Commentary: "When I Use a Word," with Respect for Lewis Carroll

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I don't believe I ever used the word "treatable" in a conversation with a patient or family. I might have said something like, "We can do something about your situation," but it would have been followed immediately by something like, "You'll need to understand more about what that could mean for you." On the other hand, I've certainly been the physician to patients who have been misled by prior discussions, often still angry that some prior physician implied that the situation would be much better than it turned out to be, and feeling duped. I don't feel that my pattern is especially virtuous. Instead, I trace its origin to the fact that I was always in the position of staying with the patient for a very long time—usually until death. I have worked in home care, hospice, and nursing home care. The very fact of continuity made it important to be honest, trustworthy, and reliable. I quickly saw that I did no one any favors by painting a rosy picture, or, for that matter, by "hanging crepe" and making patient and family confront worse outcomes than were likely.

My clinician colleagues working in specialty practices and the usual medical silos mostly don't keep serving patients during decline and death in their homes. Their context can be much more adapted to their sporadic setting, whether they know they are misleading people or are simply doing so without being corrected by an effective feedback loop. Even for shared patients in the intensive care unit, the critical care doctors won't talk about the cancer, and the oncologists won't talk about the sepsis. The family assumes that their physicians are all working together and seeing the whole patient, and they may be. However, they have few forces that ensure that this will happen, including divergent socialization in their specialties. Hospital-based specialists sometimes see people in their offices, well-dressed and behaving, or in the hospital, very sick. Both are misleading with regard to how the person lives most of the time. Some doctors work in continuity care, and some, like me, serve people in their homes and nursing homes through to their death. This group of clinicians sees the whole course, and we can readily see the downsides of providing misleading hopefulness or despair.

People living with serious illnesses and disabilities very naturally prefer to collaborate with a physician in designing plans that optimize their potential future course. They quickly realize that "cure" and returning to conventionally-defined good health are simply not plausible. So the only salient question becomes "*How am I to live as well as possible, given the constraints forced on me by my illnesses and disabilities?*" and the only available measure of what counts as living well has to be one that is customized to the patient and family.

People differ about what matters when they are up against suffering and death. One person focuses on religion and ritual, while another just wants to keep his or her social role. Most have multiple hopes and fears, and the situation ends up pushing compromises on some in order to achieve others. But the point is that the doctor is not "giving orders" as if the medical situation dictated the course.

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The doctor is working with the patient and family to make the best of a challenging situation. Usually, the doctor can see multiple possible paths, must helpfully characterize what life will be like on each, and help the patient and family decide how to proceed—a conclusion that may need to be revisited as the story unfolds.

David DeGrazia and I characterized this distinction as the difference between a "fix-it" model of medicine, and an "outcomes" model.[1] Much of medical care is delivered in the "fix-it" mode of presentation, diagnosis, and effective treatment, leaving the patient restored to health, and this model anchors the socialization of the public and profession. However, as more and more people must live and die with cure-resistant conditions, the fix-it model fails. The patient cannot be restored to "normal."

What medical care can achieve with these common persistent conditions is to help people live better with the limitations that they must face. Clinical medicine can prolong life, relieve symptoms, provide rehabilitation, and support families in most such situations, but there are substantial trade-offs among the possible outcomes, depending upon the course of interventions chosen (sometimes called the "care plan"). How are we to come to a useful plan of care? The obvious answer is that the course chosen must try to comport with the patient's priorities and preferences. The patient who is terrified of pain should generally have a different course than the patient who tolerates pain but not impoverishment. Examples are legion.

Since the patient is ordinarily embedded within a network of relationships, the capabilities, willingness, and preferences of the "kith and kin" often matter also. Even if the patient would prefer to have his daughter provide personal care, if the daughter is unable or unwilling, that course is not available.

So, I would take issue with the very first sentence in Batten et al.: "During discussions with patients who are seriously ill and their families, physicians must communicate whether the patient or medical condition is 'treatable.'"[2] There's no such requirement. What I would contend is required is an honest assessment of the patient's situation and the likely courses, including available alternative approaches (not all being 'treatment'). That discussion (or, more likely, that series of discussions) should enable settling on a preferred course. The elements of that course include medical diagnosis and treatment, of course; but they also can include plans for whatever else is important—for example, family caregiving, transportation, food, managing finances, and rehabilitation. Very often, as the patient's story unfolds, the plan of care needs to be updated, still allegiant to the patient's stable or changing preferences, as well as considering the potential outcomes with various care plans.

I don't know whether it is intentional to have the gap that Batten et al. describe between the various ways that physicians use "treatable," and the nearly universal misunderstanding that patients and families perceive. It may be vaguely perceived or even unapparent to the physicians involved. But I am sure that this obfuscatory phrasing serves to buffer what is usually a very painful narrative to all concerned. Telling a person, or his or her loved ones, about the very different future they now face, given the medical situation, feels to the physician like inflicting pain—wrenching, implacable, and unavoidable pain. It is natural to want desperately to temper that seeming cruelty with less direct prose, and sometimes that is actually kinder and justified for a short time. But the patient and family eventually have to know what they are up against. It becomes a cruelty to encourage false hopes and prevent the patient and family from doing important things that actually accommodate their situation, from adapting to disability to preparing for death.

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We have built a health care system that is so fragmented that the physicians in the hospital not only do not know their patients' backgrounds and communities, they usually don't know how the illness turned out for the patient and family. The old local doctor did, and that doctor also knew whether the illness forced the family off the farm, or required that the patient move to an institution, or simply that the course of care inflicted awful suffering on the patient and family. Our doctors now know so little about the lives of their patients that it is easier to try to fix their malfunction or to gloss over an honest assessment of the situation and its outcomes, rather than to engage with their situation and deliver on the best possible life, given the circumstances. Yet, that best possible life is what we all want.

Notes

1. Lynn J, DeGrazia D. An outcomes model of medical decision making. *Theoretical Medicine* 1991; 12:325–43.
2. Batten JN, Wong BO, Hanks WF, Magnus DC. Treatability statements in serious illness: The gap between what is said and what is heard. *Cambridge Quarterly of Healthcare Ethics* 2019;28(3): 394–404.

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