

ESOPUS



433



0 71486 23508 8

ESOPUS 22: MEDICINE USA \$40.00

Critical Conversations

A 360° Clinical Portrait

Annie Baker is a sixty-something retired English teacher in treatment for colon cancer that has metastasized to her liver. She receives medical care at a large suburban oncology practice in the northeastern United States. The office is a busy one, part of a cancer center adjacent to a regional hospital.

On a cold, foggy day in December 2014, we accompanied Annie to a routine appointment with her oncologist at this office, and we visited her a week later in her hospital room when she was admitted for inpatient chemotherapy. Over the course of those two visits we interviewed Annie and staff members involved directly and indirectly with her care in various capacities: receptionist, nurse, physician, phlebotomist, administrative assistant, and many others. We spoke to them about their lives, their work, and their experiences of illness and caregiving, in an effort to portray the delicate and complex constellation of care surrounding a single, and singular, cancer patient.

While recent years have brought an increasing number of memoirs about illness, along with accounts by clinicians, few writings have bridged the two and offered a depiction of a health-care experience from multiple perspectives. The portrait that emerges here is an extremely positive, even beatific one—these interviews resonate with their subjects' grace and courage—yet it also provokes certain questions: Which accounts of illness and caregiving are culturally accepted? How do certain narratives serve us in difficult times? Finally, what are the ethical implications of questioning or probing such stories?

Alongside the extremely affirmative reflections on this health-care experience is the pervasive erosion of agency one experiences in the face of illness and medical treatment, even when a patient is extremely proactive and well informed. And there are in these stories, finally, experiences that escape words—experiences of care, and of facing mortality itself.

All names have been changed to preserve participants' anonymity, and identification by first name or by title and surname follows usage in this clinical setting. Interviews have been edited for brevity and clarity.—*Danielle Spencer and Stephanie Adler Yuan*

ONCOLOGY PRACTICE

VIRGINIA (RECEPTIONIST)

Virginia: I'm breaking out in a sweat here...I'm just like—God, you're making me nervous. I'm really not good at this stuff. Okay, all right.

I'm a receptionist. I greet the patients as they come in, new patients. Sign them in and take co-pays, and just hope that they have a comfortable, relaxing visit. It's scary, and they're nervous when they come in. I connect with a lot of them. It's kind of sad a lot of days, when we lose people and stuff, because we do tend to connect. When they don't come anymore, you're like, "Hmmm..." You wonder. I don't know anything [about their clinical status]—it depends on how much they tell me. Some will stand there and talk to me for 10 minutes. You just see what they're going through.

I've been here six and a half years. I was actually in OB/GYN before, and there you see babies, from the beginning. So, from one extreme to the other. Of course, lots of bad things happen there also. But they're both rewarding.

I really didn't know anything before working here. I'd had family members go through cancer, but I never really knew how it affects everybody. And visit-wise, if you see people come in by themselves, you wish they had somebody with them. I don't know, it's sad. Then again, like I said, it's rewarding also, because I do enjoy the patients and stuff.

I'm sure they enjoy you.

Virginia: So they say. [laughs]

Has it gotten easier over time?

Virginia: Yeah. Some days are harder than others. We have that dreaded list in the kitchen where when people pass, it's...sometimes the minute you walk in in the morning, and it's just...that can make a day bad.

There's a list in the office kitchen of patients who have passed away?

Virginia: Yeah. It's just 8,5 by 11, so it goes down, and as the page fills up, the top goes off. It's actually right on the refrigerator.

How many names are there per week?

Virginia: It depends. On there now, I think the latest one has probably like 12 or 13 names. That could be over a two- or three-week span. Sometimes it's larger than others.

I see. That is a lot. Two or three weeks?

Virginia: Yeah, it's sad. [quiet pause]

Do you talk to your colleagues about it?

Virginia: We do, because we get close to the patients. Unfortunately we've lost a lot of good ones...I'm sorry... [starts crying] That's one thing I don't like about it.

You have to carry around that sadness and grief but also, being the first person who people see when they come in, do you feel like you have to be upbeat and cheery for patients?

Virginia: I don't feel like I have to be; it's just me. I wouldn't want to be sitting there like this when you walk in, that's for sure. So you just put on the face, if nothing else. We do it, but also the three of us working at the front desk, we're pretty close, we talk. Like, "Hey, we haven't seen this one in a while, I wonder what's going on..."

So you don't necessarily know?

Virginia: Yeah, we don't always know. We're not really told a lot.

Do you feel comfortable asking, if you're concerned about someone?

Virginia: Yeah. But then sometimes we don't really want to know. You know? If they're in a hospice or something like that...I don't know...

That first encounter in a medical office matters so much. It's an important part of patient care.

Virginia: Yeah. I don't even like going to my own doctor's office, they're just so nasty. I've told my doctor, "If I ever acted like that, first of all I wouldn't be able to go home and sleep, and it would bother me. *And* I would lose my job in a heartbeat, and so I should." I've gone into my doctor's office and I'm like, "Oh no, it's *her!*" I say to myself, "God, I hope people don't say that about *me.*" [laughs]

Everybody has a bad day, and not everybody is going to like everybody, unfortunately. There's people who come in, they are upset, and sometimes they take it out on us, like it's our fault that they're sick, and you have to try to understand that sometimes you just don't click with somebody, no matter how hard you try.

But Annie's just so pleasant all the time. She usually comes at busy times, so it's usually, "Hi, how, are you?" She'll come out with something funny. I was actually checking in a new patient when Annie came in, and she said to the patient, "Is this your first time here? You are going to have such a wonderful experience." And I was like, "Thank you." Then she goes, "And especially starting with *Virginia!*" I'm like, "Oh my God." You know what? You don't hear it a lot. When somebody does say it, then thank you, I appreciate that.

Is there anything that surprises you about your job?

Virginia: That I enjoy it. My friends say, "I don't know how

you do that.” They don’t know how I go here every day and deal with everything, but I just like the interaction with the people. I talk to the ladies about their wigs. They tell me, “I like it,” “I don’t like it,” or they might say, “Okay, you didn’t say anything, that means you didn’t like this one.” I’m like, “Oh, no, I just didn’t notice, I’m sorry!” [laughter] Yeah, it’s kind of weird. They name them. They name their wigs. One lady came in the other day and said, “This is Barbara here. This is our first time out together.” I enjoy that. It’s just little things like that.

You must see the whole spectrum of how people respond. Some with humor, and some not, right?

Virginia: Right. Some are mad. You can understand that side too. They’re just mad. Why them? So that’s a bad part of it.

Do you ever end up on the receiving end of that anger?

Virginia: Oh, yeah, all the time. You just try to defuse it. It happens mostly when they first come in, because they’re scared. Then we just try to guide them through and tell them, “Listen, you’re in a good place.” They’ll look around and see the waiting room, how packed it is, and I’m like, “But that’s a good thing, because people keep coming back.”

Some people come back a year later and they’re like, “I stood outside shaking for five minutes, and I didn’t want to walk in here.” I’m like, “I don’t blame you. But look, we’re still here!” [laughs] Everybody reacts differently. I try to keep in mind, how would I want to be treated if I were walking into some place for the first time, or any time?

[Indicating Virginia’s crucifix necklace] Do you mind my asking if you ever pray for patients?

Virginia: We do, a lot. I pray for them. Most of them, actually. Just everybody that walks in. Sometimes you see them leaving, you know you’re never going to see them again, and the family and everything.

You mean if they’re being discharged to hospice?

Virginia: Yeah.

It must be hard.

Virginia: Yeah, it is. Don’t make me cry again.

