

# Shared Uncertainty

By Lidia Schapira, MD

Language. We all know it's a powerful tool, but an often-misused one, and a potential source of many misunderstandings—especially between healthcare personnel and patients. In medicine, we often use an expression or jargon that, usually unbeknown to us, is interpreted by our patients differently from the way it was intended. Furthermore, medical terminology often has a different connotation from the use of a word in general discourse. Take, for example, the way we discuss biopsy results: In medical discourse, when a biopsy result is positive, it's bad, whereas in general conversation, when something is positive, it's usually good.

This column, then, is an open forum for your thoughts and commentary, serious or humorous. We invite your experiences where language has caused a problem in your practice or led to opportunities for better relationships with patients. Please send your anecdotes and thoughts to 'How We Say It' c/o The Journal of Supportive Oncology, 26 Cedar Drive, Huntington, NY 11743, or e-mail: jso@biolc.com.

**A**lthough the problem of language in medicine and the consequent difficulties in communication between physicians or nurses and patients are far from new, they are still vexing. Note this quote from a patient, as recorded in the archives of Dr. Samuel Tissot [1], an 18th century Swiss physician: "I don't have any trust in our physicians: they swear by systems, to which they bend all facts; they lack the ability to observe, and their fanaticism for systems and hypotheses prevent them from seeing and studying Nature."

Has time made any difference? In 1999, John Diamond, a cancer patient, wrote [2]:

"The problem with illness is that nothing is certain. I started off with a definite diagnosis—cancer—and nothing more than that. Gradually the diagnosis was refined to curable cancer. And then it was broadened out again: curable cancer, provided it's the cancer we think it is and that the bit we cut out contained its primary source.

"And all the time there are the qualifiers: the probablys and possiblys and the slippery statistics that are wonderfully accurate if you're a whole population and meaningless if you're just a single bloke lying under a lump of fizzing cobalt 90 while the radiographers run for cover behind their lead screens.

"And every extra symptom—real, imagined, predating my cancer, or newly arrived—changes the odds, and

changes them to a number that is unknowable. It is the state that we live in all the time, however, unconsciously. But in these circumstances it's difficult not to try and calculate the incalculable odds. And impossible not to want to...."

With dry wit, John Diamond articulates the essence of shared uncertainty. Speaking as a patient, he reminds us of the soothing effect of clear and precise information. As a sharp observer of human behavior, he aptly acknowledges the difficulties inherent in this apparently innocent request and basic need.

What we say and how we say it are extremely important. Giving information in clear terms, avoiding jargon, and providing visual aids and written documents have all been shown to facilitate patient retention of information and satisfaction with a medical consultation. Using plain language and including patients' own expressions in our dialog help create a relationship that is both comfortable and safe, as well as conducive to shared decision-making. However, one of the most challenging aspects of effective communication is discussing uncertainty.

Even if, as physicians, we take the trouble to "sift through the probabilities" [3] and find ways of presenting statistics in a clear and comprehensible fashion, we still often come up against a wall. We sim-

ply do not know how it will end for that individual sitting with us at that moment, eagerly absorbing every little bit of fact and anecdote, hope, and science that we are able and willing to provide. We struggle with this every day, all the time.

So, in our new age of "patient centeredness," it may come as a sobering reminder that dissatisfaction with physician-patient communication is indeed quite old, superceding geographic boundaries, technologies, managed care, and overspecialization. As Louis-Courvoisier and Mauron [1] remind us, no physician can truly be in a patient's shoes and feel what he or she feels.

Some patients are well aware that their insider's view of their own disease is unique. In our culture, patients often blame physicians for using language that is incomprehensible and only serves to widen the gap between them. In the 18th century, educated patients and physicians shared the same use of language, and yet, as shown previously, physicians were still criticized for not sharing the perceptual reality of their patients' discourse.

How is this relevant for us in the practice of oncology in the year 2004? Nowhere is the patient's testimony as crucial as in the study and practice of palliation. Central to research, as well as practice, are the details of physical, psychological, and spiritual well-being and function that we lump together under the generous heading of "quality of life." As we collect facts and histories, we "make them fit" into standardized scales and categories, using instruments that allow results to be compared and validated. Do physicians and researchers tend to "swear by systems to which they bend all facts"? They may well do so with the goal of making progress, and yet it may prevent them from appreciating the individual subjectivity that defines the human experience.

We can perhaps begin by asking ourselves how we listen to our patients' stories. Do we fast and furiously "make things fit" for the purpose of clear documentation, in a way acting as simultaneous translators from the language of first-

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person narrative to that of standardized medical jargon? Do we really listen both to what is said and what remains unspoken? Then, how do we respond? Our own choice of words ideally should be a deliberate and therapeutically motivated act. And, as much as we value our own objectivity, we must always remember that our seemingly detached and rational advice is colored by our own values and interpretation.

So, in the “saying,” we can best meet our patients’ needs by articulating our joint desire for a good outcome. What is not known and cannot be known need not separate us from our patients. Honoring requests for precision, providing detailed information, and limiting the use of “probablys” and “possiblys” may temporarily alleviate our patients’ anxieties. However, the same anxieties will resurface the next day, when patients experience a new symptom or read an item about some novel research on the Internet. It is perhaps our greatest challenge to craft a relationship that allows for expression of uncertainty without despair. Perhaps a good place to start is by acknowledging verbally and openly that we understand our patients’ need to feel secure and their natural wish for both predictability and order. In so doing, we may be able to attenuate their fears, anxieties, and sorrow and transform the burden of uncertainty into a more tolerable reality.

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## REFERENCES

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2. Diamond J. *Because Cowards Get Cancer Too: A Hypochondriac Confronts His Nemesis*. New York, NY: Crown; 1999.
3. Gearin-Tosh M. *Living Proof: A Medical Mutiny*. New York, NY: Scribner; 2002.