Living as a Cancer Surpriser: A Doctor Tells His Story

KRISTINE A. KNUTI, ROBERT H. WHARTON, KAREN LEVINE WHARTON,
BRUCE A. CHABNER, THOMAS J. LYNCH, JR., RICHARD T. PENSON

Department of Medicine, Division of Hematology-Oncology, Massachusetts General Hospital,
Boston, Massachusetts, USA

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LEARNING OBJECTIVES

After completing this course, the reader will be able to:

1. Identify the unique issues confronted by caregivers who become patients.
2. Appreciate how addressing issues of life and death affects patients, families, and caregivers.
3. Recognize the advantages and limitations of prognostication.
4. Better care for and communicate with patients and families who face life-threatening illnesses.

ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded the Kenneth B. Schwartz Center. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to the caregivers, and sustenance to the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers and gain insight and support from fellow staff members.

We tell the story of one physician with incurable non-small cell lung cancer (NSCLC) who had an unexpectedly favorable response to an experimental treatment while receiving it as a part of his palliative care. His unique insight provides an opportunity to elucidate some of the issues that arise from living both as a patient-caregiver and as a cancer “surpriser.” When caregivers face their own cancer, their reflections as patient-caregivers offer an internal perspective on the illness experience and help us as fellow caregivers to better understand and support all patients who face serious illnesses, both those who are colleagues and those who are not. Just like any patient with cancer, patient-caregivers experience the dramatic changes in health, daily life, and perspective that come with serious illness. Within the context of a life-threatening illness, caregiver-patients and their families search for new meaning as they face an uncertain future and address the issues of life and death. In addition to such processes, patient-caregivers with cancer also find that their own medical knowledge and their colleagues’ reactions shape their experiences and to an extent separate them from those of other patients. The Oncologist 2003;8:108-122

Correspondence: Richard T. Penson, M.R.C.P., M.D., Instructor in Medicine, Hematology-Oncology, Cox 548, 100 Blossom Street, Boston, Massachusetts 02114-2617, USA. Telephone: 617-726-5867; Fax: 617-724-6898; e-mail: rpenson@partners.org
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Presentation

Robert H. Wharton, M.D. is a physician who runs a pediatric development clinic with his wife, Karen Levine Wharton, Ph.D., a psychologist. In April of 2000, he was diagnosed with stage IIIb non-small cell lung cancer (NSCLC) by Thomas J. Lynch, Jr., M.D., an oncologist at Massachusetts General Hospital (MGH). Initially, he received two cycles of chemotherapy, followed by weekly chemotherapy and concurrent radiation. Within months of the diagnosis, an MRI confirmed brain metastases. During the next year and a half, he received three further chemotherapy regimens and cranial radiation. In December of 2001, the patient presented with severe eye pain, difficulty voiding, leg weakness, and visual disturbance. A lumbar puncture demonstrated carcinomatous meningitis, which has a very poor prognosis. Treatment options were discussed, and the patient, his family, and the medical team decided on a trial of intrathecal chemotherapy and more radiation. The patient’s functional status continued to decline. After a few discussions with him and his family, a referral to hospice care was made. His oncologist believed at that point that the patient would probably only live for another week to 10 days. At the suggestion of the patient, Iressa™, an oral epidermal growth factor receptor tyrosine kinase inhibitor that was part of a clinical trial and had been made available for compassionate use, was initiated to treat the tumor and its associated pain. This decision was motivated by the hope that this strategy would be better than using Percocet™ to treat pain, since the patient wanted to avoid the sedative effect of Percocet. Iressa was not expected to be an effective treatment for prolonging the patient’s life and was instead being used for pain management. On Iressa, there was unexpected and significant clinical improvement during the next several months. Chest and abdominal CT scans and an MRI of the brain taken in May of 2002 confirmed the patient’s clinical improvement by demonstrating shrinkage of the primary lung tumor as well as the adrenal and brain metastases. The patient and his wife presented their story at the Schwartz Center Rounds on June 28, 2002. Dr. Wharton died on November 27, 2002.

Dialogue

Introduction

Thomas J. Lynch, Jr., M.D. (Tom): This is the story of an extraordinary physician and individual and what he has been through over the past two and a half years with NSCLC. Rob has been a pediatrician at MGH for 15 years. He and his wife Karen run a child development clinic together. Rob was diagnosed with NSCLC in the spring of 2000, and the cancer was found to have spread to his mediastinal lymph nodes. We started with two cycles of chemotherapy, followed by some weekly chemotherapy and radiation. During treatment, Rob developed a serious pulmonary embolus and was admitted to the intensive care unit (ICU). The ICU house staff called and said that they were thinking about doing thrombolysis, which would carry with it a very high bleeding risk. Before starting the treatment, they wanted to do an MRI to confirm that Rob had no brain metastases. I said, “There’s nothing to really worry about. There aren’t any brain metastases, but we should check.” We checked and, unfortunately, at midnight that night we found out that the tumor had spread to the brain and was therefore incurable. Rob was then treated with gemcitabine and later last year with temozolomide. Temozolomide is an agent that crosses the blood-brain barrier, and we thought it would be a good agent to treat both the brain metastases and the systemic disease. A few months later, we started treatment with platinum and irinotecan. By the end of last year, which was more than a year and a half after Rob’s initial diagnosis, his symptoms had become more difficult to treat. Rob’s disease in the chest and the adrenal gland had actually done pretty well, but the brain metastases continued to grow. Then Rob developed carcinomatous meningitis. We had a long discussion about where to go from here and what this meant. I’ve had little success treating people who have lung cancer and carcinomatous meningitis, and the literature is consistent with that. It’s a very challenging disease to treat, and Rob had already received radiation and five different chemotherapy regimens. At that point, we commenced a trial of intrathecal chemotherapy, but Rob’s overall functional status worsened.

