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A FEW TIMES EACH WEEK
I give someone bad news. All doctors who interact directly with patients do this routinely. There is a small literature on the topic, almost entirely confined to oncology, accessible with a Pubmed search under “breaking bad news.” This time I was overwhelmed more by the patient’s response than by the bad news itself. Whenever I have to tell a young person he has Parkinson’s disease, or Huntington’s disease or some other life-altering disorder I always pay an emotional toll. It is less troubling in older patients who have lived the great majority of their lives in good health. In this case it was very clear that this patient had come in for an evaluation of his tremor, expecting to be given a clean bill of health, told to not worry, and then continue his usual lifestyle and plans. He was 65 or so, otherwise healthy, a regular gym-workout enthusiast, semi-retired, with lots of plans. He recently met a new physician after not seeing one in a decade. He was not taking any medications. He didn’t need any. His new physician thought he should have the tremor checked out.

Before I tell people that they have Parkinson’s disease (PD), I generally ask them what they think their problem is. Usually they say that the referring doctor thought they might have PD but wasn’t sure, or that they had scoured the internet and thought they had or did not have PD, but mentioning it explicitly. Sometimes they recognize the symptoms from a friend or family member. This, of course, makes our interaction much easier. They are prepared, at least to some degree. I can gently agree with them, “Yes, I think you’re right. I believe that you do have PD.” Then I try to explain what I found in their history and examination to make me think this, that there were no objective tests to confirm the opinion, and generally my degree of confidence in the diagnosis, since we all make errors. I immediately say that the disease won’t kill them, that it’s not Alzheimer’s disease and that we can treat the symptoms. After that there are a variety of approaches I take, depending on the circumstances, but always including something hopeful. While my news isn’t as bad as what a lot of other doctors routinely give their patients, it is, nevertheless, not something a patient wants to hear.

This patient was devastated. He had come alone. His wife had stayed home. The visit was given no more thought than a routine visit to the dentist. It was clear as I spoke that he wasn’t processing much of what I told him. I was as reassuring as I could be, gave him a source for a lot more information, and asked him to return in a 1-2 weeks, with his wife, to discuss the diagnosis at greater length. And I started to think, as I do after each time I tell people these sorts of things, how should I have handled this interaction? Is there a “correct” way to give bad news? Could I have done better?

I don’t think there’s a “correct” way to give bad news. Oncologists have developed a guideline called, “SPIKES,” for giving their bad diagnoses, but that doesn’t fit the needs of a neurological diagnosis which is often rendered on the spot at the first meeting. There are certainly “wrong” ways to give a diagnosis, but any approach that works for one person may be incorrect for another. I’ve had patients who have thanked me for my “direct” approach and others for my “sensitive” manner; and others who have complained about my being too direct and insensitive. I am sure that different approaches are required for different patients. I am also sure that doctors, like all human beings, cannot actually assess themselves. I doubt that any doctor thinks he’s too blunt or insensitive in providing an unwanted diagnosis. I also doubt that any patient objects to the doctor taking large amounts of time to support and console. But in most cases there’s another patient waiting, and endless amounts of time are not possible given time constraints in medical offices.

Giving a diagnosis is always easier if the patient is prepared, in some way.
When the referring doctor tells the patient that PD is suspected, my interaction is dramatically transformed. There is a difference to hearing bad news that is anticipated than the bolt out of the blue. Yet I don’t blame these doctors who don’t share their suspicions with the patient. In many cases, the referring doctor isn’t sure and does not want the patient to spend the next few weeks worrying about having PD and then turning out not to have it. In some cases the doctor may not feel comfortable discussing the pathophysiology and prognosis of the illness, lacking a large experience, and therefore, even though she’s sure of the diagnosis, quite appropriately, wants me to have that discussion.

The one consolation I have is that after three decades of doing this, I’m still thinking about it. I may be ossified in my thoughts and interactions but how can I tell? At least I’m ready to doubt what I do and rethink it, and hopefully do it better. I’m not sure what else I can do.

My 65-year-old patient never returned.

Author
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Disclosures

FYI
Capitalism gone wild

The NY Times carried a business section article on June 15, 2013 describing what can only be considered an extraordinary example of monopoly capitalism gone wild. Acthar is a prolonged release form of adrenocortirotropic hormone (ACTH). It is used to treat infantile spasms, a rare seizure disorder in babies, and may be used in multiple sclerosis to treat exacerbations. In 2001, “Acthar, a hormone purified from pig pituitary glands...was selling for $40 per vial.” Questcor purchased the drug in 2001, increasing its price to $1650 per vial and then to its current cost of $23,000 per vial. Now Novartis is attempting to purchase the company that makes this drug, which is the only competitor for its own synthetic version of the drug. It is unlikely that the goal is to make the drug cheaper.