ONCOLOGY PRACTICE

DR. SHANTI ROY (ONCOLOGIST)

What’s on your mind going into this visit [with Annie]?

Dr. Roy: I’m excited for Annie because I just saw the report from her surgeon and the CAT scan report. It showed that there was a response, further response, in the cancer in her

liver, the liver metastasis. All along [since I met her nine months ago] I’ve been hoping for her to have an adequate response so that she can have surgery.

She has metastatic colon cancer, and we’ve been doing chemotherapy up front to try to shrink this liver lesion. If it’s shrunk to a certain degree, she may be a candidate for surgery. And that is really her only chance for a cure. Without that, we would just be giving her more chemo and it would be more palliative. And this sort of gives us more hope that there could be a cure for her. If she can have that liver lesion taken out—and she’ll have to have colon surgery as well—that would put her in a different category, like a potentially curable situation.

I literally just got the report from her surgeon yesterday, and I spoke to him today and he also was optimistic about it. It’s going to be challenging surgically and anatomically, but he is eager to do the surgery now. Whereas previously, at every step when we had been doing CAT scans, he was like, “Well, there’s some shrinkage, but not enough. She needs more chemo.” So we’ve been going through this now for months, so this is sort of a big step. Now, she’s probably heard it from her surgeon, but I’ll be able to talk to her more about it.

Do you generally think about your patients between visits?

Dr. Roy: I do, especially if there’s a scan or something going on, and then I have to talk to them about the results. Sometimes I’ll call them before the visit because I don’t want them to wait. I always look at my schedule for the week before it starts, so I know what’s coming and who’s coming and what issues there might be and stuff. So, yeah, I do think about them in advance.

Do you ever share your thoughts and concerns and fears with the patients as you consider them privately?

Dr. Roy: Hmm. That’s a tough one. I think, no—I don’t. Because I think, as an oncologist, you kind of have to be the strong person. You have to really be the authority figure. You have to give them direction and hope. So fears, no. It’s not really about fear. It could be about making different decisions, like maybe not continuing chemotherapy but rather going on palliative care or hospice.

But it’s part of our job to be the leader, the person who gives guidance and advice. I don’t think it would do the patient any good if I were afraid or if I conveyed that to them. At times, I think it’s natural to feel that way, but I don’t think it’s part of our job description.

Do you ever dream about your patients?

Dr. Roy: Mm-hmm [affirmative]. Yeah, yeah, it happens once in a while, yes, yes. I think it probably happened earlier in my career more than now.

Why do you think that is?

Dr. Roy: It's a very emotionally taxing field. Learning how to cope with that is a process. It's part of the training, really, as much as it is learning about the drugs and the side effects and everything. There's a whole emotional learning curve that goes on with it. I think you just sort of get a little bit better at that part of it, about dealing with everything and absorbing it and communicating, and all those things.

How do you manage that aspect of your work?

Dr. Roy: It really helps to talk to people who have been doing it for longer, because they're like the Yodas. They've done it. They get it. They understand. They just know what it feels like to be in a situation where you're trying to guide somebody, you're trying to help somebody, and it's really hard, because you know there's not much more you can do, medically. There are no more drugs to offer. There are no more treatment options. So—they've been there. I think just talking about it helps.

I guess it sort of helps to be somewhat spiritual. Also, on a personal level, just to know that things could be worse—and I'm dealing with adults, not with children. So I think it helps to put everything in perspective.

How do you typically go about establishing a connection with a new patient?

Dr. Roy: I think a lot of it is the first visit. It's really important to get to know who they are the first time you see them, because that's when you have more time. I try to spend time getting to know them and getting to know who their family members are, and what kind of support they have at home. Just to know what they did for work, and if they're retired, what they do now and how they spend their days. I try to write it down, because I can't remember everything, so the next time I see, I remember: This is the guy who likes to play golf or likes to fish or whatever. It helps. Just little things that you can kind of connect with them over that are outside of their disease, that make them real people.

What do you hope to discuss with Annie during this visit?

Dr. Roy: I think we're just going to talk about these CAT scan results, her conversation with her surgeon, and then what the plan is going to be—which is that she's probably going to have surgery. But we might need to do some chemotherapy just to tide things over because otherwise it's a long gap between now and when the surgery is, and the surgeon didn't want her to have any progression of the cancer in the interim, so we might do one more hospital admission. She may or may not be excited about that. Probably not, but I'll have to talk to her about it and try to explain why that's important, and we'll see how that goes.

She always has something interesting to talk about, like what book she's reading or something. She's just an interesting person, really well read, very dynamic. We have a lot of trust and respect mutually. I really feel for what she's going through. She's had a hard life and this sort of hit her like a ton of bricks when it happened. She was really shocked, surprised, but she's come a long way in terms of coping with it. She's expressed this before, that "Anything that happens, it happens, and I feel like I'm in the best hands." She's very grateful. Many patients aren't. They're angry, and it's understandable, but she's not like that. She's just very grounded. She's an amazing person.

Do you feel like her attitude or your relationship with her impacts the care relationship?

Dr. Roy: That's a good question, and I think it does. It has to, because as physicians, we're human beings first. I think that people go an extra mile for somebody that they really know well and that they care about. As a physician, you try to have that with every patient. And I think you do, but then there are some people that make you want to do more.

Is there anything that you feel can go unsaid, not necessarily between you and Annie, but between a physician and a patient in a clinical relationship?

Dr. Roy: Yeah, I think so, because it's all about timing. For example, we deal a lot with patients who are at the end of life, and the conversation about stopping chemotherapy and moving on to palliative care and hospice has to happen at the right time—and they have to be ready to hear it. Although we may be thinking about it for a long time, the actual presentation of that discussion might not happen immediately. So that can be a little bit hard because you know you're on different planes—you're thinking different things—but you have to allow the patient some time to get closer to where you are before you can have that kind of conversation, because otherwise it might not go well.

I think the patient experience is so—what's the word—it's just a very difficult one. Having been on the other side, whether it's myself or a family member, being a patient—I always go back to that and think about what the experience was like for any of us in dealing with physicians and nurses and the whole team.

As physicians, I think we often forget what the patient experience is like. And probably for many of the staff here, everyone kind of gets stuck in their routines and forgets that the patient is the one who has the disease and they're the ones who are experiencing something that can be very difficult. There are so many things that you internalize or that you perceive as a patient that you're never really given a forum to express.

Do you also feel like you don't have a forum to express aspects of your experience as a physician?

Dr. Roy: Definitely. There's just not enough time in the day. There is just not enough time. I'd say 90 percent of what we experience gets internalized and there's no place to let it out, you know?

And I love what I do. I love my job. So I don't feel ever that it's not the right place for me. I feel lucky that I ended up doing what I'm doing. I feel that I can help people at a very critical time in their lives. And it's unlike many other fields. *Cancer*—still, it's just so hard to hear that word. I think that coming into people's lives at that moment is unique. No other medical field has that kind of impact. That's what I was drawn to.

I do talk to my husband. I think I used to talk to him much more, again, earlier in my career, when it was really heavy on my mind. But with time I think I've been able to process things a little bit better myself and kind of realize, "All right, well, this is how it's going to go, and this is what happens," and just, again, put it all into perspective. I think with time, with experience, it just naturally happens.

As you become a Yoda yourself, gradually.

Dr. Roy: Eventually, yes.

ONCOLOGY PRACTICE

ANNIE BAKER (PATIENT)

So what brings you here today?

Annie: I am here to see Dr. R. after having had 14 chemo treatments and having seen the surgeon. The tumor on my liver, which is in a very bad place—as he says, it's in the crotch of the liver—it has shrunk and he is going to do the surgery. About which I am *ecstatic*.

