

BREAKING THE TABOO ON PRIVATE KNOWLEDGE IN PUBLIC DISCOURSE ABOUT MEDICINE

With grateful acknowledgment of my co-teacher, Elisabeth Targ, MD (1961-2002), for her ongoing inspiration and influence and with thanks to the Mind Science Foundation for support.

Elisabeth Lloyd Mayer

A number of the quotations cited in this chapter are taken from the book *Extraordinary Knowing* by Elisabeth Lloyd Mayer (NY: Bantam Books, forthcoming).¹

" . . . what's hardest for me is how split I feel between what I do and what I say I do . . . so much of how I help patients happens in the reaching out that's personal and ineffable . . . I never talk about that with colleagues . . . "

" . . . what's hardest for me is how lonely I feel professionally because I know spirituality heals people and I have no colleagues I dare say that to . . . "

" . . . what's hardest for me is the language I must use to communicate to my patients . . . the perception I have that I must act and speak a certain way or I will be judged odd or out of place . . . "

" . . . what's hardest for me is the fact that under the guise and fabric of 'science' and empiricism I feel constrained, not only constrained but actually saddened by how unable I am . . . to give voice to what I intuitively know are holes in the souls of my patients . . . "

" . . . what's hardest for me is how secretive I am about my spiritual life with other doctors. . . . I pray for every patient before I operate, but I've never told that to another surgeon . . . "

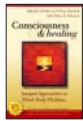
" . . . what's hardest for me is. . . the separation I have been taught to erect between myself and my patients. . . . there's a fundamental level of communication and love that is considered 'unprofessional' . . . "

The preceding are six quotations out of hundreds turned in by residents, faculty, attending staff, and other health professionals during the first session of a year-long seminar at the University of California Medical Center in 1999. My colleague, Elisabeth Targ, MD, and I had been asked to offer a course on spirituality as part of the general curriculum in psychiatry. We'd expected interest from a small group of residents. Instead, within 3 days of announcing the seminar, over 200 people had signed up. They hailed from every branch of medicine. They included every variety of health professional at every level of training. We accepted the first 60 on the list. But we rarely had fewer than 150 show up.

During the first session, Elisabeth and I lectured and then asked people to write for 3 minutes. They were to start by finishing the following sentence:

"When I think about spirituality and my professional life, what's hardest for me is . . . "

It was a private exercise, aimed at encouraging a moment's personal reflection before we began wider discussion. Nonetheless, once the floor was open, the first thing that happened was a woman raised her hand and said she'd like to read what she'd written to the group. Another followed, then another, and before long we'd heard close to 20 people read their 3-minute pieces.



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By the time we closed, there were still plenty of people with raised hands, all wanting to contribute. We offered to collect and distribute the responses. We ended up with a huge sheaf of randomly assorted pages, all starting with that same first phrase. There was no question: The exercise had tapped a nerve.

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It turned out to be a nerve that wasn't hard to tap. I shouldn't have been surprised. Two years earlier, I'd been teaching with another colleague, Carol Gilligan, PhD. We were co-teaching a graduate seminar on theories of knowledge at Harvard. Students came from all over the university-including health care, basic science research, and philosophy of science. Early on, we'd invited everyone to bring in accounts of knowing that they felt they couldn't explain. The topic wasn't spirituality, but a number of students identified spirituality as central to the knowing that they found disturbingly outside their customary ways of explaining things. The astonishing thing was the way the stories poured out. They emerged with the same eagerness we saw in the seminar at UCSF-and carried with them just the same expressions of conflict, anxiety, and inhibition. They were stories about ways of knowing that didn't fit. They were about ways of knowing that the students deemed non-rational or-more disturbingly-irrational. Many were about frank anomalies. They didn't make ordinary sense.

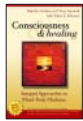
A great number of the accounts were about apparently inexplicable intuition. There was the woman who was suddenly sure her brother had been in an accident on the other side of the globe. He had. There was the young man who'd woken with chest pain at the moment his father unexpectedly died of a heart attack. There were the many reports of more ordinary moments. *"I always know when one particular friend is going to call. I'll think of her and within minutes, the phone rings-I'll know it's her. Sometimes it's after months-sometimes just 2 days since we've talked. How do I know? It's bewildering."*

Despite their eagerness to describe such moments of knowing, the students watched how hard they worked to explain away each instance. Coincidence-mere coincidence, they'd say.

