

A Case of Baffling Fatigue With a Spectral Twist

Mr Gee was so tired of feeling so tired. And his seasoned internists and subspecialists were exhausted by their futile attempts to establish a diagnosis for his debilitating fatigue. Sure, they were treating their 50-year-old patient for diabetes, hypertension, heart disease, and renal insufficiency. But, informed by their collective clinical acumen, they knew that, on any clinical scale, his fatigue outweighed any plausible measure.

Besides, Mr Gee's blood chemistries and cell counts doggedly remained near normal limits all the while his profound fatigue relentlessly progressed. Although reporting that he retired to bed every night for an eight-hour minimum, he still easily nodded off throughout the day—often at inopportune moments—which impaired his capacity for work and socialization. Despite his increasing debilitation and isolation, his physicians did not think he was depressed, and they could not implicate any of his usual medications. No evidence supported a causal role for a host of inflammatory, autoimmune, thyroid, adrenal, and sleep disorders.

Mr Gee's primary physician was even more concerned about a second diagnostic conundrum. Reportedly, for weeks, Mr Gee had experienced abrupt elevations of his systolic blood pressure to worrisome levels—beyond 200 mmHg—that tended to occur at night. During those “episodes” he also experienced headaches, tinnitus, nausea, and fear about succumbing to a stroke. Laboratory and radiographic tests in pursuit of secondary causes like pheochromocytoma failed to yield an explanation for these episodes. Multiple antihypertensive trials—with which Mr Gee had been compliant—had not diminished their frequency or severity.

A Senior Consultant Moment

Years ago, in response to an apparent need, my innovative department chief had asked me to provide a part-time clinic as a “Senior Medical Consultant,” devoted to assisting colleagues who cared for patients with elusive diagnoses, or patients with whom they had experienced a therapeutic impasse.

I don't believe that I was asked to undertake this new position because of intellectual aptitude or clinical prowess. Rather, my chief knew that I was attracted to diagnostic puzzles and drawn to the care of patients with complex multisystem illnesses. My background had included doctoring during the early AIDS epidemic, and I was actively practicing as an internist, rheumatologist, and geriatrician. My most winning qualification for “Senior Consultant” was undoubtedly my (prematurely) gray hair.

During my years as the Senior Medical Consultant, I neither cracked all the baffling case referrals nor fixed all the fractured patient-physician relationships. Still, a few triumphs prevailed, and Mr Gee's case is one of them.

When I received the referral for Mr. Gee, I prepared for the consultation in customary fashion. I began by reading all of his paper and electronic medical records, summarizing each seemingly significant clinical notation and test result in chronological order. I then took those data points and categorized them by organ systems. Finally, I tried to make connections between the organ categories and data points, hoping to construct a wholly illustrative diagnostic picture to explain the patient's troubles. Sometimes this preparatory exercise revealed a diagnosis well in advance of a scheduled consultation, allowing more-timely discernment and treatment of a patient's illness.

But that did not happen in this case. In fact, when I tried to connect the voluminous data points I'd culled from Mr. Gee's medical records, I only drew a ghostly blank.

Still, I remained optimistic. For I had learned from experience that whenever a wealth of diagnostic points proved to be utterly pointless, it was highly probable that we physicians were inaccurately pinpointing that patient's story. That generally meant a return to the drawing board for a reconstruction of the patient's narrative, with hopes of sighting new diagnostic and therapeutic possibilities.

Returning to the Drawing Board— And Blanking the Canvas

Encouraging a patient to frame his illness within his own experience of its beginning, its current middle, and its imagined ending will often expose clarifying diagnostic clues. That's because patients frequently situate their illnesses within contexts of time and events that don't match those documented in their medical records (where, for example, the beginning of an illness is frequently tethered to the sentinel date of a clinic visit or an abnormal lab report). The revised historical timelines allow previously ignored but germane symptoms to be newly included within the diagnostic analysis. Also, a patient's telling of his imagined future, living with the uncertainty of an ambiguous disorder, often reveals his projections or fears—illness expressions that you can sometimes trace back to inchoate somatic murmurings in the present that translate into useful clues.