1. NY Times June 15, 2013
Joseph H. Friedman, MD
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"M E D I C I N E," S A I D Napoleon Bonaparte (1769–1821), “is a collection of uncertain prescriptions, the results of which, taken collectively, are more fatal than useful to mankind.”

A nihilistic view perhaps, but given the lack of any medicinal oversight and the primitive level of pharmacological knowledge by the practicing physician of the early 19th century, it is little wonder that there was profound skepticism over the merit of most physicians’ prescriptions.

In the two-century interval since Napoleon’s disparaging commentary, the world has undergone substantial change in the character and regulatory oversight of medicinals. And yet, paradoxically, by the 21st century misused medications have become increasingly instrumental in hastening some deaths.

Many of the readily available medications during the early decades of the 19th century contained sub-lethal amounts of substances such as mercurial, arsenical or lead compounds, each capable of accumulating internally in amounts sufficient, eventually, to cause death. By the middle years of the 19th century, crude opium and newly developed opium derivatives dominated the death toll ascribable to medications. Most of these deaths, from freely available substances such as laudanum, were obtained without a written physician’s prescription, since they were freely sold in pharmacies.

The 20th century witnessed the first binding regulations on the use of medications, particularly those with narcotic tendencies. In many nations, the quality and standardization of medications, as well as their proof of efficacy, are now supervised by the government. And so, most prescribed medications are presently approved for use only after extensive field-testing and scrutiny by many clinics and laboratories.

Overdosage defines the present era where drugs – both licit and illicit – dominate the scene. The civilian mortality rate, in 21st century America, caused by overdosage of otherwise safe medications, would shock Mr. Bonaparte. In the state of Florida, for example, there have been 16,550 overdose deaths during a

Display of various patent medicines for teething babies. Also displayed are printed advertisements and bottle labels.
recent six-year interval. And, in recent years, these deaths have become the second leading factor – after vehicular accidents – in mortalities from causes other than intrinsic disease.

Again, looking solely at data from the state of Florida: the state medical examiners record about eight deaths per day caused by drug overdosage.

What specifically are the drugs that take so many lives?

- **Prescription drugs** (particularly benzodiazepines): A family of prescription drugs, effective in alleviating anxiety and panic attacks. These widely used medications have also been extensively employed for what authorities now call “recreational use” exhibiting clearly addictive tendencies.

- **Opioid analgesics**: A family of analgesic (pain-reducing) synthetic medications – biologically similar to opium alkaloids – including oxycodone, methadone and morphine. The street value of these drugs is now so great that pharmacies have been burglarized for them.

- **Illicit drugs**: Specifically heroin and cocaine. And while these substances had at one time been prescribed, their addictive tendencies were so great that they have been effectively removed from pharmacopoeia texts.

- **Alcohol**: The U.S. Public Health Service uses this category solely for deaths attributed to the direct toxicity of grain alcohol. Thus, while countless deaths from motor vehicle accidents are abetted by alcohol in sub-lethal amounts, those deaths were not considered as instances of alcohol over-dosage. Alcohol, whether in amounts deemed lethal or sublethal, is nonetheless the leading mortality factor in deaths between the ages of 16 and 45.

What is meant by ‘recreational’ usage, particularly with the illicit use of substances initially designed to reduce pain? A standard dictionary tells us that recreation is defined as, “refreshment by means of some pastime, agreeable exercise or the like.” It is in the negligently listed “or the like” category that these highly dangerous medications are found.

Past threats to the common welfare, such as the recurrent poliomyelitis epidemics prior to 1956, yielded far fewer fatalities that drug overdosage and yet prompted a robust response, an urgent public demand, to find a cure. Just saying no to the blandishments of agents capable of reducing pain [whether the physical or the spiritual kind] is as purposeful as writing a letter to the local newspaper objecting to a hurricane. And neither public reprimand nor criminalization has diminished the enormity of this problem.

Pain, of any sort and in any language, needs to be addressed with efforts more enduring than weekly maxims or jeremiads. Human pain has so many additional faces, whether it be from mundane grief, heartache, malaise, anomie or even boredom with life; and no one anodyne has yet been discovered to provide anything more than transitory relief.

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