We had meetings with Rob, Karen, and Rob’s three children, during which we thought the best thing would be palliative care. We thought that hospice really would be the right decision at that point. I remember feeling very strongly about that. At the same time, Rob said, “Listen, why don’t we go ahead and try Iressa?” It had

Patient-caregivers with cancer also find that their own medical knowledge and their colleagues’ reactions shape their experience and to an extent separate it from that of other patients.
been made available for compassionate use. Rob said, "Is there any harm in doing that?" I said, "I don't think there's any harm, and I think there might be some hope. But Rob, it's not going to treat the main problems, which are the brain and the spinal fluid. I have no confidence that it's going to help those things, but it might help your adrenal gland and your lung. It would be nice to prevent those from becoming a problem, and I have no problem trying the Iressa. That would be okay." So we signed him up for the Iressa, and he started taking it in January of this year.

Rob's daughter lives in New York, and I remember distinctly taking her aside and saying, "I really don't think you should go back to New York this weekend because I'm not really certain how things are going to go." In my honest, medical opinion, I really thought we were down to a week, maybe 10 days, at that point.

It was my impression that people thought that I wasn't going to be around for long, that I was sort of "old news."

Rob: So we got married and then started treatment. Impromptu parties sort of became a pattern. We didn’t realize it would, but it became a pattern in the way that we have functioned for the past two and a half years. We have had two or three big parties. One was a year after diagnosis. We had the "First Annual Shampoo and Blow Dry Party," and then we had another. So when Tom gave us the bad news about the brain metastases, we said, "Okay, let's have a party." We gathered a lot of friends, the same group by this time. These parties, plus Tom and other people's ongoing support, have been what has helped us the most.

Cancer “Survivor”

Rob: To explain how we have come to understand this experience, there are three different quotes. One is from Vince Lombardi, who was a coach of the Green Bay Packers, and his quote is, "Winning isn’t everything. It’s the only thing." I don’t like this quote for myself because Karen and I are not totally in favor of the idea that the goal is to be a survivor and that’s it. We sort of get the willies a little bit when people introduce themselves as cancer survivors. I don’t know who said it, but another quote is, "It’s not whether you win or lose but how you play the game." That’s closer. We like that a little better, but it is still missing something. So the quote that I think I’ve used the most is from Yogi Berra, who said, "When you get to a fork in the road, take it." I think the words of that philosopher have guided us the most.

Becoming a Physician-Patient and Facing Colleague Reactions

Tom: Can you comment about when you were diagnosed, as a physician, whether there was anything different about that? Obviously, you don’t know what it’s like to be diagnosed as a nonphysician, but do you think that your understanding of medicine made it harder or easier, more challenging or less challenging?

Rob: It took away hope. I heard the words "lung cancer." I knew what type it was. I didn’t know as much about it as an oncologist, but I didn’t think that there was much chance that I would survive it. The other thing that was different for me as a physician had to do with my
colleagues. Tom, you asked me at that time, “Okay, what do you want to do with this news? Who do you want to know? Who do you not want to know? Do you want them to know you have cancer? Do you want them to know you have lung cancer? How do you want to handle this?” and I wasn’t sure. I had no idea at the time, and I think I said a couple people should know. As it got out, being a physician, I knew what other physicians were thinking about me. It was my impression that people thought that I wasn’t going to be around for long, that I was sort of “old news,” that relationships shouldn’t be started and shouldn’t be continued. One physician, who was a good friend and is a pretty senior guy here, asked how I got diagnosed, why I went to the doctor. I said, “Well, I was coughing a lot, and I thought it was asthma at first. Then, foolishly, I treated myself, and it didn’t work. I wondered why and then felt a lymph node, so I knew I had cancer and went for an evaluation.” As I told him this, he said, “Oh jeez,” and started feeling around on his own neck. This was a few weeks after my diagnosis. I never heard from him again. I think it was just scary for him. Physicians were the worst, especially those around here who I knew and who looked at me as if I had no future. The relationships ended. They would even turn around as I walked down the hall. There was one physician who I was quite friendly with, and he was working in the ICU the night that I was there. I knew him very well, and Karen said, “Oh, Rob’s over there. Why don’t you go see him? He’d really like to see you.” He said, “No, he’s busy. I don’t think he would want to be bothered.” or something like that. Never heard from him again.

So it affected me as a physician, thinking that I knew what my future was going to be and terrified that I was going to suffocate to death. It was so reassuring, Tom, when you told me that I would not die that sort of death. I mean that was terrific news. You expected that I’d just get tired and more tired. I felt much better hearing that because I anticipated bone pain or not being able to breathe, which scared me terribly. Knowing the possibility of ending was very frightening to me. Knowing that it was going to be a much sooner ending than I had contemplated was very scary, not that I had contemplated anything.

Tom: Rob, in the past you’ve mentioned that you’ve found house officers relatively supportive, or more supportive than more senior people. Do you still think that’s true?

Rob: Oh, they were awesome. They were wonderful. The residents just had the ability to be more open, and we in turn felt that we could always be open with them. The house officers, the residents, those relationships never changed, and in fact, I think they got better.

“When You Get to a Fork in the Road, Take It”

Palliative Care Physician: You mentioned you were having celebrations or parties. What triggered those?

