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What do our patients want and need? A palliative care clinician's view from the trenches

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The Southern California Cancer Pain Initiative (SCCPI) Board, which extended me the invitation, is composed of people I admire deeply, and I am touched, not to say a little intimidated, by their confidence that I might actually have something of interest to say. My professional debt to SCCPI is large and not repayable. Like its siblings in the national coalition of state cancer pain initiatives, SCCPI has provided to all of us involved in palliative care a roadmap, inspiration, collegiality, and shelter. It's kind of obvious to point out that we wouldn't be here tonight without SCCPI; what's less obvious, and more important, is that thousands of patients in Southern California have been cared for *better* by all of us because of SCCPI. That is the real achievement.

It didn't take long—seconds, in fact—for doubt to intrude on my excitement about being invited to give this talk. "What would be good to talk about?" I thought. I reflected on prior keynote speakers. Scott Fishman, who spoke 2 years ago, had just published an important lay book on pain management. Assemblywoman Helen Thomsen, last year's speaker, has spent a legislative career improving Californians' legal rights to health care, including pain management. I've spent most of my professional time in the last 10 years in the clinical trenches, alongside extraordinary colleagues, trying to provide the best possible evidence-based palliative care.

As I wondered about a good topic, a comforting voice came back to me. At first it sounded a bit like Obi-Wan Kenobi, but eventually I recognized it as Robert Mezey, the distinguished American poet who ran my first college writing workshop, telling me that I ought to stick to what I know. That's why this brief talk will take a look at basic, but profound questions: What do our palliative care and pain management patients want and need? What should an ideal palliative care program look and function like?

A few orienting comments are necessary. After coming to medicine from poetry, I trained in psychiatry and eventually found my way to palliative care. I now spend most of my clinical time doing cancer pain management, with the rest dedicated to more typical psycho-oncology activities. You could probably best describe our model at Cedars as an ambulatory palliative care service that grew out of Bernard Salick's visionary concept that comprehensive cancer care might best be provided in a 24 hour/day outpatient center with diagnostic, treatment, support, and patient education services under one roof. Deane Wolcott, who is here tonight, should be credited with grafting comprehensive cancer pain management services onto the rootstock of Dr. Salick's basic model. I'm proud that our team, past and present, is fully represented here tonight.

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WHAT DO OUR PATIENTS WANT AND NEED?

1. Patients want real clinical relationships with undistracted clinicians

In the Ivory Tower Medical Center where I trained and worked as a faculty member, I gained the painful awareness that the mandates for professional survival—research, publishing, grantsmanship, followed distantly by teaching and even more distantly by patient care—were often at odds with what it seemed to me that patients needed, such as connections to an individual clinician over time. In managed care or community hospital settings, other pressures—such as mandates to see certain numbers of patients, or time limits on numbers of or lengths of clinical encounters—may conflict with optimal clinical care. Our patients want and need human connections with caregivers who are going to be around, and who have time to spend with them.

2. Patients want to know what to expect from their relationships with us, such as when they'll receive a return phone call or how to reach the doctor after hours

Any of you who have been patients in recent years know that the "standard of care" for returning phone calls is not so great. Superficially, this can be explained away merely as a function of growing patient volumes, overworked clinicians, and the limits on the kind of clinical information that can be communicated by phone. But if I were the patient, how could I trust, let alone allow myself to be reliant upon, a pain service that sometimes kinda sorta calls back and doesn't know who I am when it does? Most of the time we're fighting an uphill battle to sell our patients on the idea that they're actually entitled to seek adequate pain control, against all manner of personal and societal taboos. I've got news: Sometimes pain crises don't happen between 9 and 5. We have to gratify our patients' often tentative efforts to contact us by providing prompt, reliable, and helpful responses. At Cedars, our patients learn they'll get same-day callbacks Monday–Friday and an on-call pain doc 24/7 who carries a roster with a list of our patients' pain problems and meds; almost always, the on-call pain doc has already met and evaluated the patient clinically. That on-call doctor is supported by a 24-h treatment area that provides pretty much anything you could get on an inpatient unit, just more promptly, and that represents a welcome alternative to the ER, where we know pain is generally unwelcome and not particularly well treated.