Everyone is very, very, *very* optimistic about my outcome. When I first met Dr. R., we clicked immediately. She's just this amazing woman—and she looks like she's 12 years old. I told her I didn't know how she had done all this schooling, being 12—and she had children! [laughs] Golly. I felt like asking her, "Does your mother know you're here and wearing a white outfit?"

Anyway, my first question to her was, "Do I have reason to be cautiously optimistic?" She looked at me and said, "You have every reason to be *completely* optimistic." Dr. S. is going to be doing the surgery. I'm going to be having a procedure next Tuesday in which a catheter is going to be inserted into the lobe of the liver to block off the blood supply so that the other side will enlarge. The idea being, keep as much healthy liver as possible and also reverse the colostomy, which has been... [blows raspberry]

The brochure that one is given when one gets a colostomy is an absolutely flaming pack of lies: "You Can Live with a Colostomy." The problem with mine is that it was an emergency surgery with a blockage. I was very fortunate, because nothing ruptured. Dr. S. didn't have really an option or time to choose where to put it and to really do all of the closing up. There's a huge hernia underneath it, which makes it stick out so much more. That's why I look...I keep covering it up.

Going into this particular visit, what's on your mind?

Annie: What's on my mind now is that I'm in transition from the chemo stage to the operative stage. One thing that brings me here is that I knit a little scarf for Dr. R., and I want to give it to her. Then, just to find out when the next chemo will be, since Dr. S. wants another one before the surgery. Just to check in.

ONCOLOGY PRACTICE

DR. SHANTI ROY (ONCOLOGIST) ANNIE BAKER (PATIENT)

[Walking down the hall, Annie and Dr. Roy talk.]

Dr. Roy: How are you?

Annie: I'm good. I'm going to have surgery... I'm gonna go, baby! And I know he wants one more chemo.

Dr. Roy: You know about it? He told you?

Annie: Yes.

Dr. Roy: Okay, good, now I don't have to tell you.

Annie: It's fine. At this point—please, please. It's, whatever. Tell me where I need to be and at what time. No, but it was such good news! You should be thrilled!

Dr. Roy: [laughs] I *was*!

[They enter Dr. Roy's office.]

Annie: Okay! [gives Dr. Roy a wrapped gift] You have to open it now.

[Dr. Roy starts to open the present.]

Annie: Just look at the reindeer as seasonal...

Dr. Roy: It's very nice. [still opening paper]

Annie: Oh, just rip it! Are you one of those savers? [laughs]

Dr. Roy: Beautiful.

Annie: All right. Now, I made it small.

Dr. Roy: You made this?

Annie: Yes, I did.

Dr. Roy: Are you kidding me?

Annie: Yes. Now, I made it small because you're so petite.

Dr. Roy: That is beautiful. I love it.

Annie: I thought...get your hair out of the way. I thought it would just fold.

Dr. Roy: It's perfect.

Annie: Like that.

Dr. Roy: It folds perfectly. Thank you. Thank you so much.

Annie: Wear it with a T-shirt or a dressy dress or whatever.

Dr. Roy: Or a white coat.

Annie: Or a white coat. You're too petite to wear the big scarves that I like.

Dr. Roy: This is awesome. This is really beautiful and sweet, and I will always think of you, wearing it.

Annie: Good. Enjoy it.

Dr. Roy: Thank you so much.

Annie: Think of it is a hug around your neck whenever you put it on. Okay.

Dr. Roy: How are you?

Annie: I really am okay. I had to up the prednisone this morning because I going into a little bit of a flare.

Dr. Roy: What are you on now?

Annie: I was down to 5 milligrams for a few days, and today I took a 10. I had seen my rheumatologist and she said that if I felt the flare coming, to pop a 10 and not even think about it. I'll just call her and let her know.

Dr. Roy: All right. She gave you a little bit of freedom with that, what to do with the prednisone?

Annie: Yeah. When I call, she'll tell me how many days for 10. Then I'm scheduled for the outpatient occlusion on Tuesday.

Dr. Roy: What's that?

Annie: I'm going to have a catheter inserted into my liver to block off the blood supply. It has a long name. I called it *occlusion* because I couldn't remember it. So that the other side will grow over the next few weeks. Are you familiar with this procedure? What is it, putting a bubble in there or something...

Dr. Roy: "Embolize left portal vein."

Annie: It's probably an \$850,000 piece of sponge that's going to be wedged into the blood vessel. [laughs] So, another chemo, and when do we need to do this? Can it be after Christmas?

Dr. Roy: My preference is to do it next week, because if we do it after the holiday, then there are two things: One is that it's going to be a longer interval between chemo sessions, and then a shorter one between that chemo and the surgery, and you don't want it to be too close.

Annie: Okay, *not* after Christmas. I knew that was going to happen. Good thing I had my hair cut again. I knew it. I knew it. I was just talking about the difficulty with the rheumatoid arthritis in terms of the chemo and all of that kind of stuff. So, pick a problem: Rheumatoid? Cancer? Colostomy? Pick one.

Dr. Roy: Okay. We'll have to coordinate a little bit. All right, and your medicines otherwise: Can I run down the list that I have here?

Annie: Mm-hmm.

Dr. Roy: Ativan, as needed. The Biofreeze roll-on gel, Centrum, vitamin D, Neurontin, Plaquenil. Prednisone, 10, you told me. Sandostatin, we're going to do today. Synthroid, Tylenol, and B12. Is that everything?

Annie: Yeah. And D? Did you have vitamin D?

Dr. Roy: Got it. Two 2,000's a day.

Annie: Yeah. My rheumatologist really pushes that. Something with the arthritis.

Dr. Roy: How's your energy?

Annie: Fine.

Dr. Roy: Any new issues? Shortness of breath, chest pain, cough, palpitations?

Annie: No.

Dr. Roy: Nausea?

Annie: Sometimes I get a little queasy. I find myself taking a couple of Ativan a day. I take one in the morning just by habit, I think. I find that around 4 or 4:30, something like that, sometimes I take one.

Dr. Roy: That's fine. Then, constipation, diarrhea, anything like that?

Annie: No. Well, it's hard, no, I don't have...

Dr. Roy: Not like excessive output [into the colostomy bag]?

Annie: No.

Dr. Roy: Okay. Then you told me about the pain from your

rheumatoid. Rashes, headaches, confusion, depression, anxiety, any of that?

Annie: No.

Dr. Roy: Okay. All right. You look fantastic. You look pretty.

Annie: Thank you, dear.

Dr. Roy: You look really good. I'm so glad I was not the one to tell you that you had to get another dose of chemo.

Annie: No, it really...if my years to be, whatever they are, involved having to go in for chemo every week and a half—you and I talked about this—I would have a very serious decision to make, because it's not any way really to live your life. But it's just adding one more. I've had 14, so it's 15.

Dr. Roy: I know, but who's counting?

Annie: No. I know, and it means I can have the surgery.

Dr. Roy: It's something to look forward to. I think this is wonderful.

Annie: Yeah. I'm in the glow of the surgeon saying how happy he was about the shrinkage and that he was thinking he was going to do it. I was saying, too, as we started down the hall, that now the enormity of the surgery and the recuperation from it is starting to...but I tend to be pragmatic. It's just, you have to do it, so that's fine.

Dr. Roy: Maybe it's like the next phase and the unknown.

Annie: Right.

Dr. Roy: You have had surgery before and you recovered from it. This is good. This is where we wanted to get to. This is what we wanted.

Annie: Yes, because then, my maintenance after...it shouldn't be chemo, chemo, chemo, chemo, chemo.

Dr. Roy: We'll have to see. I think, you know, nothing is set in stone. It all depends on what he finds, how much he can take out, what he can do. Sometimes, they just don't know until they're in there—

Annie: I know.