From there, discussion would unfold. We'd agree that coincidence happens. We talked about statistics and probability, about six degrees of separation and the fact that human egocentricity tends to land us perpetually center stage. We're constantly tempted to find personal implication in the world around us, warranted or not. On the other hand, we kept encountering students' nagging subjective sense that some of these knowings came with a different feel-simply couldn't stay relegated to a category of randomness and coincidence that was meaningless. The more we investigated that sense, the more we recognized how important but worrisome students found even momentary willingness to credit their knowings. It took them dangerously outside the rules and outside acceptable academic discourse. It opened doors that were just too weird, spelling trouble in the academic, medical, and scientific worlds these students wanted to join. This, after all, was Harvard.

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That implacable quality of anxiety surrounding experiences of apparently anomalous knowing soon became the most fascinating aspect of our discussions. Our students recognized that they were not nearly as free in bringing a spirit of open-minded inquiry to apparently anomalous knowing as they were to other kinds of knowing. But the paradox was-they wanted to. They were palpably relieved at telling their stories-at bringing them out of the closet. But



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even more, they were relieved to think such experiences might be welcome inside rational discourse-might be subject to serious scrutiny and assessment. Staying rooted in the rational world while making room for those experiences was not just a relief. It was exciting. It opened remarkable possibilities. And it meant as thinking adults they could be real. They could stop leaving parts of themselves at home, excluded from life in the thinking world.

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I'll describe one more venue that produced a deluge of reports regarding experiences of knowing that didn't fit. These reports were from a discussion group at the bi-annual meetings of the American Psychoanalytic Association. I'd proposed convening such a group to the APA, and given that Carol Gilligan was no more finished with the questions we'd been considering than I was, I invited her to lead it with me. We kept going over our stack of student accounts, stories about apparently inexplicable knowing. What might they teach us not just about knowing but about the limits of knowing? Why such eagerness to tell the stories, along with all the embarrassed caveats about how they rarely revealed such things? How did both reflect on the culture of public conversation in which we live? The public conversation we find acceptable? The public conversation we rely on to further comprehension of what we know and how we know it? What might those accounts teach us about how our society handles ways of knowing that we label anomalous? Knowing that refuses to fit?

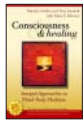
We decided that it would be intriguing to consider those questions with other people accustomed to thinking about the mind with its many capacities, defensive maneuvers, and quirks. So we issued an open invitation to APA registrants: psychoanalysts, mental health professionals, and a smattering of academics and neuroscientists. The task for the discussion group would be to undertake sober scientific consideration of anomalous experiences and the possible existence of anomalous mental capacities.

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We'd told the APA Office that we'd accept as many as 60 sign-ups for the group. Hundreds tried to register. We decided to open the group, but we wanted participants who were actively engaged, not attending as voyeurs. So we specified that attendance was contingent on submitting a written account of an apparently anomalous experience-personal or clinical. Even the requirement of writing something didn't stem the tide. Accounts arrived daily on my doorstep.

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" . . . This is about something I've never publicly revealed to colleagues. It happened soon after I finished residency. I'd been diagnosed with a viral meningoencephalitis. Over the course of my being worked up, they discovered a large mass in my chest along with infiltrate throughout my lungs. It turned out to be disseminated sarcoidosis. I lost 45 pounds, and the disease seemed to be taking its expectable course-invasion of other organs and a high probability of death not too far off. I began meditating-then running-mostly to calm myself down. I had young kids, an active career-I wasn't handling the prospect of an early death well at all. Without knowing what I was doing, I felt the impulse to focus on my actual cells- my literal physical cells-as I ran. Then I began focusing on the lesions. And something very strange began happening. It will sound hallucinatory and crazy- I thought it was totally crazy at the time-but all I can say is, it was also very real and powerful. What started happening was I literally became those cells and those lesions while I ran. And once that happened, I discovered-I know, it's crazy!-the lesions were getting smaller. I watched the lesions resolving, and I was them resolving.



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Sure enough, the mass started decreasing, and after 3 years the infiltrate was gone. Gone. Eventually the mass totally disappeared. I was written up in a medical journal as a case of spontaneous resolution of a disseminated sarcoidosis that was entirely unexpected and unexplained.

The evidence for what happened is medically irrefutable. That experience didn't just change my life because I was cured-it also opened a world of possibilities about . . . things we're normally unaware of . . . things that make no sense in the medicine we talk about with colleagues . . ."

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". . . I'm Indian, and that makes it both easier and harder for me. In Asian culture, things that the West finds inexplicable are perfectly normal as part of medicine. Nothing anomalous at all. In fact, those things are welcome. They help healing. In medical school I found out how not-normal those things seem to Westerners. They're not rational. They involve things that don't abide by limits set by space or time. Sometimes they involve physical changes through someone's mere touch-like the touch of a spiritually powerful teacher. Or they involve impossible knowledge-diagnostic or prescriptive knowledge there's no way to explain. That scares people. In the East, mind and matter aren't so separate . . . my mother, in London, always knows what I'm thinking. As a teenager, that was hard. She'd call and confront me the next morning with whatever I'd done the night before she didn't approve of . . ."

