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What is a disease?

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IN PREPARING FOR A debate on the question of whether dementia with Lewy bodies (DLB) is the same or a different disease than Parkinson's disease with dementia, I thought I'd first address the question, what is a disease? Although this is a longstanding and obvious question, I found very little written about the topic.



The concept of what defines a disease is more complicated than it might first appear. It was not until the sixth version of the International Classification of Diseases (ICD 6) was published in 1949 that mental disorders were included. While not defining what a disease is, the World Health Organization (WHO) defined "health" as a "state of complete physical, mental and social well-being not merely the absence of infirmity," in 1948, and has not revised it. I doubt anyone would consider that failure to meet this definition would constitute a disease.

A 2015 paper suggested that ICD 11, the next edition of disease classification and codes, should classify aging itself as a disease, an oxymoronic concept. The justification for such a classification is based largely on the idea that there are "stakeholders" who might profit from this notion, leading to greater investments by industry in developing interventions to retard or reverse

various aspects of aging.

I suspect that most of us, those in medical fields and those outside it, feel that they have a good grasp of what a disease is, like Potter Stewart's observation on recognizing pornography, "you know it when you see it." However, a 2012 study in Finland that sur-

veyed a large population of physicians, health professionals and the general population, found that there was a large divergence of opinion (Tikkinen KAO 2012) about what constituted a disease, at least when one focused on addictive and other self-destructive behaviors.

The problems arise when different syndromes are caused by the same pathology, or when the same syndrome is caused by different pathologies. Malaria may cause the common febrile painful illness, but may also cause a disorder that targets the kidneys, or the brain. The disorders are all "malaria," but different "variants." Even autosomal dominant inherited disorders, like Huntington's disease, may cause disparate although overlapping neurological syndromes, yet we consider the diseases the same. Parkinson's disease may be caused by a recessive inherited disorder in which different family members, although bearing the same phenomenology, have different pathologies. Does the gene or the

pathology classify the disease?

Psychiatrists have been dealing with this in a very organized fashion since the first Diagnostic and Statistical Manual. Since psychiatric diagnoses are not based on pathology or laboratory tests, their conceptualization is more fluid and subject to change based on scientific advances as well as social moirés and politics.

The classification of neurological disorders, as with all of clinical medicine, is always in flux, with diseases, previously defined by their phenomenology or laboratory biomarker profiles, are increasingly classified by their genetics, or other objectively measured markers. This is undoubtedly useful for disorders that are caused by a single gene abnormality, but not all disorders have known genetic substrates, and some have very variable genetic contributions, often confounded by different abnormalities in the same gene. In the case of dementia with Lewy bodies, all experts agree that DLB and PD are closely related to each other, for reasons I will mention below, but it is startling to realize that we're not very sure about how to define Parkinson's disease, itself. One colleague suggested, probably with universal agreement, that "Parkinson's disease" is really a group of diseases, based on the observation that certain genetic changes cause people to develop all the clinical criteria required for the diagnosis, but for some members of the same family to have the classic pathological changes

required for the diagnosis of PD, whereas others, equally afflicted, to lack the Lewy body itself, an absolute requirement for the diagnosis of PD. This undermines the current “gold standard” of PD identification, histopathology. It is obvious that sibs in a family with the same clinical disease have the “same” disease, suggesting that the Lewy body requirement is, perhaps, useful but not an absolute requirement. On the other hand, there are cases, not rare, where people who had been closely monitored with neuropsychological testing were found to have moderate Alzheimer’s disease pathologically at death who had no clinical evidence of dementia.

It used to be thought that once we find the genes or the toxic agent we would identify the disease, but the more we learn, the more difficult these problems become.

What are the controversial issues concerning PDD and DLB? Both have identical dementia findings on neuropsychological exams; both feature the

same types of hallucinations and delusions; both have the same or closely similar motor dysfunction; both have the same clinical fluctuations in dementia; both progress in the same manner; both have the same response to medications; both share genetic risk factors; neuropathologists cannot distinguish the two. Currently they are distinguished only by the onset time of dementia with respect to onset of parkinsonism. So, you might ask, why should it matter what we call the disorder?