Whenever patients use clinical terms—like “seizure” or “MI”—while telling their stories, I ask them to reword those terms in laypersons' language. This request is regularly illu-

minating because patients' translations of the "med-speak" they've adopted through clinical encounters frequently divulge idiosyncratic understandings of their illnesses and prognoses. Accurate diagnostic clues—buried under long-standing and unchallenged semantic errors that throw us off-track—can be unearthed in the rewording. For example, a patient's lay narration of having a "lupus disorder" can turn into a story about ... well, about many other alternate diagnostic possibilities.

When hesitation or silence prevails during a consultation, I try to wait it out, until the patient speaks. This practice of waiting often feels excruciating—a minute of silence seems like an eternity in the clinic or at the bedside, all the while I struggle to cultivate a comfort zone for me and for my patient. And though this practice aims to generate a welcoming space for the patient to articulate what has remained unsaid or unsayable, it also provides an opportunity for me to rest meditatively, if only for a minute, in my immediate experience of doctoring and relationship.

Above all else, my ultimate goal is to come to *see* the patient's narrative—not just hear it, but actually see it, as though it were a movie or a documentary. For me, that requires the patient's detailed exposition of his or her point of view, and full-bodied structural exhibitions of the "who, what, where, when, why, and how" of their story.

So, the day Mr Gee arrived for consultation, I would

"blank the canvas." I'd put aside my voluminous notes and diagrams, place blank paper on the table, and ask him to tell me what had happened to him—from his beginning of his story, to his telling of its imagined end.

Mr Gee's Story Unfolding

Mr Gee cast his eyes downward when I entered the exam room and greeted him. Sitting precariously on the edge of a chair and dressed in casual attire (not quite befitting his nervous demeanor), he murmured "hello" and abruptly stood. He walked toward the doorway and asked, "How long is this appointment going to take?"

"We have an hour to talk," I answered. "Is this a bad time for you?"

"No," he replied. "I just thought the nurse made a mistake when she scheduled this. A whole hour? Why so long?"

"Because," I explained, "what we need is time—not another CAT scan or blood test now—to try to figure out why you're feeling bad. Is that okay?"

Mr Gee nodded and slowly returned to his chair. I placed several blank sheets of paper on the table between us and asked, "So tell me—when was the last time you ever felt completely well?"

It had been months since Mr Gee had felt well—long before the onset of his fatigue and hypertensive episodes as recorded in his medical record. This allowed us to more

Commentary

Gathering the Patient's Story and Clinical Empathy

While nothing replaces meeting with a patient, reading another physician's description of interviewing a patient can provide insights into physician-patient interactions that we cannot get when we ourselves are involved. In my view, "A Case of Baffling Fatigue with a Spectral Twist" illustrates clinical empathy in action. Often confused with compassion, sympathy, and other benevolent emotions, clinical empathy involves emotional resonance, but is distinguished by curiosity. Whereas sympathy involves feeling as if one were "in the same boat" with another, empathy involves curiosity about another's distinct experience. Vividly and specifically imagining another's distinct world becomes possible with careful, attuned listening.

Until the past two decades, physicians (unlike other caregivers) have been skepti-

cal about empathy, assuming that it would interfere with their clinical objectivity and effectiveness. This has shifted as research has shown that empathy plays a fundamental role in both diagnostic accuracy and treatment effectiveness. Repeated studies show that patients first give superficial clues about their histories until they sense empathy, and only then disclose anxiety-provoking information (as happened in the reported case).¹ Such disclosure is crucial for making the correct diagnosis. Empathy is also important for establishing trust, and trust is a powerful determinant of adherence to treatment and thus effectiveness of care.² Even when clinicians need to deliver bad news, their empathic engagement matters, empowering patients to take earlier steps in organizing treatment and self-care.³

Clinicians today want to provide empathic care, but are unsure of just what actions they are supposed to incorporate into their daily practice. Since we cannot just will ourselves to feel certain emotions, what needs to be taught are specific skills or approaches that engender empathy. One of the best studies thus far suggests that one way to "practice" empathy is to learn to help patients tell *their* stories, exactly as Kate Scannell, MD, does here.⁴ However, readers may wonder how Dr Scannell connects so well with this patient, enabling him to share his story. What specific skills or lessons can we glean from Dr Scannell's approach?