Karen: We had planned a May wedding, and Rob was diagnosed in April. After hearing the diagnosis, my first thought was, “It can’t be true because we’re getting married in May. This can’t be happening.” Tom, I think you said, “Why don’t you just go ahead with the wedding anyway?” That’s been very much Tom’s approach to our life—just do it anyway. So that was the first one, and that was so validating. That was sort of our kick off. All of our friends and family were around, and they pulled it all together instantly. A few people came and encouraged us to do it and set it all up behind the scenes. I think there couldn’t be anything more validating than having our wedding 2 days after receiving news like that, having everybody come forward. That worked so well for us, and I think it also worked for our friends. We hear stories about people’s friends falling away. Aside from doctors, our friends haven’t fallen away at all. I think some of it is that right at the beginning everyone was involved, so it has been their journey as much as it has been ours. We’ve actually gotten much closer. I think we’re much more intimate and open just because the most important and biggest thing happening in our life is so very public. One of the other parties we had was almost a goodbye party. We had it when Tom told us things were coming to the end. Rob got well enough to come home, and we thought we better quickly have a party to see people from far away. We also had a New Year’s Eve party. Rob was in the hospital on New Year’s Eve. We’d received really bad news just before that.

Tom: It couldn’t get much worse.
Karen: It couldn’t get much worse. I had the flu and had just had surgery, and Rob was dying. Our friends came. From the twenty-first floor of the hospital, you get a beautiful view of the fireworks. The nurses were flexible, and we had wine and watched the fireworks.

Palliative Care Physician: It seems that some people can be happy and upbeat regardless of what’s happening to them, whereas other people are sad and depressed regardless. You wonder what the difference is. It’s not necessarily just what happens to them. You were able to capture that and deal with it.

Rob: I don’t know why. One time earlier, we had gotten very bad news from Tom as well, and I had to go right to my clinic from the appointment to see my patients, who are young children. I really felt that I could easily become depressed from the news because it didn’t provide much hope or many options. Tom’s always been great at giving me different options and choices. He’d say, “This may work, and this may not work. If it works, this will happen. If it doesn’t work, this will happen.” We reached a stage where he was saying, “If it doesn’t work, I don’t know.” So I was driving over to work, and I said to myself, “You know, I just can’t let myself get depressed. I can’t let it happen.” I felt that if I got depressed, I would be giving up an important aspect of myself in fighting the cancer. So at that time, I came up with an idea that I’m still working on which was: “I can’t get depressed, so what I need is to do something for somebody else.” There’s a tremendous need, not just in this state but in every state and most countries, for autistic children to be seen early so that they can start treatment. There are waiting lists of six months to one year at most clinics, and that’s typically after a late referral. So most kids are screened late, and then they have to wait an inordinate amount of time for diagnosis. Thinking about how Tom said, “I’ll see you at 6 o’clock in the morning,” and about September 11, I thought, “Well, let’s have a coalition of providers. We’ll get together a coalition of providers (as coalition was a hot word) in the state to agree to be able to form a network to see kids faster.” We’re doing that in a different form now, but Karen and I are still engaged in that type of project. For me it was, “Okay, I can’t help myself physically. I can’t help my disease, but I can help myself feel like I’m doing something. I’m doing something important. I’m doing something that matters.” It was an effort that still allowed me to be involved with my family. Karen and I have a clinic together, so we would work on this together. For my kids, it didn’t take me away from them. So it wasn’t about saying, “Okay, I’m going to immerse myself in work to forget that I have this.” It was more a collaborative project to say, “Okay, how can I help someone else right now because I just can’t fall into a depression.”

Karen: After the initial diagnosis, we did not know if we would ever be happy again, if we would ever laugh again. I remember the first time we were out for dinner with some friends, and we just found ourselves all laughing. This was after Rob’s hair had fallen out, and I remember wondering if people were looking at us thinking, “He has cancer, and they’re laughing?” Then we went to stay at some friend’s house in New Hampshire, and I got sun-tanned. I remember that when I went back to work I was wondering if people would think that was odd. How could I be out getting a suntan when Rob has cancer? So it took us a while to feel permission to be happy. Obviously, a lot depends on how people are premonitorily, but we really didn’t know that we’d be able to be happy again. We didn’t know that anybody was able to, and it was a wonderful discovery. We’ve been working on a book about our experience, and I just thought of a title: “There Is Life on Mars.” There can be happiness after a cancer diagnosis. We didn’t know that ourselves, and we sort of discovered it. I brought this hat that we made for one of our parties. It’s called “Circles of Strength,” and all our friends and family have them. We should give you one, Tom. That sort of concept is a lot of what’s gotten us through, all the different circles, the medical circles, the friend circles, family, work, our marriage.

Winter: Palliative Care and Hospice

Tom: Can you talk a little about hospice and what that was like? We refer every year probably 200 patients from the thoracic oncology group to hospice, and we rarely have people come back and talk about what that process was like. How did you feel when you made the decision to do hospice? What was it like going home and having hospice there? What was it like having your kids around and
knowing they really weren’t going to leave because they weren’t sure what was going to happen?

**Rob:** It sucked. It was very, very hard to hear that. I did some medical training in England where the hospice movement started, so I was very familiar with the hospice concept and who was eligible for it. It was another stake. Not only did the direct evidence of cancer in the cerebral spinal fluid and the scans show that I was dying, but my physician, who I think is the best in the world, said, “Listen, you’re dying.” It just got hammered in. One of the hardest problems was having to tell my kids and my father. I knew I was going to have to face that. My father’s 90. He’s been looking for cancer in himself for years, and he’s never found it. And here I am. I had to explain to him that he was going to outlive me. It was so hard knowing that I had to do those things, knowing that I was going to have to leave important people. I wasn’t finished with the relationships, and they weren’t either.