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". . . I was treating a child who's 4 years old. It was October 2, the anniversary of my brother's death. He drowned when I was 24 years old, and it was a profoundly painful loss for me. It's still very much with me; I'm always aware of him on that day. The child and I were playing. I felt we were thoroughly in tune, working well together. Suddenly, in the middle of our session, she looked up at me, panicked. 'Your brother's drowning; he's drowning! You have to save him!' I was stunned. I hadn't been aware of thinking about my brother at that moment, but as I say, he's never far from my thoughts on the day he died. Of course, I'd said absolutely nothing to the child. I'd said nothing-ever - to her or anyone remotely connected with her about the fact of my brother's death or the fact that there'd been a drowning-nothing. I know that child picked up on what I'd been thinking. I believe this kind of thing happens not infrequently-and I also think you're right to use the word anomalous for it. We don't usually admit to it, but if one is open, attuned, really connecting, really working well with a patient-it happens."

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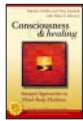
It's not just the stories. Once we start talking about them, it's also the ripple effect they have, each one bringing others out of the closet. And it's the alacrity with which people share them: testimony to their hunger for bringing crucial, private, often strikingly anomalous experiences into public conversation about the work they do.

"I can't believe I'm finally talking about this-why don't we talk like this in training . . . or in study groups . . . or somewhere! I feel so invigorated by being open about these things-finally!"

"There are colleagues in this room I've known for 30 years, and it never occurred to me they'd be sympathetic to hearing about these experiences. This is a first for me-talking this freely."

"This is-bar none-the most authentic clinical discussion I've ever been part of."

"My artist friends don't mind this stuff- I talk to them, but never to my colleagues about the ways I really get to know my patients. Sad, but that's how it is."



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"What a relief to know that others have these experiences, too. What a relief to find colleagues who also want to understand experiences that just don't fit the way we usually think."

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It's an extraordinary mass of data that comes out of all these statements—deeply personal, deeply puzzling, and ultimately deeply troubling. It's data about the culture of science and medicine we currently inhabit. It's data with a single storyline. Something is breaking inside the people telling their stories. That's bad not only for them. It's bad for everyone else—patients, health-care communities, and the systems within which our society tries to help, understand, and heal.

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At the heart of what's troubling is the profound and pervasive conflict packed inside the stories. It's conflict that's rampant in our culture. It's intensely destructive. It's destructive for society as we look for ways to help knowledge grow and develop. But it's also destructive for individual lives. It corrodes the most personal and private corners of how people experience themselves in the world. It's conflict about what to do when the potentially anomalous comes your way and you can't allow yourself to acknowledge it publicly. It's conflict that comes long before deciding whether or not the experience is true, much less makes sense. It's conflict about admitting to the experience at all.

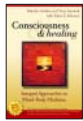
There's a sense of helplessness that ensues when people deny, half-deny, or stay purposely fuzzy about their personal experiences of what's real. The self-betrayal becomes a slippery slope, as honest people start to feel dishonest and thoughtful people stop themselves from thinking. Life gets compartmentalized. Reminders of the inadmissible are ejected from the territory of the real. They're not allowed to matter. Life shrinks down as a result. Symptoms develop. The mind works overtime at making sure the inadmissible stays firmly outside conscious awareness or explicit revelation. At best, it's a compartmentalization that's acknowledged. But at worst, the fear of appearing overly credulous or even crazy leads people to daily disavowals that can paralyze their creativity, conscience, and freedom to be themselves in the world.

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According to the outpouring of accounts, the inadmissible lives in knowing that smacks of the spiritual, the subjective, and the mysteriously intuitive. It's knowing that's generically nonrational and sometimes frankly anomalous. For people who live by science, those ways of knowing bear an uneasy relationship to the science they've loved and learned to trust. Uneasiest of all is the knowing that doesn't play by ordinary rules separating mind and matter, time and space or the boundaries that differentiate individuals. Life in the realm of the rational expects those separations to be inviolable. When they aren't, we're up against the potentially anomalous because Western science simply can't contain it. Although we may happily toy with the anomalous when it comes to science in theory, it's different when it comes to science as it's applied. We eject anomalies from science in everyday life. In the real world, anomalies turn too much upside down. In the real world of medicine, anomalies stand to change everything. At least, that's the fear.

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And that's where we lose. That's where we get our troubling stories. The first challenge facing integral medicine entails confronting the fear of what we have to lose. What happens if



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we welcome all the private knowings that have no place in conventional medical discourse? We need to face that question because the cost of our current fear is huge.

