The Myth of the Demanding Patient

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In this issue of JAMA Oncology, Gogineni and colleagues report on their empirical inquiry into patient demands,1 a nemesis that proves to be more mythical than real. The study hypothesis—that patient demands for treatments and scans drove unnecessary costs—was spectacularly unconfirmed when using data collected from physicians themselves. Only 8% of the patient-physician encounters at 3 cancer centers in Philadelphia involved a patient “demand,” and the majority of those “demands” were viewed by the physician as “clinically appropriate.” Suddenly, the demanding cancer patient looks less like a budget buster and more like an urban myth.

In the wake of these findings, the question now deserving of our attention is why does the myth of the demanding patient have so much traction? Surprisingly (as the authors note), no prior empirical study exists to tally patient demands, and a key skill is to notice when you are irritated, and rather than blurt out your defense, pause and step back for a moment. You will then recognize that your patient who is demanding something is actually upset and hurting in a way that is overwhelming their coping skills or, much less often, has a personality such that they deal with everyone in their lives by making demands. A skilled clinician, after the pause, would start with an empathic remark (“Hmm, sounds like this is really important to you”) and uncover the real issue.”

Although demanding patients are not common, they often figure prominently in our memories because our cognitive biases tend to spotlight outliers.4 One reason for this is that a demanding, dissatisfied, unhappy patient can tap into our own unhappiness about not being perfect, our own disappointment about not saving the day, and our own dismay about not being appreciated. If we do not have our own skills to emotionally self-regulate and recharge, we tend to give these cognitive biases more influence than they deserve. We have started our day with stress, multitasking, and inadequate sleep—all very common. It is even easier to let our cognitive biases run rampant. A common cognitive bias, misattribution bias, is particularly relevant for this discussion. The demanding patient leaves us with vivid memories, and it is an easy move to pin the blame for runaway costs.
The real point of the study by Gogineni et al, however, is this: we have to stop blaming patients for being demanding. In reality, it is hardly happening. The myth of the demanding patient is more about our own responses and how lackluster communication skills can contribute to difficult situations that stick in our throats and our memories. And when we have calmed down enough to look up, we see that what is really happening between patients and physicians these days is something quite different.

The demanding patient myth reflects an old paradigm of patient-clinician interactions: the paternalistic physician told the patient what to do, and the patient who did not like it had to resort to a demand to cut through the physician's cloak of authority. But that old posturing is receding in the face of a new dynamic.

We are witnessing a tectonic shift in the dynamics between patients and physicians around cancer. Patients used to come to oncologists seeking information about their cancer and recommendations for treatment. Before the Internet, they did not have any other sources. But now in the age of Wikipedia, patients and their families usually come prepared. Patients and families seek and absorb information from websites, textbooks, their own medical records, or other patients, all unmediated by clinicians, and they come to visits to verify what they have heard, ask questions, and gain from the physician's clinical experience. Patients now begin shaping their preferences and decision making before they set foot in the oncologist's office.

The new dynamic is reflected in a fresh view of interactions from other empirical studies. What patients value from physicians is being guided to the information they need and want; being given that information at a pace they can absorb; having access to the physician's clinical experience; and feeling that the physician recognizes their situation, their individuality, and humanness. This dynamic builds trust between patient and physician so that when they need to face the tough decisions, the medical decision making reflects the patient's real values and not just their fear.

It is possible that what the study by Gogineni et al documents is a point in the evolution of the patient-physician relationship when both sides recognize that the complexity of cancer care belies a simple fix. Perhaps this “negative” study is pointing to an important truth: that we need to redirect our attention from the myths that are distracting us.

In this issue of JAMA Oncology, Ross and colleagues' present results from a retrospective study of 200 consecutive carcinoma of unknown primary site (CUP) tumor specimens that underwent comprehensive genomic profiling (CGP) using the hybrid-capture-based FoundationOne assay. The DNA extracted from these CUP tumor specimens was analyzed after hybridization capture of 3769 exons from 236 cancer-related genes and 47 introns of 19 genes commonly rearranged in cancer. There were 125 adenocarcinomas of unknown primary site (ACUPs) and 75 nonadenocarcinomas (non-ACUPs). The authors reported that a large number of CUP samples (85%) harbored at least 1 clinically relevant genomic alteration (GA) with the potential to influence and personalize therapy. The mean number of GAs was 4.2 per tumor. The ACUP tumors were more frequently driven by GAs in the receptor tyrosine kinase (RTK)/Ras/mitogen-activated protein kinase (MAPK) signaling pathway than non-ACUP tumors. The authors concluded that CGP can identify novel treatment paradigms and suggested that early testing may have utility in CUP management. This study illustrates some important considerations in the diagnostic workup and management of patients with CUP.

In many ways, our viewpoints on CUP management recapitulate the broader evolution of how we approach cancer therapy. Historically, CUP was viewed as a distinct form of