**Tom:** But you did that work? You actually told your father?

**Rob:** Oh yeah.

**Karen:** That night we called everyone.

**Rob:** I had to do it several times because he is 90. He’s very smart, but he doesn’t always take in everything. So it was funny because he said, “Well, listen. I’m going away for about a week or so, and I don’t think I can get up there to see you until after that.” I said, “Dad, you need to come up now,” and he said, “I’ll look into it.” Then he called me back, and he said, “Wait a second. What’s going on?” So I had several of those conversations with him. That was very difficult, telling other people, accepting it myself, the loss.

**Tom:** Did you ever accept it yourself? Do patients ever accept that?

**Rob:** That’s a very good question. Yeah, I did. I would be afraid to go to bed at night. I got a sign to put over our bed that said, “Make sure to kiss each other every night before you go to sleep.” I read about George Harrison, who had died a month or so before. At first, I was terrified to read his obituary. I said, “I don’t want to read this.” Then I read it, and it was really helpful. He got through it. He said, “Listen. Okay, I’ve had a life.” So I decided that every night before I went to sleep, I would think of each of the people in my family, my three kids, and Karen, and what they’ve achieved. I would lie down and think of those things before I went to sleep, and that was helpful. Even though I accepted it, I also made a list of things I wanted to see and to be involved with. This was January. My oldest daughter had a birthday near the end of the month, and I wanted to be alive for that.

**Tom:** Let me just mention that we had decided to ask Rob to do Schwartz Rounds at the end of January. However, we felt you really could not do the Rounds because you were too ill at that point.

**Rob:** Yeah. Valentine’s Day was coming up, so I ordered flowers for Karen and birthday presents for my kids. I ordered Karen flowers six weeks before Valentine’s Day so that she’d get them. Normally, I’m the kind of guy who would have ordered flowers the day after Valentine’s Day. I ordered online birthday presents for my kids and told Karen what I wanted to get for my son. So even though I knew it and really believed it, I sort of was still trying to motivate myself in some ways.

**Palliative Care Physician:** Is the idea of being cared for by a palliative care team any different, or is the term better than hospice? Is there any difference there?

**Rob:** Yeah. I think that there is a difference, and I saw it one night after I came home from the hospital. Soon after I came home, I started to again have the same problem I’d had in the hospital, which was that I could not urinate. The problem had been successfully treated in the hospital either by radiation or Decadron™. A few days after I got home, I couldn’t urinate again, and I was determined that I was going to pee. By about 1 or 2 in the morning, it was clear that I couldn’t. I needed some help. Fortunately, we had hospice, and the nurse came. She didn’t know me. We had met somebody else. It wasn’t the hospice nurse who is here at Schwartz Rounds today, who is wonderful. This other nurse came in. She knew my diagnosis. She didn’t know me, and she didn’t know Karen. She took my hand in both her hands and said, “You poor dying soul,
how can I help you?” I didn’t say it, but I was thinking, “Not that way.” So that was very hard, but she was trying and being very nice.

**Palliative Care Physician:** Perhaps with hospice there’s a degree of giving up, whereas with palliative care there may be a team of doctors who are still trying. There’s not really an emphasis on giving up necessarily in palliative care.

**Rob:** That’s why I gave the example of that nurse. I wanted to catheter myself, and I felt that she was thinking, “Do we really need that if you’re going to die tonight?” I felt that she was not committed to helping me to get over the specific problem. Instead, she was more interested in making me comfortable but not solving my general care. It was hard for her to grasp that I wanted to do it myself, but she got permission for me to be able to do that. So she was helpful in that way. She was the first person to enter my life treating me as if there was absolutely nothing that she could do except relieve my distress right now and then she’s gone. So that was very hard, but the fact that she was there and able to help me was terrific. I didn’t have to go to the hospital to get a catheter.

**Karen:** I just wanted to add a spouse’s perspective on the whole hospice and palliative care experience. When Rob was at his sickest, I don’t think he was aware of how sick he was. So, his concept of all this help was, “What do we need all this for?” When Tom suggested hospice, I thought, “Oh, thank goodness!” because it was really getting pretty difficult. The last thing I wanted Rob to do was feel like he was a patient.

**Tom:** Do you think we waited too long to suggest hospice?

**Karen:** I don’t think Rob would have accepted it any sooner.

**Tom:** But a month earlier might have helped you?

**Karen:** Oh yeah.

**Tom:** Again, a lesson to all of us. It’s well established that we almost always wait too long to refer to hospice.

**Rob:** Again I think it was just the physician stuff that was the problem. Karen wanted backup. She wanted support. I wasn’t letting her get it because I was thinking, “We don’t need them.” So that was a problem for her, and I’m sorry about that.

**Social Work**

**Social Worker:** I’m wondering if a social worker was involved in your case, and if not, would you have benefited from a social worker being involved?

**Karen:** Well, we had the social worker from hospice who was wonderful, but obviously, that was just for a few months. I sought out support everywhere, and then I would try to bring that support home to Rob. It’s a typical male/female thing. Also, I’m a psychologist. I became involved in the Wellness Community†, and they have a wonderful support network. One time I cried through the whole appointment, obviously suggesting that I might need more support. Tom and one of the nurse practitioners suggested a psychiatrist here who’s attached to oncology, and it was very helpful. I’m a big believer that social work, psychiatry, and support groups should be offered right up there with chemo and radiation. It should be approached not as, “Well, let’s wait and see if things get bad enough that you need it,” but as, “This is a crisis for everyone, and if we can get this side of you supported, it will make everything else feel a whole lot better.” I think that should be offered right up front.

