

Borders without Doctors

VYJEYANTHI S. PERIYAKOIL, M.D.

THE PALLIATOR'S DIARIES

“**W**HERE WERE YOU? Andy has asked to see you several times,” my friend Karen (one of our nurses) greeted me as I walked into our Palliative Care Unit. “Why? What is bothering him? Is he in pain?” “No! Just wants to see you, I guess. He is transitioning you know . . .” *Transitioning* is a euphemism for active dying often used on our unit.

“Have you called his family yet?” I asked, knowing full well that this would have been done as a matter of course. Karen did not bother to dignify my question with a response other than to give me one of her “you-poor-doc-on-training-wheels” look.

Andy was a 52-year-old engineer with metastatic non-small-cell lung cancer who had been admitted to our unit a few weeks ago for terminal care. A pragmatic engineer to the core, he closely supervised all details related to his dying including his own funeral arrangements and financial care plans for his beloved wife and two adult children with immaculate engineering precision. Maybe because of our common interest in physics, Andy and I had struck a great rapport and we often indulged in geekspeak about transistors and transformers.

“Why this sudden and uncharacteristic urgency to see me?” I wondered walking into his room. Per nursing all his symptoms were well palliated. We had done a couple of family meetings and all the stake holders seemed to be on the same page. When I walked in, Andy was awake and alert sitting up in bed and comfortably propped with a couple of pillows. “Good, you are here!” he greeted me “I was afraid that I was not going to be able to pull this off”

After the initial pleasantries, I launched into a quick interval history and physical examination that Andy patiently tolerated. “Bed bound, very weak, stable vital signs, but no overt signs of active dying . . . the

prognosis is probably in the order of days. . . .” I categorized Andy mentally. Thus reassured that I was not missing any major medical happening, I turned toward Andy when he requested gently, “Why don’t you go grab a chair and sit down? Hate to ask you to bring the chair, but I am too tired today.”

Why was he asking me to bring in another chair when there were two perfectly good empty chairs in his room that I had used numerous times in the past? As I looked in askance at the two empty chairs near the window, Andy perceptively followed my gaze. “Oh yeah! Doc, I want you to meet my folks,” he said waving airily toward the empty chairs. “Your folks? Are they in town? But I thought you said that they were d . . .” I swallowed the last word hastily.

I recalled that Andy was an only child and that his parents had died many years ago. I instantly went into the medical mode and started barraging him with the typical orientation questions, “Do you know where you are? What year is this, what day, what date . . . ?”

“I am at the Palo Alto Hospice Unit, today is . . .” he rattled out the day, month, and year and finished with “and you are my doctor and you specialize in Palliative Care.” Now, looking a touch impatient, Andy said urgently “Doc! Listen, I think it’s time.” “Time for what, Andy . . . ?” I said in my best humor-the-patient voice. Meantime, my mind was busy formulating a differential diagnosis. The patient was acting strange . . . but he seemed alert and oriented . . . was he going psychotic on me? Delusions? Hallucinations? Maybe he is on too much morphine. Or could it be brain metastasis . . . I have to scan his head. No . . . no . . . That is silly. What am I going to do with the imaging results? No one was going to touch him, given his present condition. OK, might be best to curbside psych to be on the safe side and . . .

“Doc, doc . . .” Andy insistently interrupted my internal monologue. “Listen . . . We don’t have a lot of

time here. I really want you to meet my folks. I have told them all about you . . . they want to meet you.” he said pointing towards the still empty chairs and looking expectantly at me. Now I was starting to feel distinctly uncomfortable. Studiously avoiding making eye contact with the two empty chairs, I said reassuringly, “Andy, you are doing fine, but I do want to run a couple of tests and start some new meds and . . .” Andy, however, was not attending to me at all. Instead, he was intently focused on the two empty chairs and seemed to be listening to them attentively. Finally, he turned to me and said, “My parents want to say thank you for all you have done for our family.” Not knowing quite how to respond, I stood there awkwardly clamping down an intense urge to leave the room. “He’s delirious and that is all there is to it. A little bit of haloperidol and the rational engineer will be back again in no time,” I remember thinking.

Meantime, Andy was still looking expectantly at me, clearly waiting for me to say something that would endorse his parents’ visit. *But . . . what was I supposed to say?* My patient had ventured into a territory that was completely foreign to the field of evidence-based medicine. How then was I going to validate his experience? I was completely out of my league and had trouble finding even the right words. However, here was a patient who was clearly looking for and *needing* my therapeutic endorsement.

“Why are they here?” I asked finally, very reluctantly turning towards the two chairs (which were still empty, by the way) with an uneasy smile on my face. Even as I stood there desperately wanting to take back my question, Andy looked at me smiling peacefully and said “Oh! To lead me to the light, of course.”

Andy died peacefully a few hours later with his family (both visible and invisible) at his bedside.

DISCUSSION

A key challenge in palliative care research and practice is objectifying the patient’s subjective reality in a rigorous and scientific manner and thereby generating

a body of empirical data that has the “look and feel” of generic biomedical research. Many important palliative care questions and concepts are somewhat elusive to standard research methods thus leading to methodological challenges related to the effective categorization and the meaningful interpretation of the subjective reality of dying patients. However, the modern practice of biomedicine is grounded in and guided by a robust base of evidence. While evidence-based data is often helpful in guiding clinical practice, it cannot be denied that there are many instances in end of life care where both the clinician and the patient experiences defy the narrow precincts of Western biomedicine. Thus the conventional medical model clearly begins to fail when it demands that the disease be dealt with as an isolated entity,¹ independent of psycho-socio-spiritual contexts and that any ‘aberrations’ should be explained by measurable biochemical, neurophysiological or psychiatric abnormalities. As exemplified by Dr. Von Gunten’s intriguing patient anecdote in his pioneer essay,² sometimes the reality is that the disease manifestation is strange and can defy scientific explanation. “Unusual” clinical problems may often call for unconventional and nonmedical solutions and most importantly such solutions may bring solace to distressed patients and families and promote holistic healing. Or in the words of Albert Einstein “not everything that can be counted counts and not everything that counts can be counted.”

REFERENCES

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Address reprint requests to:
 Vyjeyanthi S. Periyakoil, M.D.
 3801 Miranda Avenue
 100-4A
 Palo Alto, CA 94304

E-mail: periyakoil@stanford.edu