Dr. Roy: —what they can do. As much as there is uncertainty about it, we have to sort of accept that.

Annie: I understand. He's going to reverse the colostomy at the same time.

Dr. Roy: If he could only do that, right? I know that that's been such a burden for you.

Annie: When I went for a checkup, Dr. S. said, "Well, if it's a problem, we can always just *move* the colostomy." No, no, no, no, no. No.

Dr. Roy: That's not what you're signing up for.

Annie: No, no, no. If I had to, I could live with it, because the hernia would be corrected and I wouldn't stick out so much. It wouldn't be so grotesque. No, no, no, no, we want the colostomy reversed, not just moved. No.

Dr. Roy: Let's be very clear about that.

Annie: Yeah.

ONCOLOGY PRACTICE

VINITA (PHLEBOTOMIST)

Vinita: I've been working here for two and a half years. I'm a phlebotomist here. I do blood draws.

You have to cause patients a little bit of pain and discomfort, even though it's necessary. Is it hard to do that?

Vinita: Yeah, sometimes. Like, sometimes the patient didn't drink, so they get dehydrated. One patient was hostile because she didn't drink any water, so I had to stick her again. I stuck her one time, and then I stuck her again, and I couldn't get the blood, because she didn't drink the water. She got mad and she was in pain, so I can understand her feelings, too. It was bad: She was in pain, and I didn't get the blood, so she was angry. I told my manager, so she had somebody else try, and then we just put some warm water over there so the circulation could get better. We got a little bit of blood from the other arm, but it was still a little bit sore. I knew it was difficult for the patient and for me, too, to stick them again. I feel bad that I couldn't get anything when I stuck a second time.

Do you find that most patients want to chat?

Vinita: Yeah, most of the patients. When I came, I didn't talk too much, but once I got used to it, with all the people, I just talk. Some of the patients always ask for me, because I talk a lot. [laughs] They're so nice. They feel the home environment here.

I've known Annie for a long time. She's always nice. She always talks about the grandkids. I always talk about my daughter. We stick her finger, but she never complains about the pain and stuff. She's good. She's always a laughing person.

What's the most difficult part of your job?

Vinita: When we pack the tubes with the patients' requisitions we have to be very careful that we don't mess up the labels. We have to make sure two or three times that we packed the right tubes. Otherwise the results will come out different, and they will end up giving the chemo to the

patients wrongly. It's a big responsibility when we do all the blood work.

We always ask date of birth first, then look at the patients. Sometimes we have the patients with the same name but with a different date of birth. When we call patients with their last name, two people come. So we have to make sure who's the right patient. You have to be very careful.

Do you know about what's happening with patients' treatment, or do they just show up for the blood?

Vinita: Yeah, we only do the blood work, so after that we don't know. Sometimes we can see the patients' face having pain or they're not feeling well from the treatments and things like that. Sometimes they come fresh, energetic. Sometimes they look so tired.

Anything else that you want to tell us about your job?

Vinita: I love my job! [laughs] That was my dream, to take care of the patients. When I was in school, I was thinking to do patient care. I wanted to be an RN, but then I just changed my mind, then I went to the phlebotomy subject. So I like my job, yeah.

ONCOLOGY PRACTICE

ABBY (LABORATORY MANAGER)

Abby: I'm the laboratory manager and I've been here for 13 years. We run a few tests here. We run CBCs [complete blood count]; we run urinalysis occasionally. We run PT and INRs [prothrombin time and international normalized ratio blood tests]. We do occult blood occasionally. That's about it, but basically everybody who comes into the office gets a CBC run and that needs to be collected and processed in the computer before either the nurse or the physician sees the patient.

So we're dealing with the patients, the physicians, and the nurses. The nurses can't do their job until we have the CBC; only then they can make sure that the patient can have their chemo, or, if they are here for a nadir check, that they may need to have a Neupogen shot or a Procrit or something along those lines. We try to make it seem like it's running as smoothly as possible and not have any issues. Sometimes it's a little hard to do when we have a staffing issue or something, but usually it works pretty well. I pretty much do whatever is needed to make sure that everything runs as smoothly as possible. One of us, a med tech, has to be running an instrument and verifying the results.

What is the instrument?

Abby: It's on the counter. It's really an amazing machine. [We call them] Pentra 1 or Pentra 2. One or two.

What do you see as the lab's role in contributing to a patient's experience here?

Abby: We try to do it as quickly and efficiently as possible, but also with the patient's personality in mind, too. I think we're a lot luckier than secretarial staff or somebody who's on the other end of a nasty phone call. People are a little apprehensive about having their blood drawn, so they are not going to complain to the person or be nasty to the person who's on the other end of the needle until after they do the needle. Most times my staff does really well, so people are very complimentary...

Even though they are actually the ones possibly causing some pain.

Abby: Yeah, but it shouldn't be painful.

When results come out when you're running something in-house, would you necessarily understand their clinical significance?

Abby: Yeah. Most times I do. Yeah. If somebody's got leukemia or something like that, we can see that maybe they're in a crisis again or that they're going to need blood. We're obviously the first people to know because we get the counts, but then we're not the ones who tell the patient. We just put it up for somebody.

Do you ever have anyone ask you for their results?

Abby: Yeah. Some of them we can give. Some of them that we know. [One patient] comes in all the time for his PT and his hemoglobin is up really high sometimes, so he'll sit and wait for the doctor, but meanwhile, I'll just give him a copy, so that makes him happy.

I've had several family members come through here and a few of them haven't survived, just because of the cancer that they've had. It's just interesting. It's like being on both sides.

ONCOLOGY PRACTICE

CAROL (ADMINISTRATIVE ASSISTANT)

Carol: I'm an administrative assistant for the nurses in the treatment room. I've been here 15 years.

It's very hard to put what I do into words. I schedule patients. We do planned admits. We do...and this is not the right word to use, but I often feel like we're doing a little social work with patients. We're comforting them and their families, for lack of a better word. I might refer people to social work if I think they could benefit. We order lab work. We do all the chemotherapy scheduling, which is new. We hadn't done that before. That's a whole other learning process for us.

I don't know, I do a little of everything. What everybody asks us to do. I mail out schedules. I talk to patients. We triage many phone calls all day long, give out all the symptom calls to the nurses. Figure out if the calls need to go to the nurse practitioner, if they need to go to a treating nurse. It's a little hard to put everything into words. I tried to do a résumé once and it came out blank, because I couldn't really put everything down that I do in any given day. It's basically a customer-service job, if you want to look at it that way; you're making sure that everything runs smoothly for the nurses.

Do you have a pretty good view of what a patient is going through at any given moment?

Carol: You do get to know what the patients are going through, what their families are going through. Annie, I've always dealt with her, so I know her. But she doesn't get her treatment in our office. She was getting it in the office, but then she got really ill. So that's when Dr. R. decided that they should admit her to the hospital when she gets her treatments. She was having reactions. She was, I guess, very, very nauseous and everything following treatments, and she would call and we'd bring her in for a hydration, and it was too much for her. So Dr. R. discussed it, I guess, with the nurses and the other docs, and they decided to admit her. Every time she gets admitted, Annie is so on top of everything. She knows exactly when she needs to be admitted. So she'll call me and say, "Arrange for my admission," and I'll say, "Let me check with Dr. R. and then we'll take care of everything for you."

You have to be aware of everything that's around you. Like, if you see a nurse running with the vital-signs machine, we stand up right away because it might be a code. The nurses will yell out, "Call a code!"—purple, blue, whatever. Yes, you have to be aware. And you see where I sit [at the hub]. I mean, my God, I hear everything. That's not a bad thing, because that helps me know what's going on. I can interject if somebody has a question without it seeming like I was eavesdropping.