**Spring: The Miracle**

**Tom:** We started Iressa in January as a daily tablet. In February, Rob came in for a follow-up appointment. Things seemed a little bit better, but I figured, “Well, he’s just rallying because Valentine’s Day is coming up.” In March, things seemed a little better still, and I said, “Well, you know, this disease has an ebb and flow to it.” In April, Rob was still on the Iressa. Suddenly, I was thinking that this is going longer than one would expect. In May, he’s still doing fine. So in the beginning of June, we got CT scans and an MRI of the brain. The MRI of the brain showed dramatic shrinkage of all the metastases in the brain. I had been at a meeting with close to a hundred doctors, who had treated more people
with Iressa than anybody else in the world. I asked the question, “Has anyone seen brain metastases shrink from Iressa?” Not a single person in the room had seen brain metastases shrink from Iressa at that point. So I was absolutely dumbfounded and thrilled by this. In addition, the adrenal metastasis was nearly completely gone, and the lungs didn’t show any problems at all. So this was really an extraordinary result from an experimental drug, which again teaches me that it’s always worthwhile trying an experimental agent if that’s what the patient wants to do. I’d be very interested to hear Karen’s perspective on this time. Karen, can you tell us about what the immediacy of those days in January and the transition from those days to the spring were like? You’re with your husband. You have “the big talk,” and suddenly it doesn’t happen. He keeps getting better. Psychologically, how did that affect you?

Karen: Well, it’s been the strangest experience. When we got the scan results back, we both could not stop crying. We knew he seemed better, but we couldn’t get our hopes up. We knew it was impossible. It doesn’t cross the blood-brain barrier. We had explained that a number of times to our relatives. They said, “Oh, it must be curing him,” and we said, “No, no, no, don’t get your hopes up.” So we were very careful not to get our hopes up too much, and then you told us about the scans.

Tom: But what was it like in the spring?

Karen: To see him getting better and better?

Tom: Yeah, to see him getting better and better after you had prepared yourself for his passing.

Karen: It was just a miracle all the time. I remember I was touching him a lot and thinking, “Oh, he’s still here. He’s still here.” It was like a physical, visceral kind of miracle. It was also a huge adjustment in every way because we’d been living as if we only had tomorrow, if that. We had gone on a trip to Italy. We had done things that we couldn’t possibly afford doing in the long run. So it was a major shift to suddenly have to think long term. At the same time, all of life sort of comes flooding back in, all of life’s everyday worries.

Should we refinance the house? What about working? I had taken a leave from work. We had to have some sort of income if this was going to go on a while. It’s amazing how quickly everything comes flooding back. We were elated for about two days, and then we thought, “Oh my God. What are we going to do now?” That flooded back in, and we didn’t want all the little worries to take over. We just recently went away to Vermont for my stepson’s college orientation. We had such a nice time just getting away from all the worry stuff and re-remembering the miracle aspect. We made a pact not to let everyday life take over because the details of everyday life are extremely complicated right now.

Chaplain: You used the word miracle, and I’m just wondering as a chaplain if spirituality has helped you to get through this and how your spirituality may have changed.

Rob: Yes, my spirituality has increased significantly. As a matter of fact, the day that Tom gave us the good news about the scans, I did something I’ve never done in my life. I went into temple without it being a Jewish holiday. I just sat in the chapel and cried. Spirituality has helped me considerably.

Karen: And we’ve become very close to the rabbi as someone who got to know Rob very quickly, and we hadn’t even belonged to a synagogue before that.

Changes in Perspective

Hospice Nurse: I’m from hospice, and I do grief work. One of the things I hear all the time from people in bereavement groups is, “I was just like the people who are avoiding me now. I’ve learned so much. Now I know. I was just as shallow. I was everything I’m mad at them for being.” I wonder if that is something you’ve reflected on as a doctor yourself? Did you use to look at your patients the way you feel you’re being looked at? Have you grown? Do you know something you didn’t know before in terms of how you look at sick people?

Karen: Rob and I work with kids with disabilities, so there are a lot of grief-related issues that we deal with anyway. I think we were pretty enlightened in that area—
maybe not in others but in that area—before Rob got sick. We had a very close colleague who also had cancer. We were very close to him as he was getting sicker and sicker. When Rob got sick, the bond became incredibly strong. If he wasn’t there for a day, we’d worry and call his wife. It was very hard when he ultimately died last winter. So we had the experience of being close to him, being open about his illness, and then becoming a little support group after Rob got sick. What it did change for me and for Rob, too, was the way we felt our patients’ pain. I like to think I was always empathic with our patients, but Rob’s illness made me feel something different from the empathy I had previously felt for my patients. I felt their pain differently. Right after Rob was diagnosed, I would cry when I told parents their child was autistic, which isn’t a great thing to do if you’re a psychologist. So I got over that, but it was almost like it was so raw for me that I couldn’t make any distance. You need, obviously, to make a little distance to protect yourself.

Rob: There was a patient I’d followed with diabetes for about 15 years. I did primary care for him from the time he was about 13. His child came up here from Florida. She was 6, and he was mostly the care provider. I became her pediatrician. He brought her in one day after I had been diagnosed, and I thought she had a brain tumor and sent her for a CT. The CT showed an incurable tumor. I had to tell this news to a man, with whom I had a very close relationship, and his daughter, who Karen has helped. I think I knew how to do it better, from hearing Tom do it with me. I knew what to tell him, how to tell him, how to tell him it’s bad but give him hope, those sort of things. I think I was much more able to do that.

Using cure as the only measure of success sends the message to patients that death is a failure, that they are no longer as valuable or important once a cure is not possible.

What Can Caregivers Do Both for Colleagues and for All Patients?

Oncologist: Your story is amazing in its own right. You gave us amazing examples of how we doctors can really do a bad job of relating to patients, even our friends who are patients. You had your doctor-doctor and your wife-doctor who hung in there, and a few of your friends who were doctors stayed close. How can we bridge this gap? What did the doctors who hung in there with you do? What can we learn?