I’m unsure what the answer to that is. Classification may affect research funding. Will it affect which type of physician cares for the patient, whether treatments will be more or less likely to be funded? Will a dementing illness be funded through the NINCDS or the NIMH? Are the “stakeholders” different? Does DLB benefit from being linked with Alzheimer’s disease, clearly the greatest threat to the elderly population?

Rationality calls for diseases to be classified by whatever markers seem

to be likely to group together the most salient aspects of the disease, knowing that single genes may be causal but that other genes may modify phenotype, just as heredity modifies how infectious and toxic agents cause disease. We have “syndromes” until we have causality. We can then hone down the varieties of clinical and laboratory pathology as we learn more, from order, family, genus, to species, just as we’ve classified animals over the last three hundred years, in an ongoing and ever exacting process. There are different advantages to lumping and splitting. ❖

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A music vigil's healing power at the end of life

HERBERT RAKATANSKY, MD

EVERY DAY FOR SEVERAL months I went to see Gregg (not his real name) in a nursing facility with music in my hand.

My friend was dying from an untreatable cancer. There was little pain or physical discomfort and thus he required little medication. He suffered from a para-neoplastic



syndrome, cancer cachexia, a condition in which appetite is depressed and the body's energy use is increased. There is no effective treatment and it inevitably leads to death. Gregg was fully aware of the situation. He had little pain and his doctors from Hospice, while readily available, were not frequently needed.

Gregg was a man whose satisfactions in life derived primarily from intellectual pursuits. He was a retired university professor and appeared to have derived little satisfaction from his personal emotional life. Years of unresolved personal and family issues had ignited flames of familial resentment and there was little if any emotional succor from his family. His "best friend" lived far away.

I knew him socially through several discussion groups and as a wine, food and music lover. Our conversations occasionally had ventured into his areas of emotional discontent but never to the extent that we could explore critical issues and facilitate helpful insight. We both enjoyed classical music and, over the

years, attended a number of symphony concerts.

Gregg and I became friends later in life and initially I was not aware of most of his and his family's underlying feelings. I wondered, and I suspect he also wondered, whether sharing these feelings and getting help in dealing with them

years earlier might have enabled him to live a more satisfying life and ultimately enabled more emotional support in his final journey.

What does one say to a friend in this situation? His terminal illness was not an appropriate subject for intellectual discussions and, due to the nature of his illness, food and wine were "off the table."

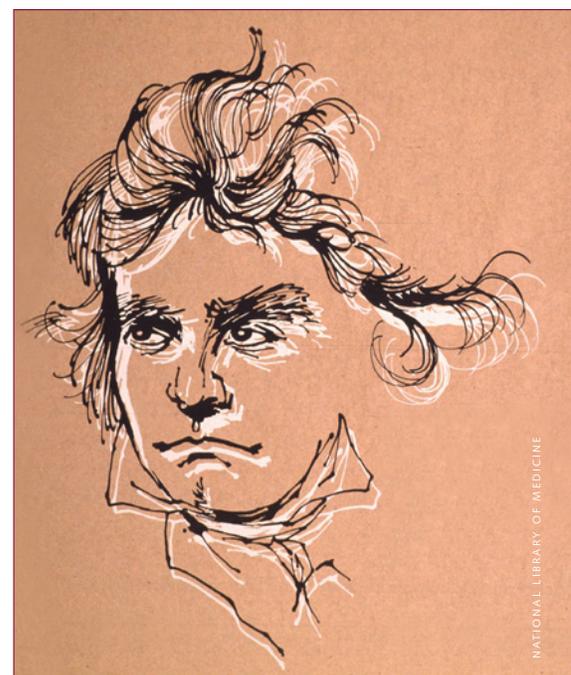
It may not be possible for persons intimately caught in the web of intense negative emotions to forgive, if not to forget, past behaviors, even when a person is dying. The emotions of friends and relatives do not disappear as death approaches, in fact they may play out in an exaggerated fashion, as they did with Gregg. These persons might say that the patient does not deserve comfort and that, even if he did deserve emotional sustenance, they, personally, would be unable to provide such support. "Death-bed forgiveness" may not be an option.