How do you balance the paperwork when there's all this human stuff happening? Is it like an improvisation?

Carol: It can be. It can be. There will be times like, especially if the others are at lunch and I'm by myself, and this one is coming at you from here and the doc is coming down this way and there's another one coming at you this way. I don't even sit. I just stand and go.

I don't know if you saw what happened today. There was a transport that came to take a patient to radiology, went into the waiting room, asked for Donna. So *Dana* gets in the chair. He starts to wheel her out and she finally realizes she's not supposed to be going in a chair. So she's like, "Help me! Where am I going?! Aren't I just getting Procrit?" I had to

make sure she was okay, calm her down. I say, "You're not going to radiology. It was a mistake." She had spent two months in ICU. She does not want to go anywhere, just get her shot and go home. While that was happening, someone else is asking a question, the phone is ringing.

It's a little of everything. It's very frustrating, but I love it. I feel I make a difference. I'm not patting myself on the back or anything. I just feel that at the end of the day, you can go home really frustrated, but this place humbles you. If you can make a little bit of a difference—I mean, I know I get paid, but you still feel good when you can help somebody or just give them a hug or whatever.

Do you talk a lot with your colleagues about the humbling aspects of the work?

Carol: Not so much. I talk—not by patient name or anything—more to my son because he is a hospital-security chief, so he understands the concept of working in a medical environment. The rest of my family doesn't. They tell me I have no sympathy for anything they're dealing with. I don't, really. I'm like, "Come work with me for a day and see." But I don't think I've really told anybody, except for my family, that it humbles me to work here, because that's a personal thing.

What about the hard parts of losing patients and the sadness? What do you do with it?

Carol: Pray. I pray a lot. My brother-in-law died at 38 of pancreatic cancer—that was twenty-something years ago. I've been through a lot of things in my own life, so I can deal with things here. Patients that we've all been really close to—even if they're older, you've gotten really close to them and it's just really sad. You have your coworkers to talk to about that, and that's good, you know, that you can say, "He was a funny guy, he was a great guy, he was always happy when he was here." You need to talk that out. You can't keep it in.

Do you think your patients understand how deeply they affect you?

Carol: I hope so. I still have it pinned to my desk from when I first started working here—somebody sent me, anonymously, a note with an angel pin that said something to the effect of, "It's not important who I am. It's important that I realize how much you do and how much you mean to me." I still have it. Because when you're having a really bad day, sometimes you need to pull that out and look at that, and remind yourself that you are making a difference. I'm not a nurse. I'm not a doctor. But I feel I'm part of the team.

This is not an end-of-your-day-you-go-home job. This is tomorrow you have to finish this up and follow through on this and make sure this was done. I've actually started keeping a pad in the well of my car because I'll be halfway

home and think, “Did I call that patient?” I scribble it down so I remember in the morning. A lot of times, I’ll just text my colleague in the morning and say, “Could you just check on this when you get in?” I know they’re coming in before I get there.

Do your friends and family understand what you do?

Carol: Here’s the thing: A lot of my family and friends think that I know many things that I don’t. My sister’s had heart problems most of her life and she’ll ask me questions, and I’ll say, “I don’t know anything about cardiology.” Or she has a friend who has breast cancer, who unfortunately just passed, and she would ask me if the medication she was getting was a drug they use here. I’d be like, “Yes, they use it, but every case is different. I don’t know.” I always say, “I’m just a secretary.”

You probably know more than you realize you know.

Carol: It will surprise you sometimes. Somebody will ask you a question and something will come out and you’ll realize, “Oh! I really did know!”

On the whole, I think this is a very good job. I work hard, and I get paid well. But it makes me feel good that I’m doing this. The doctors yell at you sometimes. The nurses yell sometimes. Everybody gets frustrated, but you have to take that in stride.

ONCOLOGY PRACTICE

ANNIE BAKER (PATIENT) KATHLEEN (NURSE)

Annie: Hey, motorcycle lady.

Kathleen: Hi! How are you?

Annie: I’m good. I’m here for a Sandostatin shot.

Kathleen: Okay, I’ll go start getting it prepped and ready. Have a seat.

Annie: Kathleen took care of my chemo once here before I started going in the hospital. She’s a motorcycle mama.

Kathleen: It’s true.

Annie: Just bought a bigger one.

Kathleen: That’s true.

Annie: And she’s so wonderful.

Kathleen: I just took your Sandostatin out of the refrigerator, so it’s got to come to room temperature first. I’ve set a timer for 15 minutes. After 15 minutes, I have to mix it. So you’ve got a good half hour to sit and wait.

Annie, when you got the diagnosis, did you have any sense of what was ahead?

Annie: I had no idea it was going to be so isolating. I really didn’t have an idea of the total impact it would have. That’s gotten me down a few times. And I have an amazing, amazing support system. Still, it’s your disease and it’s this quiet little thing doing whatever it’s doing inside of you.

But I don’t want to talk about how I’m feeling with people all the time or whatever. And so in some ways—and my friends and family understand it—I need space. Also, I am consciously protective of others involved in this process with me. Like my son in Chicago. They’re going through some stuff of their own right now. He will be here for the surgery and so on, but I said at one point, “Put me at the bottom of the concern list. If I need to, I’ll call you.” Were there times that I would have liked him to have been able to visit more? Sure. But he doesn’t have to know that.

And again, the pragmatism, what’s the choice? What’s the choice? For me it’s similar to my divorce, what I like to call my “domestic realignment.” What am I going to do, spend all my time being angry? I think I’m the only person who is not angry at my ex for all of the years of the stress and all of that, because I understand now the pathology in his personality that led to it all. So what’s the point of bad-mouthing? Please. It’s such a waste of energy, and I need my energy for this. I don’t need it for that.

In the beginning it must be an adjustment, applying that “I am a cancer patient” notion to oneself.

Annie: Yeah, it takes a while for that really to sink in. I think one’s personal philosophy has something to do with it, whether it’s “readiness is all” [from *Hamlet*] or whatever. I am not a religious person at all. Watch me get hit by lightning as I sit in my metal...my plastic chair. [laughs] I’m not religious. But I have no fear of dying. I really don’t. I never have. I’d like to live as long as I can, but there will be a time when I will stop.

Sometimes it kind of feels as if I’m watching myself going through this process. And I think that’s a coping skill. And see, I’ve been fortunate, too: I’ve kept my hair, and I don’t have the look of someone who’s been going through... [whispers so that other patients can’t hear] do you know what I mean? And that’s been fortunate for me, selfishly. It’s been important for me. So it’s not, “Aww, look at Annie.” Because I hate that crap. I hate that crap.

Have you written about your experience at all?

Annie: No. One of my girlfriends asked me, “How is your journal going?” It was at a moment when this was all fresh and new, and I said to her, “Why the *fuck* would I keep a journal of this?” On a cozy, snowy day, I’m going to say, “Oh,

Annie, why don't you go get your journal and read all about this again?" My God! I don't think so.

Have you read any other accounts by people who had cancer that interested you at all?

Annie: Oh, maybe if I'm thumbing through a magazine and there's something about someone who is a survivor and it's wonderful and all of that. Some tend to be a little too God driven and a little too religious for me. I got a card from a dear friend that said, "God only gives you what you can handle," and I thought, "If anybody ever says this to me face-to-face, I will not be able to control myself."

I think the hardest for me is when it's religious. It's wonderful that people are praying for me. I mean that sincerely. It is wonderful that they are applying their faith to my outcome. There's a wonderful, wonderful nun who comes to visit the hospital, Sister Martha. Right from the get-go I said, "I'm sorry, I'm not religious at all." She said, "It doesn't make any difference." And we just chat.