Rob: One problem was that I felt that people, doctors, stopped seeing me as who I was and started seeing me as a diagnosis. “Okay, there’s lung cancer going down the hall, and he’s going to die soon.” What they lacked was, “If he stops me, what do I say?” and I think that is one of the keys. “So I’m going to turn away because I just don’t know what to say to him and don’t know what he’s going to say to me.” My colleagues got stuck in that loop of not being able to ask the question the first time they saw me. Then a month would go by, and they’d see me again. “I meant to ask, but now it’s been a month. How do I say that I’m sorry I didn’t do it sooner?” So it’s another stumbling block. Then six months go by. “He’s still here. What am I going to do? I’ve ignored him. I haven’t talked to him. How can I say, ‘How are you?’ because I feel badly.”

Tom: Rob, what should we say? I remember a very similar example from when one of our staff members became seriously ill. I was very conscious of the fact that I wanted to treat him as if nothing had happened, to the point that I became concerned that I was overcompensating for this. I would say, “How are you? How are things going?” because from what patients have told me, they want to be treated like the people they always were. What can you tell us in terms of when one of us passes you in the hallway, what do you want to hear?

Rob: If you can’t say anything, acknowledge me, wave, do something, and then maybe that night send me an e-mail, where you don’t have to be face to face. “I’ve been thinking about you. I saw you today. How are things going?” Then I can say, “Bad, good, or indifferent?” I’m probably not going to say, “Well, why didn’t you say hello to me today?” though I might. There are times I have been irritable and felt that way, so you might hear that as well. People who don’t want to hear that should figure out, “Well, what am I going to do if I hear that he’s mad at me?” Say, “Okay, I’m sorry. Let’s try and make it better.”
**Facilitator:** The strengths that the two of you have are so much reflective of Ken Schwartz. The idea of making meaning of your life with other people is just so powerful, and I’m wondering how we can help other people do that. I think we can do it, but first we really have to deal with our own feelings of helplessness and despair. How do we help our colleagues get in touch with their aversion to the person they’re unable to help? How do we give our colleagues the tools they need to keep them from turning away? It’s just like when you first learn to interview. You get tools to start with, and then after a while you integrate them into who you are.

**Rob:** There was one thing I suggested to Tom. Tom used to make his rounds in the evening. He’d come in, sit down, and talk to me, and our discussions would be about how I was doing and where I was going. I felt that it wasn’t as much about my disease as about Karen and me. He asked about my kids and stuff like that. Then the intern would come in later and ask, “How’s your breathing? What’s your O₂ saturation?” One time I came out of my room after they had both been in my room separately. Tom was talking to the intern about the medical aspects of my care. I said, “He can learn that stuff on his own. Give him a book. Give him a website. Give him an article. That’s not what you’re here for. Bring him into the room. Find him. Bring him into the room when you’re giving me news. Show him how it’s done.” Everybody should do that. You learn. It would be something to say, “All right, I’ve learned some questions from that person. I’ve learned that you have to sit and that you have to look at the person.” So my suggestion to the oncologists, the nurses, the social workers, and the other caregivers is when you go in and talk with a patient and have to share things, bring somebody else. Bring a nursing student, bring a social worker student, bring a medical student or an oncology fellow. Show them that you can do it. You can talk to patients, and it doesn’t kill them.

**Facilitator:** You demonstrate how to treat that other person as a human being who you want to know about. That’s what Ken wrote about, and that’s what you’re both talking about—that you’re more than a disease.

**Rob:** Right.
sends the message to patients that death is a failure, that they are no longer as valuable or important once a cure is not possible. This social distinction between curable and incurable patients could also be part of why caregivers are often so reluctant to refer patients to palliative or hospice care. Additionally, financial barriers prevent hospice care from being more widely utilized. Medicare, Medicaid, and insurance benefits for hospice care are often insufficient to cover the more expensive interventions. Such benefits often do not, for example, cover palliative antibiotics and radiation therapy, and this makes caregivers question the quality of the care that patients will receive when referred to hospice [3].

While both hospice and palliative care approaches are geared toward end-of-life care, their treatment goals are somewhat different. The primary goal of hospice care is “to mitigate patients’ physical and mental pain and suffering” [4], and this type of care is “generally provided by trained nurses who visit the patient’s home” [4]. A palliative care approach has similar goals of “symptom control, psychological and spiritual well-being, and care of the family” [5], but this strategy encompasses a broader range of treatment options and interventions, such as palliative chemotherapy [3, 5, 6]. While palliative care focuses primarily on alleviating symptoms and not on extending survival, its treatment options are often more aggressive interventions than those used in a hospice care setting. There is also some gray area between the two strategies in that a patient might be referred to a hospice service while also receiving some interventions that fall more in the realm of palliative care.

**Beating the Odds**

Though a powerful clinical tool that relies on carefully obtained statistics and rigorous observation, medical prognosis is not always accurate for an individual patient. Caregivers often under- or overestimate patient survival times despite careful consideration of current clinical statistics. Nicholas Christakis addressed prognosis and how it affects both patients and caregivers in *Death Foretold: Prophecy and Prognosis in Medical Care* [4]. Christakis suggested that prognosis becomes more significant in diseases that cannot be cured because it allows physicians to gain some control over “diseases for which they have no treatment” [4]. As with caregivers, prognostication also allows patients to exercise control because they know what to expect. Christakis observed, “If one cannot control whether death occurs, one can at least control, and thus anticipate, how and when it occurs” [4]. Additionally, he argued that, though general trends are observed, prognosis remains somewhat patient specific. While “a patient’s income or religion might not be so much a factor in the biological expression of disease, they are likely to be a factor in the course of the disease” [4]. Even if a caregiver relies carefully on statistics when prognosticating, those statistics may not reflect the illness course for the patient who is receiving the prognosis, making prognosis at once powerful and fallible.