First, she is genuinely curious about the patient. This requires tolerating uncertainty, so that when the data points don't connect, Dr Scannell is intrigued rather than frustrated.

Jodi Halpern, MD, PhD, is a Psychiatrist, Associate Professor of Bioethics and Medical Humanities, Joint Medical Program, School of Public Health, University of California, Berkeley. She is the author of "From Detached Concern to Empathy: Humanizing Medical Practice" reissued with a new forward in paperback edition, July 2011. E-mail: jhalpern@berkeley.edu.

accurately examine an extended time frame in which to contextualize his complaints and search for overlooked contemporaneous somatic and psychosocial clues of potential diagnostic relevance. Notably, we newly established that when he'd begun to feel unwell, "something happened" between him and a friend—but he declined to further explain. "It's personal, and I don't want to talk about that," he said. "It makes me feel ashamed."

Mr Gee had trouble continuing his story after this poignant self-admonition, so I invited him to restart his story at its end and proceed backwards. And that's when one big missing piece of the narrative track newly snapped into rightful alignment. For, when imagining his future with his mystifying symptoms, Mr Gee twice mentioned his father in a seemingly incidental manner. This was intriguing because I had learned through family history-taking that his father had died decades earlier. How was he somehow still active in the patient's felt experience of his illness? Endeavoring to "see" the patient's story, I asked: "Can you tell me how your father looks in this future of yours?"

Silence followed. Mr. Gee looked away and stared at the wall. Maybe 30 very long seconds passed before he finally said, "He looks like a person who is dead."

A variety of images (some unsettling) sprung to my mind, so I asked for clarification. "You mean, like a dead body, someone in a coffin?"

"No," he replied matter-of-factly. "Like a ghost. Like he looked when he was alive, but he has no body."

Mr Gee then described how his father had appeared during life, and he reported that his father's ghost had most recently visited him several months earlier. I asked, "And what is that like for you, seeing your father as a ghost? Is it frightening or pleasant or—what?"

"It feels good to see him," Mr Gee replied. He explained that he'd been raised within a household that was regularly inhabited by ancestral ghosts who were revered by his Asian parents. His parents had taught him to stay ever-mindful and respectful of the ghosts who, in turn, would watch over him and fend off evil specters. To imagine his father's ghostly presence afforded him great comfort.

I was trying to see the patient now in the context of suffering his symptomatic hypertensive episodes—wanting to visualize what he actually did during those nightly attacks; wondering if he saw his father "around"; needing to envisage how he actually took his blood pressure readings and documented the spikes. So I asked him to describe these things in solid details—"like a video of your experience, in your words."

He described his bedroom and the way he slept—always on his back—when his episodes occurred. But when I asked him to show me how he used a cuff, he simply stated: "I don't."

I was distracted momentarily by the loud "thud" sound-

Further, rather than defensively presuming that the patient is either "a poor historian" or worse, covering up or faking something, she assumes that "we physicians [are] inaccurately pinpointing the patient's story." So she meets the patient with empathic curiosity rather than suspicion.

Second, we might borrow her way of framing her interview with the patient. She asked him to tell her what had happened "from *his* beginning of the story, to his thoughts about its imagined end." Many of us occasionally ask the patient for his/her beginning, but we should do so more often. Not only does this provide information about symptoms that pre-exist medicalization, but the patient's subjective reconstruction of the past also helps us to understand what motivates him/her, which is crucial for building a therapeutic alliance.