Most of us have a basic core of "humanity" though it may be more accessible in some than in others. Sociopaths and

psychopaths do not make emotional connections with others and likely are the exceptions to this rule. It is difficult to conceive of having empathy for a Nazi doctor, for example.

Reams have been written about caring for the dying. We try very hard to encourage patients to express their feelings and connect emotionally with friends and families about their lives (life review) and continue activities they love for as long as possible. But, as with Gregg, long-standing emotional conflicts may interfere and occasionally make this approach impossible.

In these end-of-life and other difficult situations we should seek that core of humanity that most of us possess. The



Ludwig van Beethoven (1770–1827)

path to this may be conversation or it may be non-verbal.

Music is a separate portal to the brain. It may be a source of pleasure and solace for all but is especially important when it is the major or sole pathway to comfort.

Last year an article in the *New York Times* described some famous (and not so famous) people who specified the music they wished to hear on their deathbed. Live music has been a part of this approach as well. Palliative care specialists have suggested that terminally ill persons may hear speech and music even when they are unable to respond.

For some persons conversation is impossible. A close relative of mine, minimally verbally responsive due to advanced Alzheimer's, responds with apparent pleasure to the music she loved, played through headphones. Music therapy for dying patients (music thanatology) is a recognized specialty and music has been incorporated in hospice care in some areas. Music is

therapeutic in many medical conditions, such as autism. Children who attend schools that have active music programs do better in their academic subjects.

There was nothing I could discuss with Gregg that could in any way alter his despair and gloom. He did not want many words and we did not have deep conversations. But every day I brought a CD of the music he and I both loved: one day a Brahms symphony, another day a Beethoven concerto, etc. We would talk about past performances we had heard and then we would just listen. As the disease progressed inexorably, Gregg would increasingly doze during the music and toward the end of his illness it seemed that he heard little, at least consciously. But I am sure that the effects of the music as he passed repeatedly from consciousness to drowsiness and then finally to eternal sleep were emotionally meaningful and brought him comfort. Certainly he was happy when I arrived for our daily "concert."

In anticipation of their final step,

many people plan their own funeral and determine the music attendees will hear. And in some cases the music is an integral component. Think about the New Orleans funerals with jazz, a musical Requiem in church, bagpipes at Scottish funerals, etc. There are a number of classical music selections traditionally played in memory of the deceased.

If an ending like Gregg's comes to befall me or if I become unable to converse during a terminal illness, I anticipate loving family members and friends sharing those sad moments. But putting some Mozart and Beethoven in the mix wouldn't hurt. And at my funeral please, some Bach fugues on the organ at full volume rather than the usual dirge. ❖

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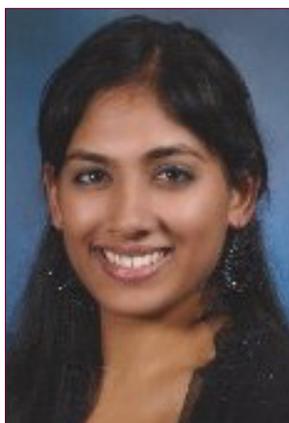
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Holding Hands

ANANYA ANAND, SCB, MSC

WALKING FROM ROOM TO room at Rhode Island Hospital, getting horrendously lost in the labyrinths of adjoining buildings, it finally dawned on me that I was now fully immersed in the medical profession. As part of my medical school's Doctoring course, I had to spend several



sessions shadowing a physician and working with patients in a nearby hospital. My first doctoring session was a flurry of struggling to communicate with patients who were experiencing tremendous pain and discomfort and trying to recall all the elements of taking a patient history as my mentor looked on. Now, for my second session, I was on my own, a 24-year-old first-year medical student set loose with a pen, notepaper, white coat and stethoscope upon a group of unsuspecting patients.