There are several examples of patients with cancer snatched from apparently imminent death [7]. Popular writer, professor, and paleontologist Stephen Jay Gould addressed statistics and prognostication in his article, *The Median Isn’t the Message*, as he discussed his own experience with abdominal mesothelioma [8]. At the time of Gould’s diagnosis in July of 1982, the median survival for his illness was eight months. Gould lived nearly another 20 years, dying of metastatic lung cancer on May 20, 2002. In his article, he recounted his initial experience with mesothelioma statistics:

> When I revived after surgery, I asked my first question of my doctor and chemotherapist: “What is the best technical literature about mesothelioma?” She replied, with a touch of diplomacy (the only departure she has ever made from direct frankness), that the medical literature contained nothing really worth reading…. As soon as I could walk, I made a beeline for Harvard’s Countway medical library and punched mesothelioma into the computer’s bibliographic search program. An hour later, surrounded by the latest literature on abdominal mesothelioma, I realized with a gulp why my doctor had offered that humane advice. The literature couldn’t have been more brutally clear: mesothelioma was incurable, with a median mortality of only 8 months after discovery. I sat stunned for about 15 minutes, then smiled and said to myself: so that’s why they didn’t give me anything to read [8].
Living with Cancer
Instead of Fighting It: “When You Get to a Fork in the Road, Take It.”

Reducing cancer to a fight where being cured is the only acceptable outcome negates much of what it means to live with an illness and devalues the many people who are living with incurable cancer. Within the school of thought where achieving a cure and being a cancer “survivor,” though honorable goals, are the only valued success stories, there is little to offer patients who are likely to die from their illness. In her book, Illness as Metaphor, Susan Sontag criticized the war metaphors associated with cancer and the use of terminology such as “invasion,” “defense,” and “colonization” to describe the disease process [9]. Sontag argued that such terms lead to pessimism about treatment efficacy even when advances are made. When the only acceptable result is a cure that eliminates the cancer completely, other aspects of treatment, such as increasing survival time and quality of life and addressing psychosocial needs, become devalued. Like Sontag, Arthur Frank refused to see his struggle with cancer as a “fight” in At the Will of the Body, his autobiographical account of his own illness experiences [10]. Questioning the separation between the sick and the well, he reflected, “Health and illness are not so different. In the best moments of my illness I have been most whole. In the worst moments of my health I am sick” [10].

Instead of success meaning the achievement of “survivor” or “cure” status, success should also include coming to terms with illness and mortality, promoting and improving quality of life, and extending life even when a definitive cure is not possible. There is more to an illness experience than whether or not a person ultimately survives the illness; there is also the meaning that comes from living with the illness. This approach is not meant to disregard the harrowing uncertainty and raw pain and grief experienced by patients, families, and caregivers who face illnesses and death. This type of approach is also not meant to imply that those who accept their “incurable” state have in turn given up their struggle to live. Gould, for one, felt it was “too trendy to regard the acceptance of death as something tantamount to intrinsic dignity” [8]. He explained, “Of course I agree with the preacher of Ecclesiastes that there is a time to love and a time to die—and when my skin runs out I hope to face the end calmly and in my own way. For most situations, however, I prefer a more martial view that death is the ultimate enemy—and I find nothing reproachable in those who rage against the dying of the light” [8]. Approaching illness in a way that values those who do not become “survivors” as much as those who do allows patients with incurable diseases and their families and caregivers to continue living in the face of uncertainty, to find and hold onto moments of joy, to persist in their struggle, and to take the “fork in the road.”

Life-threatening illness and all of the uncertainty and grief that come with it also threaten one’s permission to find joy in life. Patients and their families question their right to have moments of happiness and contentment as they face an uncertain future. Still, happiness and joy can be present even during a health crisis, and it is important for caregivers to support patients and their families and to help them recognize that moments of happiness during an illness experience should not be a source of guilt. Many patients have found that the context of life-threatening illness has intensified their appreciation of life [1, 10, 11]. Frank suggested that the “only real difference between people is not health or illness but the way each holds onto a sense of value in life” [10]. He explained, “Illness can teach that every part of life is worth experiencing, even the losses. To grieve well is to value what you lost. When you value even the feeling of loss, you value life itself, and you begin to live again.” [10].

When illness threatens to shorten life, the daily worries and frustrations become less significant, leaving patients and their families to appreciate what they hold to be most important. Anatole Broyard described this process as he reflected on his metastatic prostate cancer and the kind of physician he would like to treat him. He wanted his physician to “see that my sickness has purified me, weakening my worst parts and strengthening my best” [11]. Despite all of the pain and loss that come
with serious illness, patients and their families may even feel that they are better for having experienced the illness. Frank explained, “When I feel I have no time to walk out and watch the sunlight on the river, my recovery has gone too far” [10]. Such an observation does not disregard the pain and loss that come with illness and death, but instead, allows for the presence of joy, life, love, friendship, and compassion even within such a context.

The Patient-Physician

For caregivers with serious illnesses, medical understanding of the illness may appear to be a source of comfort and denial. However, the reverse is often true. As two physicians who have faced cancer reflected on their illness experiences, one recalled “waiting for her first dose of flame-orange adriamycin, sure that it would kill her because of the awful side-effects of this drug she had observed during her first clinical rotation as an intern” [1]. The physician-patient’s view of adriamycin as “poison” contrasted greatly with her hospital roommate’s view of it “as a powerful, healing antibiotic” [1].