And again, this is not to toot, but as far as being strong, I go, girl. I can handle a hell of a lot. Which is why, when I went in with this flare and I started crying in front of the rheumatologist, she said, "This is bad, then." I have a very high threshold for pain, but I couldn't take it. And I can take a lot.

You're in treatment for cancer and you have rheumatoid arthritis...

Annie: Don't forget my colostomy.

I'm not forgetting. Well, I guess I did. [laughs]

Annie: My melon. My melon.

But it sounds like the RA is very difficult to deal with and incredibly painful at times...

Annie: I have a disease that is ultimately crippling and I have another one that ultimately could be fatal. So I guess it's pretty helpful that I don't have a fear of dying. Because if the RA gets too bad, give me a car and I'll find a tree. I tell you. God. [laughs] Anyway.

ONCOLOGY PRACTICE

KATHLEEN (NURSE)

Kathleen: My name is Kathleen. I have worked here for a little over a year. I am a registered oncology nurse so I get to work mostly in the treatment room administering chemo, but once in a while I float into this room, which is our nadir room. Here we field patients who are coming in to have lab work done. We also administer injections when people need

them for their blood counts. We review labs if people need blood transfusions, things of that sort.

I feel that being an oncology nurse is the absolute epitome of what a nurse is, because we really get to see people at a critical time in their lives. When somebody is diagnosed with cancer, it's like no other disease. It is a scary, scary time: They don't know what they're going to encounter on their journey. Whether they come through it and they go into remission or whether their journey doesn't end, we really have the opportunity to participate in their care like no other nurse does in any other field.

Did you always know you wanted to work in oncology? How did you come to it?

Kathleen: I didn't want to be a nurse. When I was a little girl growing up my father was a police officer and I always thought I wanted to be a cop like Daddy. Right out of high school, I went to school for forensic psychology. I was a double major in criminal justice and psychology, and when I got out of school I started working for a criminal attorney and I hated it. I lasted for three months.

I got a job just on a whim working as a medical receptionist and immediately knew that I had found something that I really, really enjoyed. I worked for 11 years doing basically administrative work and I transitioned into an EMT and medical assistant and eventually I went to nursing school and I found something that I truly, truly loved. It was a second career choice for me. I have no doubt that it was the right one. I don't ever leave work at work. It's with me all the time. It's part of who I am.

How do you manage the emotional aspects of the job?

Kathleen: A lot of it is acceptance. We're all going to die someday. Everybody's going to go, one way or another, and cancer is some people's fate. It's helped me to learn a lot about the dying process. It's absolutely sad and overwhelming, but it's given me a greater appreciation for a lot of things in life and it teaches me a lot about perspective. It reminds me to be present every day.

Does your work ever enter your dreams?

Kathleen: Not really dreams, but the funny thing is, there have been a few times where I've woken up to my alarm clock and I've been convinced that it was an IV pump beeping. I'm like, "Wait a minute. I'm at work already? No, that's the alarm!"

Have you come to know Annie over time?

Kathleen: I have. I really enjoyed taking care of her when she was being treated here and I love when she comes in here because she is one of those people who is a fighter no matter what her situation is. She always has a smile on her

face and a positive view of things and nothing seems to get her down. She shares my view of positivity. I enjoy her sense of humor and she and I get along great. She's a lot of fun.

How do you usually go about establishing a connection with patients when you're getting to know someone?

Kathleen: I tend to be the resident goofball. I jokingly say a lot of times that I encourage the patients to channel their inner child and part of that is because I never grew up myself. I like to have a lot of fun and I use my sense of humor a lot. Life is too short.

I think if you take all of this too seriously—even though it is a *very* serious thing—it can be overwhelming. I'm just myself. A big part of this job has nothing to do with clinical work. It's just about being a human being and knowing that the people sitting in these chairs for the most part are completely terrified. Some of them are spiritual, some of them are not. A lot of it is about the holistic aspect. We're not treating a disease; we're treating people. If we as nurses can't recognize that, then what do we have to give?

I wear my heart on my sleeve. I share a little bit of myself with all the patients here because I feel in order to make them comfortable, I have to let them into my world, too. It makes them a little more comfortable.

Is there anything you feel patients need to know that they don't, regarding what you do here?

Kathleen: I think they need to know how much they matter to us. A lot of times they come in here and then, after their treatment, they come back to thank us. I don't think they know how much that means to us, because we wonder when they walk out the door what happens. We're like, "What happened to so-and-so?" They are such a big part of us.

How many patients do you see in a given day?

Kathleen: In our treatment room there are usually anywhere between 30 and 65, and then we'll have another 20 to 40 here in the nadir room.

What does "nadir room" mean?

Kathleen: The nadir is a low point [the drop in white blood cells and platelets following chemotherapy]. That's the room we're standing in right now, and it's for people who are coming in to get their labs checked when they've had chemo. Or they're coming in here to get injections. It's really a multipurpose room where patients come in for anything other than chemo or for seeing the doctors.

Who named it?

Kathleen: I don't know. The room is [specific to this office] but *nadir* is a common term used in chemotherapy.

I'd like to get to those patients...

HOSPITAL

JACOB (NURSING AIDE)

EDEN (PHARMACIST)

ANNIE BAKER (PATIENT)

[One week later, Annie has been admitted to the hospital for another round of chemo; she is in a gown, seated in a chair, an IV pole beside her.]

Jacob: I started as a nursing aide, and I started oncology because my mother was diagnosed with cancer. I was in med-surg [medical-surgical nursing], but when my mother was diagnosed I specifically applied to the oncology unit—so I think I was meant to be part of the oncology team.

I'm a unit representative. I'm the front line: I'm the person you see at the desk when you walk off the elevator. I'm the first person to say [brightly], "Hi, how are you?" I'm also the person who answers the call button. [The calls are] a variety; patients call if they are in pain, they call with just small, little requests that make them happy: "Can you tell me which channel such-and-such is playing on?" We get a lot of calls about different things. Sometimes it's like, "Where is my lunch?"

Annie: I think part of that is because when you're a patient receiving cancer treatment you have absolutely no control over anything. You know, the doctors tell me where I'm supposed to be, and at what time. So little things like getting a TV station or having somebody come and bring you ice water—just to feel like you have a little bit of control—becomes very important to you. And the staff has to be patient because sometimes it can be again and again and again. When I volunteered at the nursing home I saw it too. You know, there wasn't enough pudding at dinner. They wanted more pudding. To have some control over something, that's what it's about.

[gesturing at IV pole] They hang whatever they're going to hang on there. I have no clue. I mean I know that's the saline drip, and all that. But I don't know what's in the cocktail or anything like that. So they hang it and then I just wait to see what happens.

Is there anything comparable to this experience in modern life, where you go into an environment and have to surrender so much of your own personal autonomy?

Annie: I think if you're arrested and put in jail.

Eden: [laughs] Wow, okay.

Annie: No, but seriously, that's the only thing I can think of. Or if you have some kind of a very traumatic injury that puts you in a wheelchair or gives you paralysis—anything

that takes away your ability to control what you're doing. Being a nun, I guess, would also be...but that, too, they make a choice.

What about the military?

Annie: That's still a choice. It's still a choice.

Eden: Ultimately doctors try to explain as much as they can, tell you what's being treated and explain your schedule. But how much can you take in if you don't know the medical field and you're like, "What are you saying? When am I coming in?" A lot of times they have to give a med urgently. So it's not like we don't want to tell [patients] but at the same time, how much can you grasp of what's going on?

