

Both programs demonstrate that even within the current health care environment, real change is possible.

Both the Healthy People 2010 initiative sponsored by the Department of Health and Human Services and the recent statement on health care reform from the AHA embrace the elimination of health disparities as one of several prominent goals. Regrettably, the study by Bibbins-Domingo et al. shows that much work remains. As we enter an era of anticipated sociopolitical transformation, we must make the elimination of disparities in health care one of our highest priorities. Our society should no

longer accept treatment driven by economics, convenience, and familiarity; we should insist instead on care guided by science and focused on quality.

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Denial

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The medical student is watching closely. In an overfilled clinic, time is scarce and the teaching staccato. I point out a malignant lymph node here, an enlarged liver there. She witnesses the abbreviated version of my breaking bad news and I hope finds some parallel with what she has been taught. I try to offer her a window into my thinking, as I talk patients into and out of having chemotherapy. Then I pick up an unfamiliar file. In response to an urgent request from her primary care doctor, the patient has been sandwiched into a virtual slot. Ushering her in, I introduce her to the medical student, who has respectfully tucked herself behind the bed.

"How are you today?" I ask, leafing through the patient's record.

"Okay."

She is a plain-looking, overweight woman in her 50s, well protected from the winter chill in a thick green parka atop several layers of clothing. A knitted scarf cocoons her neck.

"So, when were you last here?"

"A while ago."

"I think part of your stuff is missing. The last notes are from 7 months ago."

She looks at me without comment.

"I can see that you were diagnosed with breast cancer and had chemotherapy. I can't find your operation report or any other notes." I stop jabbing at the computer keyboard. "Can you fill me in on what happened next?"

"Not much."

I sigh, realizing that I will have to slowly reconstruct her history

while the queue outside lengthens. The notes reveal that she presented to the clinic with a locally advanced breast cancer. A multidisciplinary team assessed her as requiring preoperative chemotherapy followed by a mastectomy, radiation therapy, and hormonal therapy. The file neatly charts her progress through chemotherapy before stopping abruptly.

"How was the chemo?"

"I wasn't as sick as they reckoned." I detect a note of pride in her voice.

"Good! And then the operation?"

"I didn't have an operation."

"Oh? Did the surgeon change his mind?"

She looks uncertain. "I figure so."

"What did he say?"

As if by design, a letter from her primary care doctor flutters from the file onto the floor. I scan it as I urge her to talk. It states apologetically that after a long hiatus, the patient presented for a diabetes check and was noted to still have the cancer. “She is unable to provide me with details. Could you please let me know what is happening?” it implores.

I am jolted. “The notes say you were due to see the surgeon after chemo. What did he say?”

Picking up on my concern, she quickly replies, “No, I called up for an appointment and they said they would get back to me. When no one rang, I figured I was cured.”

I nearly drop her file in surprise.

“What did you do then?”

“I went back to work.”

“But after what you had been told initially, did you not wonder about more treatment?”

“No. When no one called back, I figured I was done with treatment.”

“But you still have a breast lump,” I protest.

My questioning expression meets her passive gaze. She combats my sense of urgency with an apologetic shrug of her shoulders.

“May I examine you?”

“Sure.”

The medical student watches in amazement. As the patient unwinds her scarf, a huge neck lump comes into view. It bulges to her left, disfiguring her neck. Dilated veins snake across her chest.

I finger the lump tentatively. “How long has this been growing?”

“Ages.”

“Is it bigger now?”

“Maybe. They thought it might be my thyroid.”

“It could be cancer.”

“Oh.”

I steel myself to proceed. Her right breast is hard, transmogrified by cancer, a puckered mass, amorphous and sullen, devoid of



its original femininity. The tumor threatens to lose its patience and explode to the surface at any moment. The folds of fat in her axilla make it impossible to find any adenopathy. I stand back, dismayed and horrified.

“Did you not wonder what was going on?”

“No. I thought I was cured,” she insists, “and that this was how it was supposed to look.”

A wave of irritation washes over me. I warn myself not to be her inquisitor, but I almost can’t help myself.

“Did you never think of calling a second time or even seeing your doctor when you didn’t receive any follow-up from us?”

“I didn’t want to bother anyone.”

I open my mouth, but she preempts me, asking in a devastatingly reasonable tone, “Have you tried calling up Outpatients? You see a different doctor each time, and you never know who to ask about what.”

I change tack. “Could you be depressed?” I inquire more gently, grasping for a unifying theme between her advanced disease and her failure to show up.

“No.”

I try one last time. “I am concerned your cancer has spread. We will have to rescan you.”

“Okay.”