My first patient was Ms. F, a 90-year-old woman who had fallen a few days prior and felt like she “was taking her last breath in this world,” but had survived and ended up in the hospital, now presenting with lower-extremity edema, cardiac arrhythmia, and worsening shortness of breath. I walked into the room, excited but highly anxious to be on my own, and was greeted by a beautiful smile and sparkling blue eyes that calmed my nerves immediately. Doctors (and perhaps even medical students)

are expected to appear in control and to provide comfort for patients, but it was Ms. F who immediately eased my anxiety with her demeanor. She was lying in bed, and as I started to introduce myself, I realized that there was nowhere for me to sit in the room. Immediately, I felt a slight

sense of panic – it would have been terribly awkward to conduct Ms. F's patient interview looming over her in the small, confined space. She smiled at me, noticing my sudden-onset diaphoresis, and patted the space on the bed next to her. “Come sit here next to me, sweetie!” For the next hour, she patiently gave me her medical history and allowed me to take her vitals and conduct a brief, bumbling cardiopulmonary exam. But even more amazingly, she opened up to me in a way I could not have foreseen.

Ms. F recounted how she fell in love at 17 and had been with her husband until he passed away in 1999 from colon cancer. She still resided in her childhood home and loved to cook Italian meals with her sister, particularly eggplant parmesan. She told me about her five children and cried when she recalled how her youngest son, studying to be a physician assistant, was killed outside a hospital in a hit-and-run. In the short time we spent together, Ms. F and I truly connected. I was astounded that she felt

comfortable with me, so comfortable in fact that she revealed to a complete stranger her deeply personal experiences. I wondered whether it stemmed from the power of my white coat – that somehow patients are more inclined to trust their medical providers. Before I left Ms. F's room, she asked if I would come back to see her before I left that evening since she would be discharged the next day. I told her I absolutely would.

I wonder if my ability and desire to connect with people on a deeply personal level, which I consider a strength, is a weakness in the context of the medical profession. I recall reading an article in preparation for the Doctoring course about how, in the primary care setting, sharing personal information and experiences, referred to as self-disclosure, with patients is not beneficial and can be detrimental to the physician-patient relationship¹. I was incredulous at reading that article – understandably, there is a limit to the sharing of personal stories and information, but when patients are expected to provide extremely intimate details about their lives to doctors, is it not understandable that they feel some comfort when doctors appear human too?

Patients may have complicated medical histories but it is crucial to view them as much more than their diseases and disorders. I strongly believe that doctors are far more than alleviators of pain and curers of disease. Ours is a deeply personal profession, where

patients are at their most vulnerable and are looking for their doctors to provide care but also to be caring. Being at the hospital can be very emotional, and I think that emotion is important. It is what will keep me human and what will remind me that my patients are human too. This is probably the reason I enjoy writing about my patient encounters so much – because it gives me an avenue through which I can share my experiences and formulate my thoughts about the kind of doctor I want to be. Hopefully, years from now, I can look back on these musings and feel like I have stayed true to myself.

After I finished the rest of my duties at the hospital that day, I went back to see Ms. F. We sat opposite one other, and she reached for my hands. She held them as we looked at each other. She told me about her acceptance of her impending

mortality and how she hopes for a better world where people are not judged or discriminated for who they are. She felt blessed to have had so many wonderful memories, and she prayed that I have wonderful ones in my life as well. When I got up to leave, I was deeply saddened, knowing that I would likely never see Ms. F again, but I also felt like I could not have had a more perfect first patient. She reminded me of the reasons I decided to become a doctor.

It has been almost two years since that encounter, but I know I will never forget Ms. F, who touched my life in ways she probably never anticipated. It was difficult to tear myself away from her bedside that evening, but I know that I will always remember our time together whenever I think about the kind of doctor I want to be. ❖

Reference

1. McDaniel SH, Beckman HB, Morse DS et al. Physician self-disclosure in primary care visits. *Arch Intern Med.* 2007; 167(12): 1321-1326.

Disclaimer

The view expressed herein are those of the author and do not necessarily reflect the views of the Warren Alpert Medical School.

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