Annie: That's a very good point, because it is almost, it's almost too much to absorb. And that's why I often go with my sister or a very dear friend to an appointment. Because I just can't get it all when I'm sitting there. I just eliminate [a lot of the technical information]—I don't get it, so what's the point. It's not going to mean anything to me.

You have to be a special person to work on this floor. I think it was the last chemo—14 or 13?—there was a young man who had children down at the far end of the hall who passed away. And he was a young man. That was hard on the nurses and on everyone. He did pass away, didn't he, yes?

Eden: [nods] We had a few that week.

Annie: It's hard to be on this floor. I know this is a floor that I have to be on, because I have cancer. But it's hard to be on this floor because there are some very, very sick people here. But that's just the reality of what the floor is about. And thank heavens we have this floor. But if I—*when* I am released, shall I say—and on maintenance or whatever it's going to be, I want to volunteer on this floor. There was a wonderful woman the first time I came here, gray-haired, very attractive. She pulled up a chair and she sat right close to me—I think I was crying—and she said, "Doesn't this suck?" And she was a cancer survivor too. And I think you have to be a cancer survivor in order to understand where people are coming from.

HOSPITAL

JACKIE (NURSING ASSISTANT)
ANNIE BAKER (PATIENT)

Jackie: Normally, my shift is 3 to 11 A.M., and it's patient care. We have to do A.M. care, which is cleaning them up. If they need anything to drink, making sure they're okay. You do their vital signs. Like every four hours. Everything.

What's it like when you have to wake patients up in the middle of the night to get their vitals?

Jackie: [sighs] *Not* good. You sometimes don't even want to do it because they're sleeping, so we'll ask the nurse. It's sad because you know that they didn't sleep like the whole day or the whole night. If the nurse says let it go, then we'll go back and do them later. But if they're sleeping and we have to, we gently just put their arm up, and sometimes they don't even wake up. Not even to, like, get a sugar check.

Annie: Jackie and I connected during my first chemo here, I think. We bonded over the colostomy bag.

Jackie: Yes, the first time I learned how to empty it out was with you. I was brand-new, and I learned with her. [laughs] She goes, "I'll show you," and we just did it, and that was it.

Do patients get embarrassed at people seeing their body, or do they get used to it?

Annie: At this point, I could walk across that courtyard naked—it would be a horrible sight to see, and anybody who saw me would probably go into a monastery or a convent—and I wouldn't care.

Jackie: Yeah, they don't get embarrassed. You see them, clean them, naked. They're used to it. And you give them the confidence so they can feel okay. You keep them covered always, while you're cleaning them or something. So they can feel comfortable.

Annie: Oh, this morning it was awful, because it was just, all let go. [gestures toward colostomy bag] I was covered in... um...fecal matter. It was absolutely disgusting. I want this reversed. [pats abdomen]

Jackie: I love working here. I love caring for patients. It's just, you have to have it in your heart to do it. Not just anybody can do it. You can't even say it's for the money, because...you have to feel it and you have to really like it. You carry it with you day in and day out, that's it. You go home with them, and you think about them. It's like your second family.

HOSPITAL

TATYANA (NURSE)
ANNIE BAKER (PATIENT)

Tatyana: I'm involved with direct patient care. I do injections, I give them medications, we administer chemotherapy...

Annie: She sits and talks with me if I need to.

Tatyana: We do a lot of the education for the patients and their families. The families are a big, big, big piece of who we take care of. So we don't only get five patients per day, you know, to take care of—that's our typical ratio—but we get a whole bag of family members who are worried, who are scared just like their loved ones, who are sharing the diagnosis of cancer with them. They're holding it in their head and changing their lives, you know, rearranging it. They have to, because no one can or should be fighting the battle alone. It's really difficult.

Is there something about working here that you think most people wouldn't know, or something that would surprise them?

Tatyana: Oh, yeah. It's my opinion—and I've heard other nurses share it with me—that a cancer patient is absolutely very different from patients who have other conditions, chronic ones like diabetes, heart failure. A friend of mine says, "I will take a patient with a tumor"—direct quote—"in a heartbeat over anybody else." They have a different insight on life, you know. A totally different approach to people, how they accept help, how they ask for it. They are a little more appreciative, I want to say. They are more pleasant to deal with, and they're warm. They listen to what we tell them and actually follow it. There are a lot of people who have chronic conditions, and they have them because they don't really follow advice.

So you think it has to do with getting a diagnosis that nobody is ever expecting?

Tatyana: I think it's also the uncertainty of what the outcome is going to be, and what the future is like. When it's going to be the end of your life becomes so uncertain from the moment of diagnosis. Even people who get cured, you know—that fear that it's coming back remains in their mind every day for the rest of their lives. And the uncertainty puts a totally different perspective on their lives and how they see the world, and how they see themselves in that world. How they approach other people, and how they relate to other people.

Everybody is different. A lot of people get very depressed, very withdrawn. I think they're angry and fearful of the diagnosis and what's coming with the treatment. I think fear of the unknown is the biggest.

Annie: Every once in a while I'll get a little—have a little pity party, but it doesn't last long. Because that's not who I want to be. [pauses] But I've seen people at the cancer center, you can tell they're very frightened, especially if they're just starting out the treatment. Because they don't really know what is going to happen. And it can be a bitch, it can really be a bitch.

HOSPITAL

DR. RAJIV PATEL (HOSPITALIST)
ANNIE BAKER (PATIENT)

Dr. Patel: Annie is very popular. The nurses fight over her—

Annie: Stop, stop, stop.

Dr. Patel: No, it's really like that!

Annie: Stop, stop, stop.

Dr. Patel: When have you seen, when you've gone to a room, that the nurses have written on the whiteboard, "Welcome back"? You don't see that on any other door—

Annie: This man is amazing, anyway.

Dr. Patel: It's a pleasure to take care of her, I mean, you know, the first time we met, she was in Room 6 or, no, 8—

Annie: Well, I've been in 14 of them.

Dr. Patel: Room 8 was the first time I saw you; that was the first bad episode of the chemo that she had. She came in there, there were accidents with the ostomy. It was getting filled up so fast and we had to put her on a short TPN [total parenteral nutrition]—remember when we put in the TPN for the first time? It got better and then she went home and then that's how we got to know each other. Then the second time she came in she was all—

Annie: Loopy, I had no—

Dr. Patel: She...those 24 hours, she still doesn't have any recollection of what happened.

Annie: No, I forget. I have no clue about the 24 hours, when I'm out of it.

Dr. Patel: After which we decided that it is not safe for her to take the pump and do chemotherapy at home. After that she comes over here, and gets her chemotherapy here, and it's like every two weeks. I mean she was dehydrated, electrolyte-wise she was depleted, and there was a lot going on at that point. We gave her a very fancy diagnosis, remember? Transient global...

Annie: ...amnesia, which the nurse said means that the neurologist had no clue what happened. [laughs]

That sounds very impressive, you know.

Dr. Patel: [laughs] "I had *transient global amnesia*," yeah.

Annie: And Dr. Patel takes care of all of us on the floor.

So you're a hospitalist?

Dr. Patel: I'm a hospitalist, yes. I just stay here on the oncology floor. We have a big group, 13, 14 docs, and we used to rotate. I did a few stints over there and I sort of liked it. Then they came to me and they said, "Do you want to just stay here forever?" And I said, "Yeah, I don't mind."

And in that time, and even now, none of the other hospitalists want to come here. One of them was here just two days and she still has nightmares about it. She just can't see the pain and suffering over here. She's like, "Oncology is too much for me, I can't handle it. I'd rather deal with my cardiac patients." On the cardiac wards it's huffing and puffing, but it's the same huffing and puffing every day, you know. My group members will only do weekend stints when I'm not here.