It's huge when it comes to the progress of knowledge. Whatever truth turns out to characterize the stories omitted from public discourse about medicine, stories that stay resolutely private can't be studied. They're lost to us as data. We lose them as a basis for questions, as stimulus to new ideas, as challenges to conventional ways of thinking-even as avenues by which we convey colloquial clinical wisdom. All that represents loss of potential knowledge about what it takes to heal.

On top of that, if we listen to people telling the stories, it's not trivial data we're losing. The untold stories are ones that matter. Sometimes they matter enough to be named life-changing. We can't afford to lose whatever stories like that may teach us-even just a few of them.

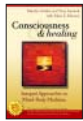
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It's not just knowledge we stand to lose. It's moral loss as well. When things go underground, they grow in the dark. When physicians love their patients and feel that they can't talk about how or when or why, it's all too easy for love to start down a primrose path. We hear about it in shocking statistics describing the number of doctors or therapists or psychoanalysts who end up having sex with patients. But we also hear agonized stories from clinicians about how insidiously it begins. They tell us how it starts with a heartfelt, powerful recognition: Loving patients is key to helping them heal. But when love feels inadmissible, unprofessional, even shameful for discussion with colleagues, then the stage is set for love to grow unmodulated by conscious scrutiny, collegial questioning, or regulation by individual conscience. What starts as love in the service of healing becomes fertile ground for love in the service of other needs. That paves the way for corruption. We call those corruptions boundary violations-as though erecting firmer boundaries rather than acknowledging love before it's corrupted were the solution.

The primrose path for closeted spirituality is no less vicious. We see health practitioners becoming self-identified iconoclasts and gurus, struggling with the knowledge that they heal in ways their training never taught them. This time it starts as they recognize how healing comes through channels that they name spiritual. That recognition isolates them in official discourse about medicine. So they claim a private lock on spiritual truth. They wander into guru status.

And medical research? The American Association for the Advancement of Sciences tells us that, in their survey of 1,500 eminent scientists, more than one quarter report having witnessed outright faking, falsifying, or theft of research data in their labs.¹ In many of those labs, the problem starts because leaps of peculiarly intuitive insight-the ones that radically alter the direction of an experiment but remain stubbornly inexplicable in origin-slip out of official accounts with disturbing frequency. That kind of omission paves the way for worse omission and greater distortion. It's another primrose path, this time one that entails apparently harmless but deceptive packaging. The trap in deceptive packaging of perfectly good science is how it sanctions deceptive packaging of far-from-good science. That can end up in glaringly dishonest science. One lead investigator from a major medical lab reflected on the process:

"I use the scientific method to communicate with fellow-scientists. I write up an experiment and others read my report. They replicate my results or not. We learn from that-sometimes we learn a good deal. But what I've written up is standard format and rarely tells how the experiment started.



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What I write is already way down the road. The insight, the intuition, the personal conviction—there's magic in how that happens, and the magic of science lies partly there for me. The big ideas come from my dreams, my prayer-time, talking with my dead scientist father—yes! My dead scientist father! Needless to say, that's never gone in any reports I've written up. You ask if that's a problem? Maybe. I don't think of it that way, but I'm good at compartmentalizing. And I have a solid New England conscience. It would take a lot for me to do anything literally dishonest. But it's also true I've expelled graduate students for the kinds of things they've kept out of experimental reports . . . Maybe you're right and there's a connection worth thinking about. I've never considered it. . . ."

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There's one more huge cost to keeping private knowing out of public discourse about medicine: the personal pain and insistent burnout that torments people who live split lives. It's a split that's profoundly disconnecting. People end up living half-lives, each half perpetually challenging the validity of the other. Nothing is more draining or exhausting. Nothing is less likely to encourage the practice of good medicine.

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Love, spirituality, inexplicable intuition—they're the ingredients of private knowledge that end up taboo in public discourse about medicine. They're the elements driving the stories people are so eager but afraid to tell. They're what carry pieces of the potentially anomalous. They're why integral medicine is about more than integrating disparate arenas of the field we call medicine—more than incorporating complementary and alternative practices into a medicine we call whole.

Integral medicine is about integral persons. It's about the personal integrity of every practitioner. A whole medicine requires whole practitioners. Integral medicine invites the full humanity of each practitioner to be part of the science of healing—mind, body, heart and soul. The radical possibility is that engaging our full humanity as practitioners may open doors for healing in Western medicine that we never imagined. Equally radical is the possibility that integral medicine may end up bringing new and restorative healing to us all—practitioners no less than patients.

1. Lloyd EL: *Extraordinary Knowing*, New York, forthcoming, Bantam Books.
2. American Academy of Sciences Survey (1991).