3. Patients want their pain clinicians to be skillful

As we all know, its not just opioids or more opioids in good cancer pain management. Our patients want us to be skillful about understanding all aspects of their pain experience—what pain means to them; what attributions they make about changes in their pain for better and worse; how they feel about the meaning and purpose of suffering. They want us to be skillful about evaluating the psychological, social, spiritual, and life contexts of their pain. They want us to be skillful about assessing their pain's pathophysiology. They want us to be skillful in communicating to them how, and with what tools, we think we can best manage the pain, and they want us to make the pain better. They want good pain control with no side effects; sometimes they fear pain medicines more than chemotherapy. Patients want us to help them communicate about pain treatments to often skeptical or misinformed family members.

4. Patients want us to be dispensable and indispensable

Nobody wants to have pain; when its present, and severe, we're pretty important to our patients. One of my favorite things is to watch patients who we've met and helped through a pain crisis then develop conditioned analgesia, so in the future they get comfortable when the pain nurse just walks into the room. But when pain is absent or minimal, we might also represent an unpleasant reminder of a bad time. Therefore, we need to let our patients have a part in regulating the intensity of their relationships with us.

It is unoriginal to point out that a lot of societal and personal ambivalence about cancer, death, and dying gets worked out around pain and symptom management. There are many wonderful examples of this in Ira Byock's (1997) book *Dying Well*, which so poignantly describes a hospice doctor's experiences with some of his dying patients. Byock often perceives profound change happening in his patients as they approach death. But their trust and comfort with him are hard-won; many patients arrive at palliative care like they've gotten off the train at the wrong station, with understandable misgivings about the whole enterprise. Are they being abandoned by their cancer doctors? Are they now officially hopeless cases? Will they be required to give up valued relationships with nurses, doctors, and other clinicians they've come to count on?

Many of our patients come to our pain service with unexpressed misgivings about our motives, our drugs, our competence, and about the encoded messages their doctors sent them by pointing them our way. One patient with whom we worked beautifully for a couple of years confessed a few months into knowing us that she had considered us the Cancer Center's "death squad," and was convinced when her cancer doctor called us in that he had thrown in the towel. So a primary task, of course, is to build trust. Generally we achieve this by collaborating to provide effective and rapid pain relief. But we've also learned that our patients value the sincerity of our efforts at managing their pain as just about as important as the actual level of relief achieved. Some of the patients for whom we've felt we've achieved the least actual analgesia have rated their satisfaction with pain services extraordinarily highly and have emphasized in their comments the importance of their perceptions of our hard work and good intentions.

As a psychiatrist, I'm not a stranger to the idea that both patients and colleagues might have some misgivings about me. Some of it, I think, comes from the old "he's not a real doctor, anyway" refrain. Another aspect of the mistrust comes from our cultural dubiousness about subjective symptoms and people who treat them: After all, depression, anxiety, and pain are all symptoms you can tell somebody about, but there isn't an accepted lab test for any of them, which makes some people question whether they really exist. As treaters who more or less accept at face value patients' reports about their subjective symptoms, we may be perceived as soft, vague, or unscientific.

In psychiatric residency training, I was taught an ironic maxim about clinical cause and effect. It went something like "anything that goes wrong with a patient after he/she's been referred to a psychiatrist has got to be the fault of the psychiatrist or the psychiatrist's drugs." Sadly, this clinical pearl translates nicely to palliative care. One example of this is the "blame it on the opioids" reflex that comes out of the mouths of our generally brilliant and wise colleagues. We all know that, by definition, reflexes involve peripheral nerve pathways that are suppressed by higher brain centers. If the higher brain centers are switched off, knee-jerk reactions keep occurring. Such is the case when opioids get blamed for bowel obstructions caused by advancing disease, or respiratory symptoms caused by malignant effusions, or focal neurological symptoms caused by brain metastases. These are not malevolent attributions—remember, a reflex doesn't require cortical function—and, in fact, they're entirely understandable as the least onerous and most preferable explanations for distressing new problems in our patients; on the other hand, and much more insidiously, the "blame the opioids" reflex reawakens our patients' barely sleeping and generally inaccurate fears about the fundamental scariness of their pain meds, often casting paralyzing doubt on their evolved trust in us and their pain regimens.

