral distress. Collectively, the report points to a much-needed path to decrease the despair physicians express in wanting to do the best for their patients and their self-doubts in accomplishing it. Although our investigation centered on neuroscience, we anticipate that our research will be equally applicable to other areas of medicine.

As the ending of the grant brings this phase of the Clinical Neuroethics Initiative to a close, we look forward to continuing to pursue the goals of the Initiative and broaden awareness of neuroethics at Sutter Health.



Welcome our New Program Director

We are pleased to announce that **Dr. Ruchika Mishra** has accepted the position of **Program Director, Program in Medicine & Human Values (PMHV)**. Dr. Mishra started her career at CPMC as a Clinical Ethics Fellow in 2008 and was later hired as the Clinical Bioethicist serving all three CPMC campuses. During her tenure at CPMC, she has been instrumental in increasing the overall visibility of PMHV, assuring bioethics consultations are available and accessible to patients, families, and the health care team. She has been active in bringing bioethics education to members of the Ethics Committee, health care providers, and external organizations. Dr. Mishra was instrumental in expanding the ethics service from just one Sutter Health

hospital to the current seven Sutter Health affiliates that the program now serves across the Bay Area.

In 2016, Dr. Mishra was promoted to become the Senior Bioethicist overseeing the bioethics fellowship program and other professional bioethicists. Her experience in clinical consultation, bioethics education, and policy development blends perfectly with the additional responsibilities in her new role. She will oversee all of the Bioethics Services at Sutter Health, Bay Area. Dr. Mishra has served with distinction and has earned the reputation of being one of the distinguished clinical bioethicists in the country. We are delighted to have her leadership at PMHV.

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for extended care. Despite some tension between them, the two men expressed a desire to work together to do the right thing. They also agreed that Helen's current partner, Lisa, should be consulted before any final decisions were made. A subsequent conversation with Lisa led to the same conclusion; Helen would wish to be allowed to die naturally.

As news of Helen's condition spread rapidly through her tightknit community, many of her friends indicated a wish to visit before life-support was stopped. We all agreed the respirator would be withdrawn two days later. Helen's room was quickly decorated with memorabilia, messages, and pictures showing a cheerful, vibrant Helen and those whose lives had intersected with hers. Many of her friends shared touching stories about Helen's unselfish service to them, a family member, or another friend.

It soon became obvious that Helen played a prominent role in her community. For decades, she had been the go-to resource for people immigrating from her home country to the Bay Area. New photos and videos were always ready to be viewed, including a clip of Helen dancing and laughing at a party the weekend before her stroke. Watching as a woman, once believed to be completely alone, was transformed into a central figure of an admiring community, was a truly inspiring lesson in the power of human connections.

A number of Helen's circle wished to be present before and after her breathing tube was withdrawn. As I coordinated their

request with the medical team, suddenly and surprisingly, I found myself in the middle of a festive crowd of 30, who laughed and cried as they outdid each other in sharing happy memories. One by one, they held Helen's hand, said their goodbyes, and expressed gratitude for her contribution to their lives.

During the time that Helen's life support was withdrawn, and extending to her peaceful death two days later, the gratitude expressed by her partner and friends seemed to flow warmly over and around me, personally and as a representative of the hospital. They offered thanks for the diligent efforts made to contact them, the support they received in wanting to be with her, the clearly understandable explanations concerning Helen's medical situation, and for simply being there and caring every step of the way. Feelings of loss were balanced with the peace of knowing that Helen had been well cared for and treated with respect.

Although I didn't accept her friends' invitation to become their personal physician, I appreciated being asked. I felt affirmed in my decision to not only work in the medical field, but, specifically, to complete a fellowship in clinical ethics. Although we are always committed to doing the best for our patients, the beneficial results are not always recognized, even by ourselves. Cases like Helen's provide a much-needed reminder of why we do what we do and the positive difference we can make.

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Annual Summer Ethics Workshop

CALIFORNIA PACIFIC MEDICAL CENTER
PROGRAM IN MEDICINE & HUMAN VALUES

SATURDAY, JUNE 8, 2019
8:30 a.m. – 4:45 p.m.

Challenging Patients:
New Solutions to Recurring
Problems in Ethics Consultation