I've had a couple of patients say, "Where were you over the weekend? I was here! There was some other person who didn't know anything—he kept on asking questions and questions, and I kept on saying, 'But why are *you* here? Why isn't Dr. Patel here?'" [laughs] Like, yeah, you know, I have a family also!

Do you ever take a vacation?

Annie: He took one to Canada.

Dr. Patel: I took one, yeah, that was the day I discharged you.

Annie: Yes.

Dr. Patel: I discharged you and we *ran*.

You were saying that your colleagues can't or won't work here—why do you think you can?

Dr. Patel: I don't know; I don't think that there is anything special with me. I sort of developed a soft corner toward some of the cancer patients. It's not like sympathy or pity or anything like that, it's just that I feel for them. I mean I...it's just that I want to, you know—it's a difficult journey. I just want to take the trip together, that's it. [pauses]

Nobody can understand their pain. It's wrong to say, "I understand what you're going through." *No, you can't*. None of us here can understand what Annie is going through. None of us can. We can try, but we can't. It's very individual, and every person has different issues. Emotional issues, physical issues, pain issues. It's a systemic diagnosis. It's not, let's say, Annie's colon [cancer]—it's not just the colon. It's everywhere. I mean it alters their lifestyle. It alters how they do things, how they travel—you know you have to take into consideration so many factors now.

People all shout about heart attacks and hypertension and everything. How many people became depressed after having a heart attack? There are statistics of depression in people post-MI [myocardial infarction], but you know, cardiology is so advanced now. You put a stent in, you put

them on this drug, that drug, you function. People are going about their usual lives. My dad had a bypass seven years ago, and he is very active now. He's feeling younger after the bypass, which is normal.

Annie: Yeah, my father-in-law said, "I feel 25 years younger," because he had new plumbing put in.

So is cardiology more like plumbing?

Dr. Patel: Technically, all of the human body is wiring and plumbing—but it's all alive. At home you are in control of the plumbing and the wiring: You can turn the switch on and off and the tap on and off. Here, it's all automatic inside.

You were talking about how everybody's experience is individual and also holistic, and I wonder if your training in internal medicine contributes to that perspective?

Dr. Patel: It does. I mean the oncologist usually tells me the same thing, he's like, "Okay, we'll just give the chemo, so you will take care of the rest, right?" In that way it feels okay. I mean, I shouldn't be bothering them about the patient's blood pressure going high or the blood sugar going here and there. They should be focused just on trying to get the patient better with *their* magic. And I can take care of the rest.

Annie, do you ever talk about your rheumatoid arthritis when you're here?

Annie: Well, yeah. [to Dr. Patel] What did you say, my hand was—swan something?

Dr. Patel: Swan-neck deformity.

Annie: Yes.

Dr. Patel: It's not there yet.

Annie: I know.

Dr. Patel: It won't be.

Annie: [holds out her wrist, turns it to the side to demonstrate] "Oh, look, you're going to have a swan-neck deformity." "And good morning to *you*, Dr. Patel!" [laughs]

Dr. Patel: I was just telling her, it's so weird that, you know, they describe these deformities in such beautiful language. You know when you look at a swan, you look at how elegant it is, and then they describe the rheumatoid-arthritic changes as a swan's neck. [laughs]

Is there anything about working here that you think people on the outside would be surprised to hear or that would be important for them to know?

Dr. Patel: Yes. Cancer is not a terminal diagnosis, you know. If this person wants to live, it's not what *you* think

that matters. It's what *they* think that matters at this point. You can't make a decision for a patient. You can give them information. You can guide them, but you can't make the decisions for them. And plus, you cannot make a prognosis based on a diagnosis. In the ER the patient may just be acutely ill for some reason and you just treat the patient and carry on, you know, and that's it.

I have arguments like this with medical residents, and with some of the ER attendings. They are like, "But she has cancer." It's like, "And? How does it differ? How does it differ in how you're treating the patient?" I just feel when you say that, you're saying, "surrender," you know, white flag.

Annie: "Go get your affairs in order."

Dr. Patel: You didn't even *do* anything. You have to *do* something before you say, okay, you know what, we tried everything.

Annie: And there is so much that can be tried now.

Dr. Patel: Yeah, there are so many options nowadays. It's not 10 or 15 years ago. I mean, we have Dr. X. over here who has exclusive pancreatic-cancer patients who are surviving for two years and three years. I mean he has something going on over here—you go anywhere else in the world, and in six months you're *done*, with pancreatic. If you're *lucky* you have six months.

Annie: Overall, there is not a gloom-and-doom feeling on this floor at all. You felt it when you got off the elevator.

Absolutely.

Annie: It's not, "Give up all hope, ye who enter here."

What is it, then? What is the motto that crystallizes the experience here?

Annie: Hope, I think.

Dr. Patel: Yeah, exactly. It's hope.

Annie: Hope and cooperation. Hope, cooperation, and commitment on the part of the staff.

Dr. Patel: And I give 100 percent to these people that are here. I don't know how they do it. They've been working more than me, I've been here just three years with the staff. One of the nurses has been here for more like 25 years, and some people for 12 or 13 years working on the same floor.

Annie: They do a lot of taking care of cancer patients. I don't get down because certain people won't let me. I feel very optimistic about the outcome, if I can get through all the surgeries and stuff like that.

And you were thinking you were done with the chemo, right? When we saw you with Dr. Roy last Tuesday—

Annie: [sighs] Yes, I thought I was done at 14 cycles, and then little petite Dr. R., in her very mild-mannered way, says, "The surgeon feels that you should have one more chemo," and I said, "How about after Christmas?" Then she pulls out that invisible cudgel from behind her that no one sees and says, "Ohh, I don't think after Christmas would be good," and the cudgel goes *whack*. Okay. [laughs] And she's only 12 years old. I said that to her the first time I met her: "Does your mother know that you're out pretending in a white jacket?"

Dr. Patel: Did you really say that? She has two kids! [laughs] It's not just you. I hear nurses over here say, "Oh, Dr. R. could drive a car over me and I wouldn't even say anything."

Annie: She's wonderful. She's a sweetheart, and she's smart as anything.

Dr. Patel: She is very smart, yes.

Annie: Well you're no slouch either. You're smart. He's also a reader. I mean, honestly, and don't be modest. Don't you think that your attitude is in part responsible for mine?

Dr. Patel: No, I—

Annie: I'm a positive person anyway, but don't you think that you reinforced—

Dr. Patel: No, it's human nature, Annie. I try to do the same thing for everybody. Okay? I try to encourage even the most negative people. I have a very difficult patient on the floor; she even tried to fire me twice, and I said, "No, that's not happening, I'm not going to abandon you." She said, "I have my rights," and I was like, "Yeah, even I have my rights. I'm still going to come here and see you. I'm not abandoning you." But you know, she can't bring that out of me, what you bring out of me. So, part and parcel I think some of the patients are also responsible for how I react. When they say, "Oh, you're so good," it is because *they* are so good, you know?

Annie: Yeah, but you *are* good. [gets up and gestures toward IV pole] This is my buddy—I'm going to start making faces for these.

Dr. Patel: Yeah, I call it Tommy. [n.b. "Tommy" is a common pet name in India.] I used to cover the cardiac floors, and I used to tell the patients, "You know, Tommy over here has a bladder problem, so take him for a walk."

Is it always Tommy, or do they have different names?

Dr. Patel: It's always Tommy. [laughs]

[Annie and Dr. Patel exit together.]

We thank everyone who agreed to be interviewed and are particularly grateful to Annie for her generosity and kindness.