So what I mean by "*dispensable and indispensable*" is, I hope, a bit clearer: Our patients and our colleagues need for us somehow to have the personal and professional grace to be at once scrutinized and needed; to be devalued and idealized; to be vilified and reconstituted; and finally, to be most present and available at a time when others may feel they have little else to offer.

5. Patients need us to be accurately empathic

In a perfect world, we palliative care clinicians would get to witness every interaction our patients have with their cancer team, their families, their internet chatmates, and their inner somatosensory apparatus—in other words, all their data sources—so that we could help process all the disparate information. Sometimes our patients feel like they've landed on Mars. After a week of escalating bone pain, a young woman with metastatic breast cancer described to me her oncologist's furrowed brow as he carefully and caringly parsed his interpretation of the bone scan results to show "new but healing metastases." This kind of doublespeak was for her a source of iatrogenic misery: Though it may in the moment have avoided a painful reckoning, its hollowness over time generated anxiety, mistrust, and assailed appropriate hope. We can be helpful by recognizing the bewilderment or cognitive dissonance, confirming to our patients that they aren't crazy, and helping them find their voices to begin again to try to make sense of things.

Empathy is finally getting serious attention in the medical literature. In a study published just last month, a group of medical educators from Philadelphia measured empathic abilities in more than 700 physicians using a validated scale (Hojat et al., 2002). The researchers defined clinical empathy as ". . . a cognitive attribute that involves an ability to understand the patient's inner experiences and perspective and a capability to communicate this understanding." Their findings won't surprise us: Women physicians scored generally higher empathy ratings than men (this result approached but did not quite achieve statistical significance) and, controlling for gender, physicians in the more cognitively oriented fields of psychiatry, internal medicine, pediatrics, emergency, and family medicine had statistically significantly higher mean empathy ratings than anesthesiologists, orthopedists, neurosurgeons, radiologists, ob/gyns, and general surgeons. In their conclusion, the authors wonder whether the differences among specialists reflect the results of socialization and training in residency, or perhaps simply uncover more hard-wired traits that govern who pursues what specialty in the first place. Though we all know people whose empathic capacities defy these stereotypes, the findings, which confirm common biases about who chooses what, might have important implications for future training and allocation of clinical responsibilities. For example, in an optimal setting, perhaps anesthesiologists and internists together would obtain informed consent for surgeries; possibly radiation oncologists and nurses or social workers would together talk with patients about the risks and benefits of a course of treatment; or maybe empathy scores above a certain minimum would be required for oncologists to be granted clinical privileges to perform the procedure of making a hospice referral.

Jodi Halpern (2001), a psychiatrist-ethicist-philosopher, has recently published a book challenging static definitions of empathy such as the one offered up in the study just mentioned. Halpern agrees that empathy requires from the clinician the capacity to resonate with, or indirectly experience, the affects of the patient, but suggests that the clinician should actually use his/her own emotional reactions to those affects as a guide for understanding the patient and responding helpfully. It is not uncommon, for example, when caring for a patient who is feeling overwhelmed and helpless, for clinicians themselves to feel related emotions of ineffectiveness or inability to help. The ordinary clinical response would be for most clinicians to try to act definitively to "do something" to comfort the patient and rid him/herself of the uncomfortable affect. Though "doing something" like giving a dose of pain medication may be helpful, Halpern advocates also for the imaginative use by the clinician of the received affect as another way of offering comfort: the comfort that comes from feeling understood. While these ideas may seem quite elementary to trained psychotherapists, they are groundbreaking as applied to ordinary day-to-day medical care. Emotional resonance with patients does not inherently threaten our objectivity or effectiveness, and may enhance it.

How does this bear on what we do all day? Accurate empathy is crucial to meaningful dialogue about pain and symptom management and end of life care. Our emotional resonance with patients helps us understand when patients have the psychological reserves to take on crucial decision making, and allows us to help them pace themselves and manage the doses of stressors. Sometimes we must recognize that patients who are paralyzed by pain, fear, or intractable hopelessness may have temporarily lost their capacity for free-agency and future-oriented care planning. Other times we may come to see that the barriers to addressing important clinical issues come primarily from the clinician side, and must be moved out of the way for the well-being of the patient.