Asking for the patient's imagined view of the end of the story is rarely done, and strikes me as a crucial innovation that we should all adopt. Dr Scannell describes beautifully how we can learn of the patient's "projections or fears—illness expressions that you can sometimes trace back to inchoate somatic

murmurings in the present that translate into useful clues." This patient mentions his father, long dead.

What happens next is crucial. Dr Scannell does not challenge the patient on the facts, but rather invites him to tell her how his father looks in his imagined future. This is the gateway to his sharing his experience of ghosts, of needing the lights on and never sleeping. Insofar as empathic listening is an act of imagining, not an exercise in deductive reasoning, inconsistencies and irrationalities are crucial clues, rather than errors to be corrected.

Importantly, what invites this frightened patient to share this information is not just Dr Scannell's lack of suspicion and criticism. It is her positive presence. Her question about his father is followed by a long silence before the patient shares highly private thoughts. What is this silence like for the physician and for the patient?

Dr Scannell, like other very busy clinicians, finds it hard to wait and not interrupt. In reality, given the severe time constraints most physicians operate under, letting a patient talk without interruption might seem impossibly

demanding. Despite some research studies showing that good communication can often be achieved in a time-efficient way,⁵ patients like Mr Gee clearly take more time to interview than current systems of care allow. Current systems are shortsighted to put clinicians under so much time pressure that listening to patients with complex histories becomes impossible. Careful listening not only directly improves patient satisfaction and effective care, it might actually save overall time by preventing conflicts and misunderstandings down the line.

Dr Scannell shows how patient listening contributes to history taking. She stays quiet to "cultivate a comfort zone for me and my patient ... an opportunity for me to rest meditatively—if only for a minute—in my immediate experience of doctoring and relationship." Being calm and truly present with the patient is a powerful way to establish a therapeutic alliance. Taking a quiet moment is especially valuable for highly caring clinicians, who are more likely to become anxious when seeing patients whose treatment is not going well, which can interfere with empathy.⁶ Research shows that pausing and

ing within my head. A moment later, I was able to ask the obvious question: “Then where do those high blood pressure numbers come from, Mr Gee—the ones you’ve been reporting to your doctors?”

Med-speak translation revealed that Mr Gee’s notion of “blood pressure” and its metric assessment could be wholly subjective. As he explained, the discomfort he felt during the “episodes” felt like some terrible build-up of internal pressure that, when extreme, would merit his assignment of a “200 or more” point rating.

“Oh,” I managed, understanding now that his hypertensive crises were ... well, not hypertensive crises. I wondered what other essential elements of his story had been lost in our translation. Scrambling for answers, I then asked Mr Gee to describe in detail what he actually did during the attacks.

“Nothing,” he said. “I am just in bed, and I stay there.”

“But you said you felt like vomiting when your pressure was high. Don’t you sometimes get up, maybe turn on the lights and run to the bathroom or —”

“No. The lights are already on,” he explained. “I don’t get up.”

“But why are the lights on if you’re in bed, sleeping?”

He looked directly at me, and the subsequent tone of his voice made it sound as though the answer was obvious. He said, “I keep the lights on while I am in bed because the

ghosts come out in the dark. I keep the lights on to keep them away, so I do not sleep.”

Within that illumination, the rest of the story became increasingly visible. Importantly, we could now see that the diagnosis for his cryptic fatigue was not-sleeping, for fear of ghostly visitations.

But why was his father’s ghost no longer visiting and capable of comforting him? Where were the protective ancestral ghosts?

Mr Gee explained that they had abandoned him. Whatever had caused him to experience shame—marking *his* defined onset of feeling unwell—had also merited their strong disapproval.

“I am sorry,” I said, handing a tissue to Mr Gee.

I interpreted Mr Gee’s subsequent silence as continuing indication that he did not want to speak about that troubling event. Still, I could not see what he was actually afraid of, what caused him to wear himself down and become so ill. I asked, “What do the bad ghosts look like?”