Robert J. Pensack, M.D., addressed similar issues in Raising Lazarus, his autobiographical account of living with hypertrophic cardiomyopathy (HCM), a rare and progressively debilitating genetic heart condition [12]. He described working in a heart catheter lab as a medical student and “assisting in the very procedures I endured as a child and adult.” Recalling the release and “false sense of confidence” he felt at the thought of being a doctor instead of a patient, he explained, “I silently repeat to myself like a mantra that I shall remain the doctor. The confusion in my imagination is deeply reassuring, though it is based on a lie I unwittingly tell myself” [12]. He recalled how he made this false separation while observing cardiac surgery. He explained, “I do not ask myself if I am witnessing my future. I have a different disease than these patients, a genetic illness that has nothing to do with plaque-laden coronary arteries, typical heart attacks” [12]. Pensack tried to separate his own illness experience from those of his patients and to escape being a patient by becoming a doctor. Despite this false separation, he could not elude the anxiety and fear that came with the progression of his HCM. Later, while he watched a rib resection not long after having heart surgery himself, Pensack felt a “grip of deep panic” [12]. As his illness progressed, Pensack found it more difficult to separate his own experience from those of his patients and was affected by his patients’ suffering in a way that his colleagues were not.

When physicians become patients, their illnesses also affect their relationships with colleagues. Many patient-caregivers find that their colleagues distance themselves. Pensack recognized this separation as he described his experience in a transitional care program. When he began to have panic attacks that involved seeing distorted images of the world around him, Pensack worried that he had schizophrenia and entered a transitional care program for schizophrenic patients at the suggestion of one of his physicians. Pensack later learned that he was not suffering from schizophrenia but instead from phobic anxiety depersonalization syndrome, a treatable disorder that had resulted from the many traumatic medical experiences he had endured. While he was receiving treatment through the program, he encountered one of his former classmates walking with another medical student. He recalled, “No words are spoken as they drift by, but the communication is clear: Poor Pensack...he would have been a good doctor, now look at him. He’s ruined” [12]. The patient-caregiver can feel avoided by his or her colleagues and alienated from the professional world of caregivers. At the same time, the patient’s colleagues may feel unable to interact with the patient, either because they do not know what to say or see the patient as an example of their own mortality. Patients with cancer who are not caregivers also note how some people in their lives distanced themselves [10]. Describing the distance and denial that he experienced from friends and caregivers, Frank remembered, “Some people I expected to be supportive denied that I was ill at all; medical staff denied that I was anything but the disease. Others affirmed that although I was ill and illness counted, we still had a relationship” [10]. However, he also recognized that his own stigmatized status affected the way that he approached others and made him more cautious [10].

To truly care for patients and address their needs as people, we must first recognize and then cross the barriers that exist between the curable and the incurable, the well and the sick, the caregiver and the patient.

A Different Kind of Empathy

While sympathy involves feeling sorry for another person, empathy requires understanding that person’s situation, being able to picture oneself in a similar situation, and...
communicating that shared witnessing. After facing serious illnesses, patients often describe a new sense of empathy for and camaraderie with others who face illness, suffering, and loss. Frank explained, “When I talk to other persons with cancer, we do not compare frequency of nausea, duration of hair loss, or length of scars. Persons with cancer respect each other’s experiences. They recognize that having cancer is no small thing” [10]. This empathy does not involve comparing illness experiences, but instead, witnessing and honoring another’s experience and narrative “for what it is” [10]. This new perspective of others’ suffering and needs also occurs for caregivers who have experienced illnesses in themselves or their loved ones. For example, Pensack, who eventually went into psychiatry, found that he identified with Vietnam veterans suffering from post-traumatic stress disorder. Many of these veterans had been misdiagnosed with schizophrenia just as Pensack nearly was during his episodes of panic and depersonalization. He explains, “Between us I sensed the immediate and strong bond of recognition” [12]. Pensack also found comfort as a medical student in thinking about another student with a serious illness and knowing that the two of them were “in this together” [12]. Caregivers who have themselves faced serious illnesses acquire a unique viewpoint. While even they cannot fully understand the intensely personal suffering of their patients, their awareness of their patients’ experiences and needs may be heightened by their own personal struggles and illness experiences.

CONCLUSION

“In learning to talk to his patients, the doctor may talk himself back into loving his work. He has little to lose and much to gain by letting the sick man into his heart. If he does, they can share, as few others can, the wonder, terror, and exaltation of being on the edge of being, between the natural and the supernatural.”


A caregiver who becomes a patient also becomes a translator, a bridge between the world of caregivers and that of their patients. This person provides a window into the heightened awareness, suffering, joy, support, grief, and uncertainty that accompany illness. At the same time, this person also offers us a patient’s view of our own strengths and weaknesses as caregivers. Acknowledging our own fears of inadequacy, lack of control, and mortality will help us not only to become better friends to our colleagues but also better caregivers to our patients. To truly care for patients and address their needs as people, we must first recognize and then cross the barriers that exist between the curable and the incurable, the well and the sick, the caregiver and the patient.

ACKNOWLEDGMENT

Robert H. Wharton, M.D., died on November 27, 2002. Rob wanted the article published regardless because, to quote Karen, he felt that “even in death it was the wonderful living that mattered, and that was what he wanted to share.” We thank Rob and Karen for so openly and generously sharing their story with us so that we might learn how to be better caregivers and, more importantly, better people.

The Wellness Community is a national non-profit organization that provides a full range of support services for cancer patients and their loved ones free of charge. The organization’s national website can be found at http://www.thewellnesscommunity.org.

ADDITIONAL READING

For more information about lung cancer and Iressa:
REFERENCES


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