TOWARD OPTIMAL CANCER PAIN MANAGEMENT PROGRAMS

In the last few minutes, I'd like to do some pipe dreaming. What should an ideal pain management or palliative care program look and function like? As a foundation, I'll remind you of the WHO (1990) definition of palliative care:

> The total active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological and spiritual problems is paramount . . . many aspects of palliative care are also applicable earlier in the course of illness in conjunction with anti-cancer treatment . . .

How close have we gotten?

First, let's note what's been achieved: Pain is on clinical and accrediting agency radar screens like never before; nationwide, cancer pain initiatives are thriving; state medical boards have published intractable pain statements; there is an Internet full of quality sites with great information for patients and clinicians alike; physicians are being pain-educated by statutory requirements; world-class researchers and institutions are investing whole careers and millions of dollars on pain and palliative care research; and there are wonderful books, journals, national and international organizations.

And yet, new versions of some of the same old barriers remain: Deep-seated fears and beliefs live on in our ever-more multicultural, multiethnic patients; physicians remain in many settings opioid- and triplicate-phobic, or just plain ignorant, and institutions, though compelled to meet JCAHO standards, may still not support or may even be abandoning, pain services.

So, in a few words, what are some ingredients of an optimal program?

1. *Enfranchised leadership by experts*. Cancer pain management programs should be staffed by a core group of clinical experts from multiple disciplines, who are financially and administratively supported by their host institutions, and who are charged with providing culturally, linguistically, and ethnically sensitive biopsychosocial clinical services to patients in those institutions more or less seamlessly, across the spectrum of care, from diagnosis to remission, progression, or death, from outpatient to inpatient to home.

2. *Palliative care research and training made possible by the primary mission of patient care*. Research and clinical training can and should fit into these models, but not at the expense of the primary patient care mission. Successful examples include Neal Slatkin's program here at the City of Hope, or Russell Portenoy's program in New York, or in Eduardo Bruera's program in Texas.

3. *Get the right people with time to do the work*. Optimal cancer pain management clinical programs will recognize the generally low-tech, highly cognitive-service and time-intensive nature of the clinical work and will recruit program leaders who possess interests and aptitudes aligned with these clinical requirements. The clinical program leaders will quarterback the patient care that will include appropriate technology (like PCA pumps) and interventional specialists (anesthesiologists/neurosurgeons) based on need, and without a stewardship relationship to health care dollars.

4. *Deliver what you promise*. The ideal service will provide to patients coherent spoken and written materials related to the content of and the process of pain management care. The deeds of the service, like returning phone calls and providing responsive and informed on-call coverage, will be consistent with the words of promise delivered in person and in the written materials.

5. *A 24-h treatment area or day hospital is a great thing*. The ideal service will have a clinical resource other than the Emergency Room or the inpatient unit to deal with after-hours or weekend pain problems. We know this is good business, we know this provides better care, and we know this keeps people out of the inpatient units.

6. *It lives in the cancer center*. Optimal services are provided when the pain clinicians office and work in the same environment as the primary providers of oncology care. That way, arbitrary barriers to access are abolished and pain problems are assessed and treated in real time. Pain management is delivered as *part of* not *distinct from* the rest of oncology care.

7. *It breathes in the cancer center*. As part of a culture that recognizes palliative care and pain management as inherently meaningful pursuits which enrich the environment of the cancer program, the pain service should actively participate in the program's intellectual life: staff education, invited speakers, grand rounds, quality improvement activities, and other activities.

8. *It has a sense of humor*. Palliative care clinicians receive daily lessons on the limits of their power and knowledge. This generally leads to humility and a keen sense of humor, or to leaving the field. A good pain service needs mirth from any and all available sources.

SCCPI, the American cancer pain advocacy movement, and all of us together have come a great distance, with the help of angels and giants, some of whom are among us in this room. I love the work I do, and the people I do it with, and I know how incredibly fortunate I am to have landed at a place that comes pretty close to meeting the impossible criteria for excellence that I've outlined. Still, we have a long way to go and we know we can always do better for our patients with pain. Tonight we take a break from the work to appreciate emerging stars. I thank you for your attention!

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