I have no idea what she is thinking. Her passivity overshadows any apprehension or remorse she may feel. But then she says simply, “I will have whatever test you want me to. I guess I should have come back earlier.”

Signing a host of slips, I look up. “Is there anything else?” Here is another opportunity, I tell myself. An opportunity for her to show some emotion — fear for her future or anger at being lost to follow-up. It would make it easier for me to continue the conversation.

“No.”

“Are you sure you will come back?” I probe.

“Yes, I want you to do a full checkup.”

Stopping myself from chastising her again, I see her out.

When I return, the medical student exclaims triumphantly, “She has a huge lump! That’s denial! She has to be in denial, don’t you think?”

I am momentarily tempted to embrace this on-the-spot diagnosis, which conjures up the image of an incapable patient and absolves the physician of respon-

sibility. That single word scribbled in her file could change the way every physician who comes after me views — and treats — the patient. In a busy clinic, it is only too easy to seize any label that may speed up the consulta-

mates probably thought it inappropriate to ask an apparently fit colleague about her illness. Thus, multiple individually plausible assumptions collectively compromised this patient's outcome.

To most doctors, it may seem

care depends on the environment in which it is delivered. Though physicians recognize that disease management needs to be tailored to the patient, we often assume that when it comes to navigating the labyrinthine health care system, one size fits all. One can Google the management of the most obscure disease, but how can we ensure that the patient gets to the appointment? For many patients, dealing with the vagaries of outpatient care is almost as great a challenge as enduring prolonged treatment.

The corollary of steering away from medical paternalism, especially in an age of superspecialization, can sometimes be the relinquishing of responsibility for patients. But if physicians no longer take the reins, dedicated nurse practitioners and physician assistants could be a useful link in ensuring that there is a primary provider — whether physician or allied health professional — in charge of each patient's care. Perhaps we can also learn from industries that manage vast numbers of goods and services by using active tracking systems that can locate products throughout their journey and provide alerts in case of mishaps.

At many hospitals and clinics, minimal active efforts are made to determine the reasons for a patient's failure to keep an appointment. Breakdowns in communication are distressingly common, both between health care institutions and patients and between hospitals and community-based physicians, who are frequently left out of the loop, losing track of, and then interest in, the de-

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tion a little. But given what the patient has told me, applying this label would not make me feel exculpated.

Even with the most well-intentioned and robust health care infrastructure, the care of individual patients sometimes goes astray. This patient's journey began unremarkably: she presented promptly, complied with her workup, underwent grueling chemotherapy, and attended every scheduled appointment. Then, the theoretically seamless transition between the medical oncologist and the breast surgeon failed. When the patient's call to the outpatient department was not returned, she took the silence and past encouraging assessments as signals that she was out of danger. To her thinking, no news was good news — not an uncommon belief among chronically ill patients who long for normality. The diligent breast care nurses inexplicably lost track of her. Her primary care physician assumed that her follow-up was taking place at the hospital and did not worry about not having seen her. Over the next several months, the patient continued to feel well and work full-time. She had little family, and her work-

incomprehensible that the woman did not register the essential elements of her care plan. But in reality, it is not so extraordinary for a patient to forget or even not to understand the treatment plan in the first place, especially when confronted with complex details at a vulnerable time. When we counsel patients about multidisciplinary care, we often assure them that things will gradually fall into place. The intention may be to avoid information overload, but sometimes vital messages are left unconveyed. Was the patient wrong to have trusted that if her disease were grave, someone would have made a more concerted effort to reach her? Though she is powerless to call a mammoth system to account, we can hold her accountable with a single word — denial.

In an era of increasingly outpatient-oriented medical care, this patient's story represents an urgent cautionary tale. Our gray-ing society faces a sharp increase in the prevalence of chronic diseases, and hospitals are under pressure to broaden access to physicians and treatments. But the ability to maintain a high standard of health

tails of their patients' care. The more complicated a patient's illness, the less empowered the primary care physician feels and the more reliant the patient becomes on hospital services, including emergency room visits. Ensuring a smooth transition from hospital to community care is vital to reducing the burden on hospital services. Time spent now to implement efficient systems may, in the long run, save time that would be wasted dealing with avoidable distress, and

money thus spent should reduce expenditures for reactionary medicine when things go wrong.

I return my attention to my medical student, trying to find in the incident a lesson other than disillusionment with the public hospital system. I explain that we should be careful not to label patients prematurely. Although I saw this patient as someone with end-stage disease, she saw her lump as a nuisance that had not gone away even after all the treatment she had endured. Her chal-

lenge was to find a way to trust us again; ours was to suspend judgment and resume her treatment. For treatment represented her only chance of healing — and our only hope for making amends. She was not really in denial. Neither should we be.

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