“No—It is just one ghost,” he answered. “He was a neighbor in my apartment building, and he died.”

Through his further detailed telling of the “who, what, where, when, and how” of his illness, it was revealed that the neighboring tenant had died a few days after having accidentally witnessed Mr Gee’s self-incriminating indiscretion.

taking a breath decreases clinicians’ anxiety and improves communication.⁷

How did the patient experience the silence? Research shows that patients judge the trustworthiness of the clinician on the basis of their nonverbal attunement or lack thereof. Being silently present with the patient as Dr Scannell describes is a good example of nonverbal attunement. Interrupting at such moments, in contrast, has repeatedly been shown to cut off patient disclosure. Assuming that Dr Scannell’s facial and other gestures conveyed to the patient that she was present and not just spacing out, the patient is likely to have felt accompanied by her during the silence. Patients appreciate it when they feel a sense of “being with” their caregivers.

There are other specific lessons from Dr Scannell: ask the patient to restate medical terms in his or her own words, and ask them to describe medical procedures they do at home. In this case, for example, the patient tells her that he doesn’t actually measure his blood pressure, so we realize that his description of blood pressure going up to “200 or more” is meant to describe the boiling up of intolerable feelings of guilt, fear, and anxiety.

In summary, empathic communication can be enhanced by specific practices, many of which are illustrated in this case report. When possible, invite the patient to tell you his or her own story, from its beginning to its imagined ending. Try to pause when the patient is obviously processing an emotional issue. Practice patience by becoming more aware of your own embodied reactions, and if you feel anxious, take breaths or otherwise relax yourself, to give the patient the message you are truly present and not in a rush. Your tone and gestures will convey your genuine emotional resonance, but be wary of making overreaching statements like: “I know how you feel.” When a patient says something contradictory or seemingly irrational, avoid correcting him or her and ask instead, “Tell me what I’m missing?”

Beyond all these suggestions, cultivate an overarching attitude of engaged curiosity. This involves recognizing that patients bring in complex histories that we often misunderstand, and that we truly need to listen to their accounts to help us help them. Crucially, empathic curiosity is not the curiosity of a detective. Patients will not tell their stories if they feel barraged, or under an inquisition.

Thus clinicians need to be mindful of their own emotional responses, and take quiet moments when necessary, so that they can be truly present and nonverbally attuned to their patients. ❖

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Consequently, Mr Gee believed the tenant's ghost had come to haunt his apartment in punishing retribution, taking advantage, too, of his protector ghosts' parallel abandonment.

In essence, the only thing to do was to keep the lights on throughout the night. Not sleeping. Abiding panic attacks. Waiting for the ghost of a chance at redemption.

Dénouement

I saw Mr Gee once more, for a final visit two months after our initial one. By then, he was happily in treatment with the psychiatrist I'd consulted who had helped to ease his insomnia and panic attacks, while not pathologizing his cultural beliefs. He was also able to reveal to her the nature of his shame, and that seemed to open up another avenue for healing—down-to-earth talk-therapy in the psychiatrist's office. His primary care physician and subspecialists were relieved that rational diagnoses had been established for Mr Gee's clinical complaints, and they were able to downscale his

antihypertensive protocol. Mr Gee was grateful that "all the blood testing and x-rays" in pursuit of diagnoses had stopped.

As we shook hands goodbye, Mr Gee said, "Thank you for letting me tell about the ghosts. You did not make me feel stupid."

It pained me in the moment to hear how he had felt silenced by his fear of such judgment from my profession. But I also made note to remember his words on behalf of future patients, to stay vigilant for the confounding power of shame to subvert diagnostic clarity and create perplexing distances between physicians and patients.

"Mr Gee," I called out as he passed through the exit. "Did your father ever come back?"

He turned to me and pointed his index finger upward. "Not yet. But I know he is coming soon." ❖

Note: Personally identifiable features have been altered to protect the patient's identity.